Outcomes Related to the Quality of Life of Oncology Patients Aged 65 and Older Following Initial Cancer Treatment

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OUTCOMES RELATED TO THE QUALITY OF LIFE OF ONCOLOGY PATIENTS AGED 65 AND OLDER FOLLOWING INITIAL CANCER TREATMENT

by

Rosemary Clare Zivic

A Dissertation
Submitted to the
Faculty of The Graduate College
in partial fulfillment of the
requirements for the
Degree of Doctor of Public Administration
School of Public Affairs and Administration

Western Michigan University
Kalamazoo, Michigan
April 1997
The purpose of this study was to determine whether there were changes in the quality of life of cancer patients aged 65 and older (N>488) following initial treatment for cancer. A Quality of Life conceptual model was developed. Quality of Life refers specifically to physical, social, and functional status. The study analyzed data from a larger longitudinal data set and compared data for patient's with prostate, breast, lung, and colon cancer at three observation points: (1) three month Recall, (2) after surgery and prior to chemotherapy or radiation (Wave I), and (3) fourteen weeks following surgery, during chemotherapy or completion of radiation (Wave II).

Changes in functional status were measured through Physical Function Subscale of SF-36, CES-D, and total symptom severity instrument.

The mean age of sample was 72.4 (S.D. = 5.5) years. The sample was predominately male (53.3%), 93% Caucasian, and 76.2% lived with someone. One-third of sample (33.3%) was diagnosed with prostate cancer, followed by breast, lung, and colon cancer. Surgery was the predominate treatment (31.3%). Most of the cancer patients did not experience substantial Activities of Daily Living limitations.
However, vigorous functioning, measured by a Physical Function Subscale of SF-36 showed a precipitous decline in means from a high of 2.60 (S.D. = .58) at Recall to a low of 1.61 (S.D. = .58) at Wave II. Possible answers ranged from one (limited a lot) to three (not limited). Three-quarters of the cancer patients reported two or more comorbid conditions. Data were analyzed using Repeated Measures Analysis of Covariance. There was a significant decline in physical functioning regardless of time ($p < .005$) and over time ($p < .008$). Decline in physical functioning was greater among the patient group with fewer comorbid conditions when compared to the patient group with two or more comorbid conditions. Cancer site had no effect on physical functioning. There was no difference in symptom experience and depression scores based upon the patient’s number of comorbid conditions.
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This dissertation is dedicated to my husband, Peter, and my daughters, Susan and Christy and loyal friend, Billy -- with all my love for without them, this dissertation would not have been completed.

Rosemary Clare Zivic
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CHAPTER I

INTRODUCTION

Statement of the Problem

Cancer patients have a number of needs which vary during the diagnostic and treatment phase of their illness. Cancer research has primarily studied the needs of a cancer patient at the end of the patient's life. Little is known about the care needs of a person diagnosed with cancer during the acute treatment phase of the illness. The purpose of this study is to explore the needs of the oncology patient aged 65 and older related to her or his quality of life as measured by the individual’s functional status at three observation points. The first observation was a patient's retrospective self-report concerning her or his physical functioning three months prior to the cancer diagnosis. The second observation, Wave I, occurred as soon as possible following surgery, or before the patient began chemotherapy or radiation. The third observation, Wave II, occurred 14 weeks following initial surgery for those patients having no adjuvant therapy. For those receiving medical therapies, the interview occurred in the midst of the cycle of chemotherapy or at the end of radiation.

The risk of cancer increases with age (Balducci, Lyman and Ershler, 1992, p.xi). However, due to improved treatment and diagnosis, cancer is now considered a chronic disease (Hileman & Lackey, 1990, p. 907). As a chronic disease, cancer
places many demands on a patient. The requirements of care increase when treatment of cancer shifts from the inpatient hospital setting to the home. The shift in care settings is due to shortened hospital days, changes in reimbursement patterns, and advances in technology and treatment.

Emphasis in reducing national health care expenditures has focused on providing care in the lowest cost environment, without decreasing the quality of care. Health care networks continue to face significant problems as they address the needs of the elderly in the United States. The problems facing health care networks include providing high quality care, yet remaining cost effective.

Care for patients age 65 and older is now focused outside of the traditional hospital environment, and more frequently at home. Responsibility of care for the patient diagnosed with cancer has also shifted from the hospital to the patient and the patient's caregiver(s). This changing onus of responsibility has precipitated specific needs for a person receiving care and treatment at home or in an outpatient setting.

As the population continues to age, the needs of the older adult living at home with a chronic disease will continue to escalate. Demographics of the aging population indicate that adults 65 years and older has greatly exceeded the growth rate of the population as a whole. The elderly population increased from 3 million in 1900 to 30 million in 1994. About 1 in 8 Americans were elderly in 1994. The U.S. Census Bureau projects that about 1 in 5 persons will be 65 and older by 2030 (Hobbs, 1995, p.52).

The aging of the population represents a concern for the prevention, diagnosis,
treatment, and outcomes of cancer therapy for persons aged 60-79 (Parker, Tong et al, 1996, p.13). Understanding the patients' needs related to cancer treatment, and how their sociodemographic characteristics, functional status, and symptom experience change over time, will assist in the formation of health care policy.

National health policy continues to focus on reducing health care expenditures while providing quality care. It is essential for public administrators to understand the needs of those aged 65 and older who experience a devastating disease, and whose treatment and care occurs largely at home and in outpatient settings.

Purpose

The purpose of this study was to explore the self-reported needs of persons aged 65 and older, diagnosed with one of four types of cancer. The needs of the patients were identified at three observations during the initial course of treatment. Functional health status was measured during each of the observation periods. Treatment modalities were defined as surgery, radiation, chemotherapy or a combination of therapies. Intervening variables included: the site of the cancer, the patient's health condition prior to diagnosis and hospitalization, and the functional health status during treatment.

Each patient in this study received an initial treatment for one of four cancers (breast, prostate, colo-rectal and lung). Utilizing a panel design, the study explored the needs of oncology patients age 65 and older over three time periods, the treatment prescribed, and most importantly, the treatment's impact upon the three domains of
the patient's quality of life measured by the three dimensions of functional status (1) physical, (2) mental, and (3) social.

This study analyzed data from a larger longitudinal study. The larger study is following incident diagnosis of breast, colo-rectal, lung, and prostate cancer (5R01NCA0915-0, "Family Home Care for Cancer--a Community Based Model"). It was anticipated that approximately 800 cases (200 cases each, of prostate, breast, colon and lung cancer) would survive the six month observation period. Patients were recruited into the study following an incident diagnosis of one of four cancer types diagnosed at one of the 23 community hospitals in the study. The hospitals were affiliated with the Michigan State University College of Medicine, College of Nursing, and the Cancer Consortium of Michigan State University.

The study provides new information about patients aged 65 and older, and their needs related to functional status measured three times during their initial therapy for cancer. The research expanded the original conceptual framework of the home care model of Given, Collins and Given (1988), and quality of life factors pertaining to the three domains of functional status (Schipper & Levitt, 1985, p. 117).

Statement of the Research Question

The premise for this research is reflected in this study's hypotheses where it was assumed that the functional health needs of a patient change from the initial diagnosis to post-cancer therapy. Patient need (the three domains of functional status
are physical, mental and social) was measured to ascertain if there was an improvement, decline, or no change for oncology patients aged 65 years and older, after receiving cancer therapy (surgery, radiation, chemotherapy, or any combination).

Incorporation of patient needs and treatment outcomes into clinical practice results in improved health care policy decisions, and assists health care planners to evaluate the needs of patients who have at least one of the four described cancers.

Research Question

What differences occur in the quality of life as measured by functional status for adults age 65 and older who undergo initial cancer treatments?

Research Hypotheses

Hypothesis I

Adults age 65 and older with a cancer diagnosis experience a progressive loss of physical functioning from baseline.

Hypothesis II

Adults age 65 and older with a cancer diagnosis experience a progressive loss of physical functioning from baseline.

Hypothesis III

Adults aged 65 and older with a cancer diagnosis experience a progressive
loss of physical functioning from baseline associated with cancer treatment.

Hypothesis IV

Adults age 65 and older who have two or more pre-existing comorbid conditions, report an increase in symptoms associated with cancer site and treatment when compared to those with one or no comorbid conditions.

Hypothesis V

Adults age 65 and older who have two or more pre-existing comorbid conditions report a greater loss of physical functioning associated with cancer site and treatment when compared to those with one or no comorbid conditions.

Hypothesis VI

Adults age 65 and older with a cancer diagnosis and two or more comorbid conditions attain higher depression scores on the CES-D scale when compared to those with one or no comorbid conditions.

Hypothesis VII

Adults age 65 and older who live alone experience a greater increase in symptoms associated with cancer treatment when compared to those who do not live alone.
Hypothesis VIII

Adults age 65 and older who live alone experience a greater loss of baseline physical functioning associated with cancer treatment when compared to those who do not live alone.

Significance

This study provides new information about patient self-reported care needs at three observations during the initial treatment for cancer relative to three domains of the patient’s functional status. According to Mor and associates (1992, p. 829), longitudinal studies investigated cancer patients during the terminal phase of their illness, but little is known about patient needs during and after the active treatment phase.

Accreditation and certification agencies, such as the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) and the Community Health Accreditation Program (CHAP) of the National League of Nursing (NLN), stress the importance of outcome-based quality improvement. Health care providers and third party payers anticipate that outcome-based quality improvement will be mandated by Medicare to monitor patient care within the next few years (Shaughnessy & Crisler, 1995, p.35).

The study contributes additional information to an expanding body of knowledge related to patient care need and outcomes for the oncology patient age 65
and older.

Definition of Terms

The following is a list of terms that are utilized in this research study:

Cancer

A general term for more than 100 diseases that involve uncontrolled, abnormal growth of cells that can invade and destroy healthy tissue (National Cancer Institute, 1990, p. 44).

Cancer Patient

A person aged 65 years and older who has been diagnosed with cancer and received initial treatment for one of four cancers—breast, colon, lung, and prostate.

Individual Characteristics

A set of factors associated with the person. These factors include: age, gender, education level, marital status, and race/ethnicity.

Patient's Baseline Functional Status

A set of factors associated with the patient's quality of life as measured by functional status prior to cancer treatment. These factors include the three domains of functional status which are physical, mental, and social.
1. **Physical Domain** activities of daily living, instrumental activities of daily living, vigorous physical functioning, and symptom experience;

2. **Mental Domain** affective measure of depression;

3. **Social Domain** care giver support and living arrangements.

Each component of the three domains of functional status may improve, deteriorate, or remain stable (Schipper & Levitt, 1985, p. 1,117).

**Physical Domain**

1. **Activities of Daily Living (ADL)** is the ability to perform basic self-care activities. Four activities of daily living (ADL) were measured for this study. They are dressing, bathing, toileting, and transferring.

2. **Instrumental Activities of Daily Living (IADL)** is a range of activities more complex than those needed for personal self-care. For this study, IADL's is assessed on how cancer may interfere with transportation, shopping, cooking and preparing meals, housework, and laundry.

3. **Vigorous Activity** is assessed on how cancer may interfere with aspects of vigorous mobility, such as: the ability to drive a car, run, lift heavy objects, bend and stoop, climb one flight of stairs, and walk a block unassisted.

4. **Symptom Experience** was specific symptoms related to the treatment for cancer. Symptoms vary due to the treatment. The most common symptoms include fatigue, nausea, vomiting, and diarrhea. Symptom experience also includes the severity which the symptoms were perceived.
Social Domain

1. Social support is defined as a relative, friend, or significant other of a care recipient, who provides unpaid but important components of care to an ill, infirm, or dependent care recipient in the home or community (Davis, 1992).

2. Living arrangement is defined as the patient's residence prior to the diagnosis of cancer. Living arrangement also includes changes in the patient's residence required because of the need for assistance.

Mental Domain

Depressive symptomatology is measured by the Center for Epidemiologic Studies Depression Scale (CES-D). Major components in the depression scale include depressed mood, feelings of guilt and worthlessness, psychomotor retardation, loss of appetite, and sleep disturbance (Devins & Orme, 1985, p.148).

Disease Profile

1. Site of Cancer in this study are those diagnosed in one of the following four areas—breast, colon, lung, and prostate.

2. Comorbid Conditions are illness or abnormal condition(s) (Anderson, Anderson & Glanze, 1994, p. 1,013) in addition to the diagnosis of cancer that compromises the patient's health status.
Treatment Therapy

The treatments prescribed for one of the four types of cancer (breast, prostate, colo-rectal and lung) include radiation, chemotherapy, surgery, or a combination of the three.

1. **Radiation Therapy** is the use of high-energy radiation that includes x-ray, an electronic beam, or cobalt-60 gamma rays that kill cells or keep them from growing and dividing (National Cancer Institute, 1990, p.3-9).

2. **Chemotherapy** is the use of anticancer drugs that destroy cancer cells by stopping them from growing or multiplying at one or more points in the cell cycle (National Cancer Institute, 1993, p.3).


Patient Care Need

Patient care needs for this study are the three domains of functional status.

Assumptions of the Study

For the purpose of this study the investigator makes the following assumptions:

1. There are certain pre-existing factors that influence functional status for the oncology patient, age 65 and older.
2. There are individual patient characteristics that contribute to the type of treatment modality utilized for the oncology patient age 65 and older, such as age, comorbid factors, site, and stage of cancer (although this study does not include this data).

3. Age, comorbid conditions, status at hospital discharge, the site of cancer, and deficits in functional status, living arrangements and care-giver support at baseline are predisposing characteristics that a person brings to the cancer treatment. These predisposing factors may influence the change in functional status.

4. The type of treatment is a contributing factor to changes in functional status.

5. All participants in the study will require a medical and/or surgical intervention during the study period.

6. The participants in the study will experience different needs related to their functional status during cancer treatment.

Overview of the Chapters

This study is organized into five chapters. Chapter I includes the introduction, background, statement of the problem, purpose, definitions of terms, hypotheses, limitations and assumptions underlying the research.

Chapter II provides a review of the literature relevant to the research questions, methodology, instrumentation, and statistical analysis. The conceptual framework and how that framework relates to the problem under study are delineated.
Chapter III describes the methodology and procedures. This chapter includes an explanation of the research design, sample population, setting of the study, instrumentation, data collection methods, and coding procedures.

Chapter IV presents the research findings. Chapter V provides a summary and interpretation of the results of this study, along with their implications for public policy and future research.
CHAPTER II

LITERATURE REVIEW

Overview

The scope of this review will include literature concerning elderly health care utilization rates, cancer incidence in adults age 65 and older, patient needs related to hospital discharge, care at home, functional status, and symptom experience associated with the side effects of the treatment protocol.

A conceptual framework was developed based upon literature related to quality of life and the Given's Home Care Model. A schematic representation of the conceptual model pertaining to the study's research questions is provided.

This chapter includes a review of research studies relevant to older adults who have been diagnosed with one of four types of cancer. It also explores how the treatment affects the person's functional status.

Health Care Utilization Rates for Adults Aged 65 and Older

According to Holloway and Pokorny (1994, p. 24), older adults are the greatest users of health services. Older adults consume 21% of all in-patient days and 50% of all acute care admissions. Adults age 65 years and older comprise 13% of the United States population. It is projected that by the year 2010, the aged 65 and
older cohort will account for 20% of the population. One out of every five persons in America will be age 85 years and older. The age 85 years and older cohort will become the fastest growing segment of the population (VanderMeer, 1993, p. 350).

In 1995, an estimated 99 million people in the United States had chronic conditions, characterized by persistent and recurring health consequences, lasting for periods of years (Hoffman and Rice, 1996, p. 8). Of these, 41 million elderly people were limited in their daily activities by their comorbid conditions. Hoffman and Rice (1996, p. 67) noted that by the year 2020, there will be 12 million people age 65 and older with a limitation in a major activity due to a chronic condition. There are significant implications for national health policies and health care expenditures related to an aging population.

Expenditures for health care have more than quadrupled since 1960. The average rate of health care spending is projected to grow 13.5% annually for the next five years according to a United States Commerce Department report (Wagner, 1994, p. 2).

As a result of efforts to reduce rising health care expenditures, the overall admission rate to community hospitals declined 1.1% for all age groups. Admissions for the 65 and older age group have continued to increase by 7.3%, while inpatient days have decreased by 2%. However, both admissions (-5.5%) and patient days (-10.8%) decreased for those under age 65 (Levit et al., 1994). Of the 64% of revenue from inpatient hospital care in 1993, public funding accounted for 56%, with the primary payers, medicare and medicaid, contributing 41.4% of the revenue (Levit, et
Conversely, home health care expenditures increased faster than any other category in four out of the past five years. According to Levit and associates (1994, p. 256), growth in spending decreased from 27.4% in 1992 to 23.8% in 1993. Home health care expenditures attributed to public financing grew with a large part of that increase due to the rise in Medicare payments from 53.4% in 1989 to 70.9% in 1993. Out-of-pocket spending for home health care decreased from 24.7% in 1988 to 20.8% in 1993.

According to Burner & Waldo (1995, pp. 231-32), Medicare is projected to pay an increased share of personal health care expenditures between 1993 and 2005. Personal health care expenditures covered by Medicare are projected to increase from 19.3% to 22.6% by the year 2005. The shift from hospital inpatient services to other services is projected to continue, due to Medicare’s prospective payment system.

Although the projected increase in the use of skilled nursing facilities and home health care is expected to continue, the anticipated growth is considerably lower than in the past ten years. By 2005, such growth is not projected to continue, due to a changing statutory payment system and managed-care plans.

It is anticipated that the needs of the older adult in the community will increase with the shift from hospital to outpatient care. The proportion of functionally dependent individuals is expected to reach 38% by the year 2000. While aging will account for 60% of the functionally-dependent individuals, 40% will be under 65 years of age. (Hafkenschiel, 1990, p. 16).
In summary, the literature reviewed concerning health care utilization rates for adults age 65 and older indicates that older adults are the fastest growing population, and are the highest users of health care. As the population ages, it is anticipated that the health care expenditures will also increase proportionately. In order to reduce national health care expenditures, there has been a shift from hospital care to care at home.

**Cancer Incidence in Adults Aged 65 and Older**

The incidence of cancer increases with age. According to Balducci, Lyman and Ershler (1992, p.xi), over 50 percent of all cancers occur in people aged 65 and older. The most common cancers in that age cohort are cancers of the breast, stomach, colon, rectum and prostate. The age-adjusted cancer death rate has decreased for those under age 55 and increased for those over age 55 (Balducci, Lyman, & Ershler, 1992, p. xi).

Estimates of new cancer cases for 1996 indicate that for persons aged 65 and older, the most common primary sites of invasive cancer are prostate, lung, breast and colo-rectal. The age 60 to 79 cohort have the highest probability of developing invasive cancers for all sites. Males aged 60 to 79 have 36% chance or a 1 in 3 probability of developing invasive cancers for all sites (Parker, et al., 1996, p. 13). Females aged 60 to 79 have a 22% chance or a 1 in 4 probability of developing invasive cancers for all sites (Parker, et al., 1996, p. 13).

Heart disease has remained the leading cause of death for all Americans.
Cancer remained the second leading cause of reported deaths. For adults aged 55 to 74, cancer was the leading cause of death. Heart disease was the leading cause of death for females in that age cohort. However, for the aged 75 and older cohort, cancer was the second leading cause of death for both males and females. The leading cause of death for both genders was heart disease (Parker, et al., 1996 p. 17).

The incidence of cancer is a major concern for African-Americans in the United States. Cancer is the second leading cause of death for the African-American population (Wingo, et al. 1996, p. 113). The five leading causes of cancer death for the African-American population are in descending order of prevalence: lung, colorectal, female breast, prostate, and pancreas (Wingo, et al., 1996, p. 114). Prostate cancer is the most commonly diagnosed cancer in African-American males, while breast cancer is the most common for females. African-Americans age 55 to 74 have a high incidence of mortality from cancer, more than any other age cohort for the African-American population (Wingo, et al., 1996, p. 119). Satariano and Associates (1986, p. 779) noted that African-American women are more likely to be diagnosed with more advanced breast cancer than Caucasian women. However, Caucasian women have a higher age-adjusted incidence rate for breast cancer than African-American women.

In summary, 50% of all cancers occur in people aged 65 and older. The most common cancers in that age cohort are cancers of the breast, stomach, colon, rectum and prostate. Prostate cancer is the most commonly diagnosed cancer in African-American males, while breast cancer is the most common for African-American
females. African-Americans age 55 to 74 have the highest incidence of mortality from cancer than any other age cohort for the African American population. Health care needs of the older adult also increase, due to the increased risk of cancer for the aging population.

Patient Need Related to Hospital Discharge

Weaver & Burdi (1992, p. 447) developed a model of discharge planning based on patient characteristics. Patient information was abstracted from medical charts by random selection (n=77). A stepwise discriminate analysis was conducted using four variables: the presence or absence of a care giver, medical care needs at discharge, functional status, and patient compliance. The results of the findings indicated that functional status, care giver availability, medical needs and patient compliance were all significant (p < 0.0001) outcomes.

Jones, Denson & Brown (1989, p. 643) studied 737 hospitalized elderly patients discharged home in suburban Chicago. Only 19% of the patients discharged home were referred by the hospital to community service agencies. In the immediate post hospitalization period, a large portion of the help was given by relatives in both personal care and housekeeping. The community referrals were reported most frequently for females living alone, who needed assistance with one or more basic activities of daily living (ADL's). Of the group, more than one-third (37.3%) required assistance with ADL's. Mamon and associates (1992, p. 155) examined the contribution of hospital discharge planning in meeting the needs of patients for care.
after their return home. A random sample of 919 admissions age 60 and over from five hospitals were studied to obtain information on characteristics of discharge planning during the patient's stay. Data was gathered through a patient questionnaire administered two weeks post-discharge, and through a review of the patient's medical record.

The findings of the study suggested that treatment-related benefits resulted when someone was responsible for the discharge planning of the elderly patient, such as a case manager. There were no reductions in activity limitations, other self-sufficiency needs, or overall needs. All the hospitals that participated in the study used several criteria for screening admissions to identify those who were at increased risk of needing more intensive and coordinated discharge planning. The criteria were: age (usually those 75 and older), living alone, inadequate health insurance, and a major disabling problem. Severity of illness, length of hospital stay and one or more inappropriate days of stay showed the strongest relationship to the receipt of formal discharge planning.

Morrow-Howell and associates (1991, p. 6) studied four independent variables in relation to discharge planning for elderly patients. The four constructs were the patient, social support, discharge planning process, and the discharge plan. The patient variables included demographic data (age, gender, race), living arrangements, insurance coverage, primary and secondary diagnoses, and mental condition at discharge. Social support variables were marital status, living arrangements post-discharge, relationship and age of primary care giver. Discharge planning process
variables included timeliness of the planners involvement with the patient, patient and family involvement, and the key decision maker in the discharge process. Variables related to the discharge plan were patient's destination post-discharge and the type of services provided. The findings revealed that all four sets of predictor variables were important in understanding the adequacy of discharge plans and identifying patient groups which are at risk due to less-than-adequate post-hospital care.

Branch and associates (1993, p. 24) evaluated descriptive information of 2,873 Medicare home health clients and their pattern of service utilization. The majority of the clients were women over age 65. Over one-fifth (21.9%) were over age 85. One of every three clients lived alone; nearly one of two lived with a spouse. Three of every four patients were discharged from the hospital and the vast majority of clients required mobility assistance. Clients in general had multiple limitations. The most prevalent diagnosis was malignant neoplasms, followed by heart disease and cerebrovascular diseases.

Hing (1994, pp. 1-2) reviewed the characteristics of elderly home health patients, and her findings were similar to Branch's (1993). The patients served by home health agencies were predominantly caucasian, female, and married. The most frequently noted activities of daily living where assistance was needed in bathing (56%), dressing (49%), transferring in or out of bed (27%), and eating (13%). In addition, 13% of current patients had difficulty controlling bladder functions. The most frequent instrumental activities involving daily living (IADL) requirements were assistance with light housework (38%), taking medications (27%), preparing meals
(25%), shopping for groceries and clothes (16%), using the telephone (4%) and managing money (4%).

Holloway and Pokorny (1994, p. 27) utilized a retrospective chart review to study the relationship between the functional status of the older adult and early hospital readmission (within 31 days after discharge). The discharge dependence findings indicated that in all instances except bathing, the dependence scores were higher, indicating greater dependence at the time of discharge than among the comparison group who were not readmitted in thirty days.

In the literature pertaining to patient care needs after hospital discharge, the researchers found several common characteristics. The majority of the patients were over 65 years of age and lived alone (Jones, Denson, & Brown, 1989; Mamon et al., 1992; Marrow-Howell et al., 1991; Branch et al., 1993). The presence of a change in functional status was also a significant indicator of patient care needs (Jones, Denson, & Brown, 1989; Weaver & Bryant, 1992; Branch et al., 1993; Hing, 1994; Holloway & Pokorny, 1994).

Social support variables, such as caregiver availability, were also significant (Jones, Denson, & Brown, 1989; Marrow-Howell et al., 1991; Mamon et al., 1992; Weaver & Bryant, 1992; Branch et al., 1993; Hing, 1994).

A change in health status or a disabling limitation was also noted as an indicator for patient care needs (Jones, Denson, & Brown, 1989; Marrow-Howell et al., 1991; Weaver & Bryant, 1992; Branch et al., 1993; Hing, 1994; Holloway & Pokorny, 1994). Branch et al., (1993) reported that the most prevalent diagnosis

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needing assistance was malignant neoplasms, followed by heart disease and cerebrovascular diseases.

The most frequently noted activities of daily living (ADL) were bathing, dressing, and transferring in or out of bed. The most frequent instrumental activities of daily living (IADL) were assistance with light housework, taking medications, meal preparation, and shopping for groceries. The vast majority of patients required mobility assistance.

**Patient Need Related to Care at Home**

The rapid growth in home health care has increased dramatically over the past 30 years, due in part to the aging population, and the increased public funding of home health services through Medicare and Medicaid reimbursement (Albrecht, 1990; Hing, 1994).

Hing (1994) published the characteristics of elderly home health patients from preliminary data of the 1992 National Home and Hospice Care Survey. Findings from the survey indicated that home health care is the fastest growing segment of the health care system. In 1991, expenditures for home health care were 29 percent higher than in 1990; 65 of every 1,000 Medicare enrollees received home health services, compared to 16 out of every 1,000 Medicare enrollees in 1974. In 1992, there were 929,500 elderly home health patients, who represented three out of four of the 1.3 million patients served by home health services.

The primary diagnosis of elderly home health patients on admission was heart
disease (15 percent), followed by diabetes mellitus (8 percent), arthropathies and related disorders (7 percent), cerebral vascular disease (6 percent), and malignant neoplasms (6 percent).

Technology that once was provided only in an acute care setting is now provided at home. Patients who normally would have remained in a hospital setting are discharged home earlier, and many patients have multiple needs.

In summary, preliminary data of the 1992 National Home and Hospice Care Survey indicated that home health care is the fastest growing segment of the health care system. Elderly patients diagnosed with a chronic disease are cared for at home instead of a hospital setting. Because patients are cared for at home, hospital expenditures have decreased, but home care expenditures have continued to increase.

Patient Need Related to Functional Status

Kane and Kane (1982, p. 21) define three domains of functional status (physical, mental and social). Physical functioning is measured through the ability to perform basic self-care activities. These self-care activities are known as Activities of Daily Living (ADL) such as bathing, feeding, toileting, and dressing. More complex instrumental activities of daily living (IADL) are cooking, cleaning, laundry, shopping, and other more complex tasks. The researchers included symptom discomfort, cumulative disease, and physiological dysfunction under this domain. Mental domain consists of both cognitive and affective functioning. Cognitive functioning was measured by the ability to assess orientation to time, place and
person. Affective measures determine the extent of depression or anxiety (p. 22).

The social domain included items such as social support and social satisfaction (p. 22).

Ware (1984) discussed measures of health status related to disease. Disease may affect a person's dependency on others relative to personal functioning. Ware defined personal functioning as the capacity to perform tasks such as self-care, mobility, and physical activities (p. 2,318). Ware also defined role functioning separately from physical functioning. Role functioning is the capacity to perform an individual's usual role such as employment, school work, volunteer activity or homemaking (p. 2,319). According to Ware, a larger number of factors influence a person's role.

It is not just disease that influences personal functioning. Ware (1984) cautioned researchers that functional status measures are often less sensitive to disease status than the less subjective ratings of health. Ware found that only about one-third to one-half of the persons in the general population with a chronic disease have any measurable limitations in personal or role functioning. Personal functioning was only weakly related to emotional functioning (p. 2,318).

Mental health, according to Ware (1984), is important because psychological distress and well-being are often altered by disease and its subsequent treatment. Ware noted that mental health measures must be separate from personal functioning conceptually and in terms of empirical testing. Disease may significantly affect a person's life without a corresponding change in physical functioning (p. 2,319).
Stewart and colleagues (1989) studied the functional status and well-being of patients with chronic conditions. Chronic conditions account for the majority of health care utilization and cost of care within the United States. Stewart noted that multiple studies focused upon the impact of chronic diseases on health care outcomes, but there has been little study of certain chronic conditions and their impact upon functioning and well-being.

Patients with nine chronic diseases were compared to patients without a chronic disease, with reference to variations in physicians' practice styles and outcomes. The nine diseases were hypertension, diabetes, myocardial infarction, congestive heart failure, arthritis, chronic lung problems, back problems, gastrointestinal disorders and angina. Function and well-being for both groups of patients were measured by the MOS Short-Form General Health Survey. The MOS Scale measured physical, social, and role functioning. Patient well-being through mental health, health perceptions, and bodily pain were also measured. Internal-consistency reliability coefficients ranged from .82-.88 (Stewart et al., 1989, p. 909).

The results of the study indicated that 29 percent of the total sample had two or more comorbid conditions. There was a high percentage of the sample that had at least one comorbid condition which ranged from 63 percent (hypertension) to 88 percent (angina) depending on the initial diagnosis.

Differences were noted for functional status and well-being for each chronic condition when the mean scores were adjusted to reflect the sociodemographic characteristics of the patient sample (p < .01). There was also substantial variation in
the health scores within each chronic condition. The variance in health explained by
the regression model (squared multiple correlation coefficients) was greater for health
perceptions (.29), physical functioning (.24), role functioning (.20), social functioning
(.14), mental health (.12), and pain (.14).

There was a difference among the nine chronic diseases studied with health,
function and well-being. Each disease appeared to have developed a specific profile;
however, the majority of variance in function and well-being was not predicted by the
presence of chronic disease. The researchers suggested that additional predictors such
as severity of disease, treatments, duration of condition, and style of medical care
need to be studied in order to explain the variance.

Leon & Lair (1990) studied the functional status of the noninstitutional elderly
in the 1987 National Medical Expenditure Survey (NMES). The researchers noted
that in acute conditions there is a link between diagnosis and functioning. There did
not appear to be a correlation, though, between a chronic condition and functional
status.

Data from the 1987 NMES indicated that approximately 21 percent of older
adults have at least one deficit with ADL’s, IADL’s, or walking. Among those age 65
and older, 12.9 percent, or 3.6 million, had difficulties with at least one ADL, or with
walking. Another 2.3 million, or 8.1 percent, had a need related to IADL. The most
common difficulty identified by the IADL was getting around in the community,
while bathing was frequently mentioned in the ADL. Most older adults needed
assistance from others to perform their ADL tasks. A far greater number of people
were entirely dependent upon someone else for IADL assistance. Functional
dependence was associated with age and gender.

Satariano, Ragheb, et al. (1990) examined physical functioning as reported by
middle-aged and elderly women with breast cancer. Breast cancer is the leading form
of cancer for older women. However, once diagnosed, they have relatively better
survival rates than those with other forms of cancers (p. M3). The authors noted that
functional status, if associated with health statistics, could be an outcome indicator in
conjunction with morbidity for women diagnosed with breast cancer. Functional
status was also strongly associated with quality of life.

A total of 422 newly diagnosed women, aged 55 to 84, with invasive breast
cancers were interviewed at three and nine months after diagnosis. Interviews were
also conducted with a control group (n=478) of similar age through random-digit
dialing. The results indicated that at three months after diagnosis, patients aged 55-64
and 65-74 reported greater difficulty than the control group in physical functioning
that involved completing tasks requiring upper-body strength. There was little
difference in upper-body strength in the 75-84 age group. Among the 55-64 age
group only pushing and lifting remained problematic (p. M9).

In summary, there are at least three domains of functional status that need to
be evaluated when assessing the quality of life of an individual, due to treatment,
disease or program. Although physical, mental and social domains are interrelated,
each domain may not be directly affected by disease or its treatment. Research
studies have addressed the relationship between chronic diseases, functional status,
and symptom experience. However, there has been little research in the area of cancer treatment related to the three domains of function, and its effect on the care demands or needs of the patient over time.

Patient Need Related to Cancer Treatment

A longitudinal study examined the impact of age, type of treatment and symptom experience that affected the physical functioning and the mental health of cancer patients age 50 years and older (n=111), by Given and colleagues (1994, p. 2128). Scales which measured physical health as it related to activities of daily living, instrumental activities of daily living, and the vigorous functioning items from the Medical Outcomes Study were used. Mental Health was measured by using the Center for Epidemiological Studies' Depression Scale.

Results of the study indicated that age, gender, treatment, and change of treatment had no impact on symptoms, functioning, and mental health at intake. Symptom experience predicted physical functioning and mental health over time. Furthermore, the primary site of cancer had no affect on age, symptom experience, functional limitation, or mental health.

Kurtz and associates (1994, p. 2071) studied the interaction of age, symptoms, and survival status on physical and mental health of patients with cancer and their families (n=208). The sample included patients 20 years and older who were diagnosed with a solid tumor or lymphoma. Measures included frequency and severity counts of patient symptoms, functioning, depression, frequency of caregiver
assistance, and caregiver reactions to care. Functional deficits were measured by the FS-36 from the Medical Outcomes Study. Patient depression was assessed with the Center for Epidemiological Studies' Depression Scale. The data was analyzed with an analysis of variance to test for significant differences between age and survival status. The results indicated that symptoms did vary significantly by survival status. However, age demonstrated no independent effect on symptom effect, symptom severity, patient depression, or functional dependence.

Cancer patients' needs were studied in longitudinal research by Mor, Masterson-Allen and colleagues (1992). The point prevalence of needs and unmet needs were documented at baseline, and at follow-up interviews after three and six months. The research focused on specific functional areas, which included met and unmet needs in the areas of personal care, home health tasks, and transportation among patients receiving outpatient cancer therapy (n = 629). Patients were selected for the study who were likely to have functional decline as a consequence of treatment or disease progression. The sample consisted of patients ages 21 and older with non-localized, recurrent, inoperable disease. The primary sites involved solid tumors of the breast, lung, head and neck, gastrointestinal, genitourinary, Hodgkin's disease and non-Hodgkin's lymphoma.

The needs assessment was based upon two functional assessment instruments (the Index of Activities of Daily Living and Katz's Index of ADL). The prevalence and relative risk of new need, new unmet need, and new symptom experience were calculated. The results of the study indicated that at baseline, less than ten percent of
the sample required assistance in personal care and home care tasks. At the end of the six month period, at least 19 percent of the sample required assistance in personal and instrumental tasks.

The patients' symptom experience affected their personal needs. Dyspnea was found to increase as the disease progressed. In addition, there was a higher likelihood of requiring personal assistance. Symptoms associated with chemotherapy (nausea and diarrhea) decreased from baseline to follow-up. Married patients appeared to have a decreased risk of acquiring need for personal care and household tasks. A cross-sectional analysis of the data suggested that physical condition and social support were related to unmet needs.

Patients receiving chemotherapy had fewer unmet needs for personal care than those receiving radiation as a treatment. The data suggested that patients who had higher need requirements did not receive enough assistance to consider their need met.

Kurtz and associates (1993, p. 276) studied patients 20 years of age and older diagnosed with a solid tumor (n=279). The study examined relationships between the loss of physical functioning, symptom experience, and comorbid conditions. The patients were surveyed at intake, and again at six months. At the study's inception, 79.4% of the study participants had received some form of cancer therapy. Chemotherapy was the primary cancer treatment (69.4%), followed by radiation therapy (9.4%), and surgery (8.1%). Patients completed a self-administered booklet at intake (Wave I) and again in six months (Wave II). Of the 279 patients who
participated in Wave I, 160 (57.3%) remained in the study at Wave II. Of the 119 patients lost between Wave I and Wave II, the predominant reason was death (75.6%), followed by refusal, hospitalization, and relocation (24.4%).

The McCorkle Symptom Distress Scale was used to measure nine symptoms commonly associated with cancer or cancer treatment: nausea, pain, poor appetite, weight loss, sleeping difficulties, fatigue, constipation, diarrhea, and vomiting. Comorbid conditions were assessed through self-identification of 15 common chronic conditions. Loss of functioning was measured using a scale from the Medical outcomes Studies.

Research questions were analyzed using multiple regression, step-wise regression, analysis of variance, and covariance. The results of the study indicated that age and comorbid conditions were significantly correlated. Age was significantly correlated with loss of function at Wave I but not at Wave II. Comorbid conditions were not significantly correlated with symptoms or loss of function at Wave I but was significantly correlated at Wave II. Loss of physical functioning at Wave I was significantly correlated with loss of physical functioning at Wave II. Comorbid conditions were significantly correlated with the under 60 age group but was not significant for the over 60 age group. Pain, fatigue, and weight loss were statistically significant predictors of loss of physical functioning.

Kurtz and colleagues concluded that symptom distress appears to be directly related to loss of physical functioning, thus affecting the quality of life. Although the older adult reported fewer symptoms, those reported were related to function.
In summary, the literature indicated that symptom experience predicted physical functioning and mental health over time. Primary site of cancer may have an impact on symptom experience, functional limitation, mental health, and patient needs. However, comorbid conditions and the progression of loss of physical functioning were not consistent among age groups. There were no studies that specifically focused on physical functioning and symptom experience of adults age 65 and older during the initial phase of cancer treatment. It is important to examine patient need, the change that occurs due to the treatment for cancer, the relationship between symptom experience, and the patient's functional ability. By doing so, we can begin to provide the optimal level of care, and determine the cost of services needed.

Theoretical Perspective

The conceptual framework for this study was based upon the construct of quality of life, as it relates to the patient's functional status and symptom experience. As such, it relies heavily on the Given and Given's Family Care Model (1995). This section of the literature review will address how the quality of life and the Family Care Model's theoretical perspective interface with oncology patients age 65 and older, during the treatment phase of their illness.

Quality of Life

Quality of life provides a theoretical perspective related to the patient's health
status. As early as 1902, Mark Twain wrote about the value of life in his essay the "Five Boons of Life" (Mark Twain Foundation, 1976). Since the 1960's, the era of the Great Society, there has been renewed interest in understanding the well-being of the population (de Haes & van Knippenberg, 1985, p. 167). To achieve this end, public policy analysts and health care researchers have promoted the construct of quality of life. Researchers have developed specific disease-related instruments and models that measure a quality of life construct (Schipper & Levitt, 1985; Holmes & Dickerson, 1987; Mor, 1987; Warner & Williams, 1987; Grant, Padilla, et al., 1990; Grady, 1993; and Santoro-Loose & Fernhall, 1995). Quality of life has been used to examine how an individual functions, the symptoms he or she experiences, and the consequences of the impact of a disease.

Schipper & Levitt (1985) define quality of life as a continuous variable that is ongoing throughout a person's life. The authors describe quality of life as a pattern of function and dysfunction over time. Quality of life is characterized by the authors as comprising four domains. They are: physical/occupational function, psychological state, sociability, and somatic discomfort (p. 1117). According to Schipper and Levitt, quality of life is looked at as a composite of factors. A longitudinal comparison between groups and individuals is appropriate in analyzing this model for quality of life studies. Such a comparison should be disease-specific, to detect differences in functional status.

Mor (1987, p. 2046) examined the correlates of the Quality of Life Index in three samples of newly diagnosed cancer patients (n=194), all of whom were
recipients of chemotherapy, and hospice patients. Physical, emotional, social, and
disease symptom characteristics were compared across samples. The measurement
constructs from three studies (National Hospice Study, Concrete Needs Study, Brown
Cancer and Aging Study) were included: physical functioning, depressive mood,
severity of pain experienced, severity of nausea experienced, disease characteristics
(diagnosis), social contact, social support, and demographics including age, income,
marital status, and living alone (p. 537).

Multiple regression analyses were performed to estimate the relative
importance of each possible explanatory factor and a two sample regression model
analyzed whether physical functioning was a predictor of different performance
levels.

The results of studying the relationship of quality of life to explanatory
constructs indicated that age was slightly negatively in relation to virtually all quality
of life elements. The authors interpreted this to mean that older adults manifested
slightly poorer quality of life. Gender, marital status, and living arrangements were
not related to quality of life in the three samples. Pain was strongly related to
functioning. The higher the pain intensity, the poorer the quality of life. Depressed
mood was strongly related negatively to quality of life, and more strongly related to
function and health elements than to psychosocial outlook. The strongest correlate
was function. The more functional the patient, the higher the quality of life scores.

Warner and Williams (1987) developed a meaning of life scale that pertained
to the psychological state for patients in hospice and rehabilitation programs. The 15
item scale measured sense of purpose, beliefs, and faith for 257 English and French patients in a long-term care facility in Montreal. A depression scale was not included in the study, although depression was noted to be high within this population of patients.

Santro-Loose, & Fernhall (1995) examined the effect of a cardiac rehabilitation program on the difference in quality of life among male and female cardiac rehabilitation participants. The Sickness Impact Profile (SIP) was used to measure the quality of life of patients with a chronic disease, including cardiac disease.

Variables such as age, educational level, socioeconomic status, and cardiac function influenced quality of life. The study dealt with men and women (n = 103) of similar age and documented cardiac disease who were enrolled in a cardiac rehabilitation program. The results of the study indicated that women who participated in the cardiac rehabilitation program experienced poor quality of life, when compared to men with significantly greater impairment in emotional behavior and psychosocial functioning (p. 230).

Grant, Padilla, Ferrell and Rhiner (1990, p. 260) noted that quality of life is reported as an outcome variable in the evaluation of cancer treatments. The researchers defined quality of life in three domains—physical well-being, psychological well-being, and interpersonal well-being. Psychological well-being was the most frequently studied domain. Instruments used to measure quality of life have distinct purposes, depending upon the subject examined. The authors noted that the
purpose of quality of life research should include: responses to different types of
cancer, symptom management, response to different treatments for the same disease,
and the effects of rehabilitation.

Ware (1984) conceptualized the impact of disease on health status. Ware
defined health as "completeness" and connoting proper function (p. 2317). The
author noted that the challenge is to identify and understand the course of the disease,
and its impact on health status and quality of life. Ware conceptualized a disease
impact model that considers how individuals experience disease, treatment, and the
changes in health over time (p. 2317).

Bloom (1984, p. 2323) wrote in answer that Ware (1984) should be defining
response to illness instead of health status. The author noted the importance of a
person's subjective reality. Bloom purported that there is a difference between being
diagnosed with a life-threatening illness, and actually experiencing the disease.
Bloom found that individuals not only define themselves as ill, but begin to behave as
if they were ill.

The ideal strategy for measuring the impact due to cancer was suggested by
Bloom (1984, p. 2325). Standardized scales of the model should be measured at two
or more points: the first, ideally at pre-diagnosis, and the second, early after
diagnosis. Bloom suggests that using a comparison group would rule out changes
that were not due to cancer.

Levine (1991) noted that quality of life led to debate because the concept is
abstract. Quality of life, according to Levine, encompassed the physical, social and
emotional health of the patient. Three major purposes exist for using quality of life as a theoretical framework in clinical trials and research. They are to: (1) discriminate different health states between populations; (2) predict patient outcomes; and (3) to evaluate a therapeutic or diagnostic test over time (Levine, 1991, p. 106).

In summary, quality of life, although an abstract construct, has been used in research to connote life satisfaction. Researchers have used quality of life as a theoretical basis to measure chronic diseases, such as cancer, regarding the effectiveness of treatment, functional ability, and symptom experience. Ideally, measuring disease impact should be at pre-diagnosis, immediately after diagnosis, and at several points during the course of illness.

**Family Care Model**

The Family Care Model was based upon a decade of research. The original model (Given, 1995, p. 930) was developed from a caregiver grant ("Caregiver Responses to Managing Elderly Patients at Home," Grant No. R01AGO6584 from the NIA). According to Given (1995), the model was later modified from focusing on caregiver responses to patient symptom management. Two additional studies added to the model's development. "Rural Partnership Linkage and Cancer Care" (Grant No. R01 CA56338) examined nursing interventions for state-of-the-art cancer care in rural areas. "Family Home Care For Cancer: A Community Based Model" (Grant No. R01 NR/CA01915) studied the inception cohort of elderly patients with cancer (Given, 1995, p. 931).
The model focused on family caregiving for those with chronic illness and health problems. Integral components of the model included caregiver characteristics, patient characteristics, patient status in the course of the illness, severity of illness, comorbid conditions, treatment, demands of care, caregiver involvement in the tasks of care, family and informal support, formal care, outcomes, caregiver health status, patient's functional and mental health status, utilization of formal services, and formal and informal costs of care (Given, 1995, p. 931). An element of the family care model addressed the nature of disease and subsequent treatment (Given, 1995, p. 933).

Given (1995, p. 933) depicted patient characteristics (age, gender, marital status, role obligations, and comorbid conditions) in the model. Age may affect the response to the diagnosis of cancer and available support. Both gender and living arrangements may affect the role responsibility and availability of caregiver support. Symptom experience (number of symptoms and functional dependencies) may influence response to care and symptom distress.

Schematic Representation of the Conceptual Model

The schematic representation of the hypotheses is represented in Figure 1. The basic premise of the hypotheses, visually represented, is that the needs of a patient change from the intake interview at diagnosis, and again following initial cancer therapy. Two dimensions of patient need, functional status and symptom experience, were measured to ascertain if there had been a self-reported improvement,
Figure 1. Outcomes Related to the Quality of Life Oncology Patients Aged 65 and Older Following Initial Cancer Treatment.

Source: Adapted from the Family Care Model (Given, 1995, p. 930).
decline, or no change, for the oncology patient age 65 and older, after receiving cancer therapy (surgery, radiation, chemotherapy, or any combination thereof).

The research model was based upon the elements of Ware's theoretical construct of the impact of disease on the quality of life and on the Family Care Model (Given, 1995). It is within this context that the study examined how cancer site, comorbid conditions, the three domains of functional status (physical, mental and social) and the type of cancer therapy interacted to produce care demands or needs of the patient. The schematic model hypothesized that there are sequential, time-related requirements pertaining to patient-care demand and patient needs. The arrows indicated a relationship between all elements of the model that directly and indirectly affect these elements.

The baseline data consisted of patient characteristics (age, gender, marital status, race, and education), social/environmental characteristics (living arrangements and caregiver support), and patient health characteristics (functional status and comorbid factors). All three elements of the baseline data were reciprocal not only in

The arrows show that once treatment therapy was instituted, there was a relationship between all variables. The post-treatment impact on the patient (quality of life) was related to the three domains of functional status. The arrows following Wave II indicated a circular relationship. An individual either returned to baseline or continued with the treatment process.

In summary, the study looks at the impact of treatment on the three domains
of function. The post-treatment timeframes were measured for changes from baseline to Wave I and Wave II observations. Quality of Life could be positively or negatively affected by the patient, social/environmental, health characteristics, disease profile and type of treatment instituted.

Based upon the literature reviewed, additional research was indicated to determine how the physical, mental, and social functioning effect on the Quality of Life for those age 65 and older who are diagnosed with one of four cancer types.
CHAPTER III

METHODOLOGY

Overview

A panel design was proposed to examine patient need at three observations during the initial treatment phase of incident cancer. The three domains of functional status (physical, mental and social) will be examined for oncology patients who are aged 65 years and older.

The independent variables for the study are patient characteristics (age, gender, marital status, race/ethnicity, and education), baseline functional status (physical, mental and social domain), patient disease profile (comorbid factors, and cancer site), and treatment therapies for cancer (surgery, chemotherapy, radiation, or a combination of these therapies).

The dependent variables comprise the patient’s current health status or outcome after cancer treatment (the three domains of functional status—physical, mental and social).

There are two types of covariables for this study; they are time independent and time dependent. Time independent measures are those that do not vary over the observations. The time independent measures are age (month and year of birth), gender, education, and race/ethnicity. The time dependent measures that will vary
over the observations include the three domains of functioning (physical, mental and social), comorbid conditions, and treatment status.

The study used secondary data from a larger panel study. The larger study followed incident diagnosis of breast, colo-rectal, lung, and prostate cancer (Given & Given, 1994) remains in progress. The research project was a collaborative effort between Michigan State University's (MSU), the College of Nursing (CON), College of Human Medicine (CHM), Departments of Family Practice, Medicine, and Surgery, the Cancer Center at MSU (CCMSU), and the MSU Cancer Treatment Center (MSUCTC).

The following is a discussion of the methodology and procedures that were utilized in this study. The sample, collection sites, questionnaire, and human rights protection procedure are delineated.

Pilot Studies

Two pilot studies were conducted. The first pilot study (Zivic, Unpublished Manuscript, 1994), The Characteristics of Patients and the Key Decision Makers in Home Care Referrals (n = 20), examined key patient attributes that would indicate the need for a home care referral while the patient was hospitalized. The results of the study indicated that severity of illness and the patient's diagnosis were the overriding factors that determined a home care referral. This was based on interviews with hospital discharge planners and case managers.

A second pilot study, (Zivic, Unpublished Manuscript, 1995) entitled Post-
Surgical Cancer Patient Attributes Related to Hospital Readmission Within One Month Post-Discharge, explored the relationships between post-surgical cancer patient attributes, and hospital readmission rates within one month post-discharge.

The data for the pilot study was derived through a secondary analysis obtained with permission from the Family Home Care for Cancer—A Community-Based Model Grant (No.2R01 NRCA01915-03A3, Given & Given, 1994). A sample (n=86) from the first Wave (six weeks post discharge from the hospital) consisted of patients with one of four incident cancers (breast, colo-rectal, prostate, and lung). The age range of subjects was 56-90 years of age with a sample mean of 70.4 years. Male subjects comprised 58% of the sample and 42% were female. Patient's age (p = .05) was a significant predictor of readmission. The variables examined included the number of deficits in patient's activities, instrumental activities of daily living, and the number of health care activities the patient required per day.

Panel Quasi-Experimental Design

A panel quasi-experimental design was employed for the present study. The following was a symbolic representation based on the notional system adopted by Campbell and Stanley's classic monograph on Experimental and Quasi-experimental Designs for Research (1963).

\[ O \times O O \]

The symbolic representation indicated a time-series design. According to the notation, the “X” represented an exposure of a group to an experimental variable or
event. The event in this study was an initial treatment for cancer. The effects of these exposures were measured. An "0" represented an observation or a measurement (Creswell, 1994).

Sample

The target population consists of patients in their 65th year and older who were discharged from the hospital during the years 1994 and 1995. Each patient in the study received an initial treatment for one of four types of cancer—prostate, breast, colo-rectal, and lung cancer. The projected sample size is 800 persons (200 patients for each type of cancer) who survived the six months observation period. The individuals agreed to participate in the study (Given & Given, 1994).

Sample Inclusion Criteria

Criteria for inclusion of patients in the study were: (a) recently admitted to an acute care setting with a diagnosis (an incident case) of either breast, colo-rectal, lung or prostate cancer; (b) no hospitalization within the 60 days prior to the admission for the cancer diagnosis; (c) 65th year and older; (d) received some form of treatment beyond palliative therapy; (e) english-speaking; and (f) cognitively intact.

Data Collection Site

Hospitals in the State of Michigan affiliated with the College of Medicine and the Cancer Consortium of Michigan State University were selected as data collection sites.
Data Collection Procedures

The patients were initially contacted in the hospital at the time when their cancer was first diagnosed; the medical record was then examined retrospectively for the patient's functioning prior to hospitalization. The focus then shifted to the transition period, which included the patient's status at discharge and then at two observation points. The first observation occurred either following surgery or before chemotherapy and radiation. The second observation occurred at 14 weeks following surgery or during a point where the patient was well into receiving adjuvant therapy.

Participants in the study were informed that they would be taking part in a longitudinal study that would involve several encounters by telephone. They were told that participation was entirely voluntary and that they could withdraw at any point. Confidentiality was explained to the participants, and informed consent forms were signed.

Data Collection During Hospitalization

Nurse recruiters were identified to approach patients during hospitalization. The nurse recruiters, following criteria for accrual, reviewed medical records and identified patients eligible for the study. Patients were enrolled in the study while they were still in the hospital. Participant consent forms were forwarded to Michigan State University (MSU). The participants were then tracked up to 52 weeks by the
MSU research team. The patients were recruited through 23 community hospitals affiliated with CHM, CON, AND CCMSU. The nurse recruiter then explained study to the patients, distributed a brochure, and obtained their consent. Once consent was obtained by MSU, participants were then assigned to interviewers for data collection.

Training of Data Collectors

Nurses, medical students, and epidemiology students were recruited and trained as data collectors by the principal investigators. The interviewers participated in elaborate training that included the use of protocols and training manuals. The interviewers practiced taping interviews with each other, with the principal investigators, and with the initial client. The client interviews were audited by the principal investigators (Collins, Given, Given & King, 1988).

Quality assurance measures included submission of one taped interview per month to insure that protocols were followed. Monthly booster sessions regarding protocols were held. Ten percent of the records of the actual interviews for each data collector were checked by the principal investigators or their designees. The monitoring assured that protocols relative to specific timeframes for calls were followed.

Operational Definitions of Variables

The following is a list of terms and definitions that were employed in this research study:
Patient With Cancer

A patient in their 65th year and older who has been diagnosed with one of four types of cancers—breast, colon, lung and prostate.

Cancer Treatment Therapy

The treatments prescribed for one of the four types of cancer (breast, prostate, colo-rectal, and lung) include: surgery, radiation, chemotherapy, or any combination thereof.

Progressive Loss of Physical Function

A progressive loss of physical function means a deterioration in the ability to perform personal self care, activities more complex than self care, and vigorous activity due to cancer site and treatment.

Patient Observations

Patient observations included a hospital interview, two telephone interviews and a self-administered questionnaire sent to the patient following the telephone interview.

1. Hospital interview consisted of pre-enrollment and signing of consent form.

2. Observation I was a patient's retrospective self-report concerning their physical functioning three months prior to their cancer diagnosis.
3. Observation II data was collected by a telephone interview as soon as possible after the patient was discharged from the hospital. The query was done either following surgery or before chemotherapy or radiation. The telephone interview lasted between 45 and 90 minutes.

4. Observation III occurred 14 weeks following surgery for those patients having no adjuvant therapy. This was calculated by adding six weeks—the time from surgery to the time they would have begun adjuvant therapy—and then by adding eight weeks which would have put them well into their therapy. Patients receiving therapy were interviewed in the midst of their cycle of chemotherapy or at the end of radiation (eight weeks after initiating radiation or chemotherapy). It was at this point that it was expected that there would be the maximum impact upon the patient.

5. Self-administration booklet (SAB) was sent to the patient approximately one week after each telephone survey. The patient completed the survey and returned the questionnaire within two weeks of receiving the document. The patient self-administration instrument surveyed the patient health status. It measured their current feelings (CES-D), symptom experience, type of cancer therapies utilized, community service attitude inventory, and the patient's view on life.

Patient Characteristics

Sociodemographic data was collected at Wave I. The parameters calculated in the sociodemographic section included: age (birth date), gender, marital status, education and race/ethnicity (items #1, #2, #3, #4, and #5).
**Patient Profile**

The patient profile defined for this study included the site of cancer and comorbid conditions.

1. Site of cancer was determined with the initial interview and is discussed in item #4, in the section entitled “Physical Health Patient”.

2. Comorbid Conditions were measured using a list of conditions found in research by Given & Given (1994) and Satariano et al. (1990). Comorbid conditions were operationalized as scores on relevant portions of the section entitled “Physical Health Patient” at Wave I. The patients were asked fourteen questions pertaining to certain health related conditions (1 = yes, 2 = no, and 3 = unsure or refused). The health related conditions were hypertension, diabetes, cancer, chronic obstructive lung disease, heart disease, stroke, emotional problems, arthritis, fractured hip, urinary incontinence, cataracts, vision and hearing loss, and other health problems (see Appendix A).

**Type of Treatment**

The type of treatment for the patient (surgery, chemotherapy, radiation, or a combination) was operationalized as scores on relevant portions of the “Service Utilization” section (see Appendix A).

1. **Surgery** was determined by two questions (items #1 and #1a) which indicated if the patient visited a surgeon and the date of surgery.
2. **Chemotherapy** was determined by one question (item #2) which indicated if the patient visited a medical oncologist for her or his cancer treatment and the date treatment began.

3. **Radiation Therapy** was determined by one question (item #3) which indicated if the patient visited a radiation therapist/oncologist for cancer treatment and the date treatment began.

4. **Combination Therapies** for the person's cancer treatment included three questions (items #1, #2, and #3). Combination therapy may include surgery, radiation, chemotherapy or a combination thereof.

**Physical Domain**

The physical domain for this study was defined in terms of activities of daily living, instrumental activities of daily living, vigorous functioning and patient symptom experience. These may be found in the sections entitled “Ability to Perform Activities”, “Instrumental Activities of Daily Living For the Patient”, “Physical Function Subscale of SF-36”, and “Patient Symptom Experience” in Appendix A.

**Ability to Perform Activities**

Three subscales were developed to measure function among the elderly. The first subscale contains five indicators of dependencies in personal care (eating, bathing, toileting, transferring and grooming). The second subscale assessed the
patients' mobility (walking inside the house, transferring in and out of bed, and lifting and turning in bed). The third subscale measured the ability to perform vigorous activity.

1. **Activities of daily living** measured six basic self-care activities in the “Ability to Perform Activities” section. They included: dressing (items #1a, #1b), bathing, eating (items #2a, #2b), bathing (items #3a, #3b), walking inside the house (items #4a, #4b), toileting (items #5a, #5b), and transferring in and out of bed (items #6a, #6b).

2. **Instrumental Activities of Daily Living (IADL)** is a range of activities more complex than those needed for personal self-care. Physical functioning was operationalized using scores from the modified version of two scales, the Medical Outcomes Study Health Status Questionnaire-SF36 (Stewart, Hay & Ware, 1988), and the Older American Resource Scale (Filienbaum & Smyer, 1981).

   For this study, IADL’s were assessed on how cancer may have interfered with aspects of mobility in the “Ability to Perform Activities” section. These aspects were: transportation (items #7a, #7b), laundry (items #8a and #8b), shopping (items #9a, #9b), housework (items #10a and #10b), and cooking and preparing meals (items #11a and #11b). Each functional ability was assessed as (3) Yes, limited a lot, or (2) Yes, limited a little, or (1) No, not limited at all.

3. **Vigorous Activity** section contained nine questions. The questions pertained to the amount of moderate and vigorous activity the patient was able to perform three months before the cancer diagnosis, and any current health limitations
on these activities. The questions included: moderate activity (item #a), vigorous activity (item #b), lifting (item #c), climbing several flights of stairs (item #d), climbing one flight of stairs (item #e), bending, kneeling, stooping (item #f), walking more than one mile (item #g), walking several blocks (item #h), and walking one block (item #i). Each activity was reported on a range from “not limited”, “limited a little”, to “limited a lot”. The scores ranged from one to three. Physical Functioning Subscale was operationalized using scores from the modified version of the Medical Outcomes Study Health Status Questionnaire-SF36 (Stewart, Hay & Ware, 1988).

4. **Symptom Experience** is measured by 37 symptoms for the 65 years and older cancer patient. The symptoms are associated with the type of cancer and treatment. The 37 symptoms (items 1-37) included: nausea (item #1), pain (item #2), trouble sleeping (item #3), fatigue (item #4), difficulty breathing/short of breath (item #5), diarrhea (item #6), coordination problems (item #7), vomiting (item #8), difficulty concentrating (item #9), weakness (item #10), dizziness (item #11) numbness, tingling, loss of feeling (item #12), poor appetite (item #13), weight loss (item #14), fever (item #15), cough (item #16), dry mouth (item #17), constipation (item #18), frequent urination (item #19), dehydration (item #20), mouth sores (item #21), itching (item #22), leaking of urine (item #23), urgent need to urinate (item #24), hot flashes (item #25), breast tenderness (item #26), waking up at night to urinate (item #27), difficulty swallowing (item #28), sweats and night sweats (item #29), lack of sexual interest (item #30), bleeding and bruising (item #31), altered taste (item #32), mood changes (item #33), vaginal dryness (women only) (item #34), arm
swelling (item #35), limitations in arm movement (item #36), and leg swelling (item #37).

5. **Symptom Experience Index** was reported as to the presence and severity of the symptoms. Subjects were asked if they experienced the symptoms in the last two weeks (1 = yes, 2 = no) and, if yes, how severe were the symptoms. The range of severity was one to three. The severity of symptoms was reported as mild (1), moderate (2), and severe (3).

**Mental Domain**

Depressive symptomology was measured by the Center for Epidemiologic Studies Depression Scale (CES-D). Major components of the depression scale included depressed mood, feelings of guilt and worthlessness, psychomotor retardation, loss of appetite, and sleep disturbance (Devins & Orme, 1985, p. 148).

Mental health was measured at Wave I and Wave II. Each of the 20 items in the CES-D entitled “Current Feeling” asked the subjects if they experienced the “feeling” within the past month, almost all the time, most of the time, some of the time, and rarely or none of the time.

**Social Domain**

The social domain for this study included living arrangements. Living arrangements was assessed at Wave I and at Wave II. One question addressed living arrangements (item #8). The question asked “Who lives in the household with you”?
Instruments Used in the Study

Physical Domain

Physical domain in this study was measured utilizing three modified instruments: the Medical Outcome Study--FS36 (Stewart, Ware, & Brook, 1981), the OARS Multidimensional Functional Assessment Questionnaire (Filenbaum & Smyer, 1981), and the Symptom Experience Index (Given et al., 1994, Appendix A).

1. **Functional status** was measured by the modified version of two scales, the SF36 and OARS. The SF36 is a 36 item, self-reporting multi-item scale measuring each of eight health care concepts (Ware & Sherbourne, 1982, p. 474). The health concepts included in the survey focused on mobility and the ability to perform certain tasks. The SF-36 is the overall scale. Nine items of the SF-36 were used as a modified physical functioning subscale, scoring for the SF-36 is standardized against 100. The nine items measured how cancer may have interfered with aspects of vigorous functioning, such as climbing stairs, transferring in and out of bed, ability to drive a car, run, lift heavy objects, bend and stoop, climb one flight of stairs, and walk a block unassisted were used for this study (Given et al, 1993, p. 279).

Psychometric testing validation, through components and factor analysis, was completed, and this tool was found to be psychometrically sound (Stewart, Hay & Ware, 1988). Low scores on the Physical Function Subscale of the SF-36 indicated a limitation in the area; high scores indicated that no problems were noted (Ware and Sherbourne, 1982, p. 475).
2. Oars Multidimensional Functional Assessment Questionnaire (Filenbaum & Smyer, 1981, p. 429) consisted of counting the number of dependencies in four activities of daily living (ADL): dressing, eating, bathing, and toileting (Given et al., 1993, p. 279).

3. Symptom experience was measured by the Symptom Experience Index (Given, et al., 1994). It included 37 symptoms that were rated for severity by the patient. Patients were asked to report the presence of symptoms, and the severity of each symptom on a three-point scale from moderate to severe. This tool has not been widely used or tested. The tool is a modified version of the McCorkle Symptom Distress Scale (McCorkle & Young, 1978). This scale has been widely used and tested for reliability based on internal consistency using Chronbach's coefficient alpha (McCorkle, 1987). In their study of 111 patients, Given et al. (1994) assured psychometrically sound measures of symptom experience. This was done by examining the bivariate correlations among the symptoms, and between each symptom and the physical functioning score.

4. The McCorkle Symptom Distress Scale contained items which could indicate symptoms of depression (appetite, fatigue, concentration, and general outlook). To reduce multicollinearity between the symptom scale and the patient's depression scale, these items were removed (Given et al., 1993, p. 2132; Kurtz et al., 1995, p. 840). The symptoms remaining in the scale used by Kurtz were cough, bowel problems, pain, severity of pain, nausea, and severity of nausea. The reliability coefficient for the reduced symptom scale was 0.71, compared to 0.83 for the full

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Mental Domain

Mental Domain in this study was measured by the Center for Epidemiologic Scale, CES-D (Radloff, 1977). The 20 item scale has been used for screening patients for symptoms of depression, especially when focusing on non-psychiatric populations. The CES-D has been validated by several authors including Given et al. (1993), Roberts and Vernon (1983), and Meyers and Weisman (1980). Each of the 20 items on the CES-D scale was scored on a scale from one to four. The composite score was computed by averaging the scores for the 20 items on the scale. The scores could range from 0 to 60 (Given et al., 1994, p. 2133).

A total CES-D score of 0-15.5 could be interpreted as "not depressed"; 16-20.5 may indicate "mild depression"; 21-30.5 may indicate "moderate depression"; and a score of 31 and higher may indicate "severe depression" (Devins & Orme, 1985, p. 149).

Reliability and Validity

Given & Given (1994) developed and tested the questionnaires for this study. The researchers developed three subscales that measure function among the elderly (Given & Given, 1994, Appendix 3). Given and Given (1994) measured co-efficient alpha for each of the subscales evaluating function and their interscale correlations. The interscale correlations were measured in previous research with alzheimer...
disease, stroke, and chronic degenerative diseases. Coefficient alpha ranged from .72 to .84 for five items on self-care. Coefficient alpha for the four item mobility ranged from .83 to .84. Coefficient alpha for two item continence ranged from .77 to .84 (Given & Given, 1994, Appendix 3).

The interscale correlations from previous research for physical function and symptom limitations ranged from .26 to .42 (Given & Given, 1994, Appendix 3). It was anticipated that there would be a lower coefficient alpha score with the patient symptom experience scale, because the scale measures multiple body systems.

Threats to Internal Validity

In this research study possible threats to internal validity were:

Telephone surveys are less effective with sicker patients, as they are not able to respond to the questions.

Incomplete or no responses to the Center for Epidemiologic Studies Depression Scale (CES-D) was found in 60% of the returned Patient Self-Administered Booklet.

Statistical Analysis of Data

The data for the study was analyzed to determine if there was a difference in the three domains of function (physical, mental and social) among those who received cancer treatment (surgery, radiation, chemotherapy or a combination of these therapies) over a six month period. Numbers, percentages, means, and standard
deviations were used to compare participants according to their sociodemographic characteristics.

**Analysis of Variance and Analysis of Covariance**

A Repeated Measures Analysis of Variance (ANOVA) was employed to test the significance of differences between the means. The statistic computed in an analysis of variance was the F-ratio. According to Norusis (1985, p.257), a repeated measures design is used when the same variable is measured on several occasions. Variability due to differences between subjects can be eliminated from the experimental error. Hypothesis testing for this design is similar to a single factor design. Each effect is tested individually. Both multivariate and univariate results can be obtained for each effect. When a factor has only two levels, there is one contrast for the effect and the multivariate and univariate results are identical (p. 270).

Analysis of variance decomposes the total variability of a set of data into two components: (1) the variability resulting from the independent variable and (2) all other variability, such as individual differences (Polit & Hungler, 1987, p. 408).

Analysis of covariance (ANCOVA) was also employed to statistically remove the effect of the extraneous variables on the dependent variable (Polit and Hungler, 1987, p. 193). With the variability of the extraneous variables controlled, there is a more precise estimate on the effect of the dependent variables. Variation between treatment groups is contrasted with variation within treatment groups to yield an F-ratio. If the difference between groups receiving different treatments is large relative...
to random fluctuations within groups, then it is possible to establish if there is a systematic difference (Polit & Hungler, 1987, p.408).

Protection of Human Rights

The main longitudinal proposal, Family Home Care For Cancer--A Community-Based Model, was reviewed by Michigan State University, University Committee on Research Involving Human Subjects and approved on July 11, 1994 (Appendix C).

This study was approved by Western Michigan University's Human Subjects Committee under the exempt category of research on June 19, 1996. The approval was based upon the use of secondary data without identifiers (Appendix B).

Confidentiality and anonymity were maintained by the use of number coded raw data. All data were entered in the computer as raw numbers and analyzed in aggregate form.

Overview of Remaining Chapters

Chapter III has presented a discussion of the methodology utilized in this study. That discussion detailed the research design, sample, collection site, collection data, questionnaire, and statistical analysis.

In Chapter IV the sample will be described in relation to findings reported with respect to the hypotheses. All sociodemographic and clinical characteristics will be indicated. Findings will be reported concerning the sociodemographic
characteristics and functional status of the subjects.

Chapter V will discuss the study findings and the implication of the findings for public administration, health planners policy and future research.
CHAPTER IV

DATA ANALYSIS

Introduction

The sociodemographic and clinical characteristics of the sample will be described in this chapter. In the first section, the results will be presented and analyzed, through the provision of both descriptive and inferential statistics. In the final section, the hypotheses will be tested and discussed.

Results

Sample Characteristics

The sample of cases ready for analysis consisted of 488 as of August 1996. For a case to be included in the analysis, at least one of the major outcome variables had to be available in the subset of cases that were diagnosed with breast, colo-rectal, lung, and prostate cancer between 1994 and 1996. Cases in which the data were missing were not included in the analysis. The outcome variables in the subset of cases included two symptom and symptom severity scales, three physical functioning scales, and two depression scales.

The sociodemographic variables are depicted in Table 1. The mean age for the sample was 72.4 (S.D. = 5.5) years. Over one-half of the sample (53.3%) was male,
### Table 1
Age, Gender, Race, Marital Status, Living Arrangements and Education of Sample ($N = 488$)

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</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th>Variables</th>
<th>n</th>
<th>M</th>
<th>SD</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marital Status:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single/Never Married</td>
<td>9</td>
<td></td>
<td></td>
<td>2.2</td>
</tr>
<tr>
<td>Married</td>
<td>271</td>
<td></td>
<td></td>
<td>65.1</td>
</tr>
<tr>
<td>Divorced/Separated</td>
<td>31</td>
<td></td>
<td></td>
<td>7.5</td>
</tr>
<tr>
<td>Widowed</td>
<td>105</td>
<td></td>
<td></td>
<td>25.2</td>
</tr>
<tr>
<td>Total Sample</td>
<td>416</td>
<td></td>
<td></td>
<td>100.0*</td>
</tr>
<tr>
<td>*Missing Value</td>
<td>72</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living Arrangements:</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Lives Alone</td>
<td>116</td>
<td></td>
<td></td>
<td>23.8</td>
</tr>
<tr>
<td>Lives with Others</td>
<td>372</td>
<td></td>
<td></td>
<td>76.2</td>
</tr>
<tr>
<td>Total Sample</td>
<td>488</td>
<td></td>
<td></td>
<td>100.0</td>
</tr>
<tr>
<td>Education:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; High School</td>
<td>125</td>
<td></td>
<td></td>
<td>30.2</td>
</tr>
<tr>
<td>High School</td>
<td>126</td>
<td></td>
<td></td>
<td>30.4</td>
</tr>
<tr>
<td>&gt; High School</td>
<td>163</td>
<td></td>
<td></td>
<td>39.4</td>
</tr>
<tr>
<td>Total Sample</td>
<td>414</td>
<td></td>
<td></td>
<td>100.0*</td>
</tr>
<tr>
<td>*Missing Value</td>
<td>74</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

93% Caucasian, 65.1% married, 76.2% lived with someone, and 39.4% had more than a high school education.
Clinical Characteristics

Patient characteristics were analyzed to determine the distribution of primary site of cancer, treatment, activities of daily living, instrumental activities of daily living, symptom count and severity, comorbid conditions, and depression (CES-D) scores for the patient population.

One-third of the sample (33.3%) were diagnosed with prostate cancer (Table 2), the largest diagnostic group, followed by breast, lung, and colon cancer. Surgery (31.3%) was the predominant treatment for the sample.

The means, standard deviations, and medians for limitations in activities of daily living (ADL) are shown for three time periods (Recall, Wave I and Wave II). The variables represent averaged responses to questions about limitations in eating, dressing, bathing, toileting, and walking. The possible scores range from 1 to 4 where complete independence = 1 and heavy physical dependence on others = 4. The mean ranged from a low of 1.04 (S.D. = .20) at Recall to a high of 1.07 (S.D. = .24) at Wave I; thus, most of the cancer patients do not experience substantial ADL limitations.

The means, standard deviation, and median for limitations in instrumental activities of daily living (IADL) are presented for three time periods (Recall, Wave I and Wave II). As with the ADL items, the possible answers ranged from 1 to 4 with 1 indicating living independently to 4 requiring total help. The mean ranged from a low of 1.20 (S.D = .59) at Recall to a high of 1.55 (S.D. = .89) at Wave I. The mean,
Table 2

Primary Site of Cancer, and Treatment at Wave II

<table>
<thead>
<tr>
<th>Cancer Site:</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast</td>
<td>134</td>
<td>27.6</td>
</tr>
<tr>
<td>Colon</td>
<td>81</td>
<td>16.7</td>
</tr>
<tr>
<td>Lung</td>
<td>109</td>
<td>22.4</td>
</tr>
<tr>
<td>Prostate</td>
<td>162</td>
<td>33.3</td>
</tr>
<tr>
<td>Total</td>
<td>486</td>
<td>100.0*</td>
</tr>
<tr>
<td>*Missing Value</td>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Treatment:</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surgery only</td>
<td>136</td>
<td>31.3</td>
</tr>
<tr>
<td>Chemo only</td>
<td>8</td>
<td>1.8</td>
</tr>
<tr>
<td>Radiation only</td>
<td>1</td>
<td>0.2</td>
</tr>
<tr>
<td>Surgery &amp; Chemo</td>
<td>59</td>
<td>13.6</td>
</tr>
<tr>
<td>Surgery &amp; Radiation</td>
<td>106</td>
<td>24.4</td>
</tr>
<tr>
<td>Chemo &amp; Radiation</td>
<td>90</td>
<td>20.7</td>
</tr>
<tr>
<td>Surgery, Chemo, &amp; Radiation</td>
<td>29</td>
<td>6.7</td>
</tr>
<tr>
<td>None</td>
<td>5</td>
<td>1.2</td>
</tr>
<tr>
<td>Total</td>
<td>434</td>
<td>100.0*</td>
</tr>
<tr>
<td>*Missing Values</td>
<td>54</td>
<td></td>
</tr>
</tbody>
</table>

standard deviation, and median for the Physical Function Subscale of the SF-36 to
determine physical functioning are presented for three time periods (Recall, Wave I and Wave II). The possible answers ranged from 1 (limited a lot) to 3 (not limited). The mean ranged from a high 2.60 (S.D. = .53) at Recall to a low of 1.61 (S.D. = .58) at Wave II (see Table 3).

The ADL and IADL instruments measures an individual’s ability to perform self-care tasks without assistance such as dressing, bathing, and driving. Physical deterioration is captured only in extreme measures. The Physical Functioning Subscale of the SF-36 measures a different aspect of physical functioning. The Physical Functioning Subscale rates physical ability such as walking distances, climbing stairs and bending or stooping. Since the Physical Function Subscale evaluates body deteriorations, this subscale appears more appropriate for cancer patients receiving initial cancer treatment. For these reasons, the Physical Function Subscale was chosen for hypothesis testing.

Patient symptoms are captured in three kinds of variables: (1) a simple count of all reported patient symptoms; (2) average severity ratings across all symptoms reported (from 1 = mild to 3 = severe); and (3) a summated score multiplying the number of symptoms by their respective severity ratings. Means, standard deviations, and medians for all three measures are reported in Table 4. Since symptom recall is not possible over a 3-month period, only two measures are available for current symptoms at Wave I and Wave II. Reported symptoms on a scale of 1 to 37 ranged from a mean of 8.09 (S.D. = 4.54) at Wave I to 7.33 (S.D. = 4.74) at Wave II.
Table 3

Means, Standard Deviation and Median for Limitations in Activities of Daily Living (ADL, Instrumental Activities of Daily Living (IADL), and for Physical Function Subscale of SF-36

<table>
<thead>
<tr>
<th>Instrument</th>
<th>n</th>
<th>M</th>
<th>SD</th>
<th>Mdn</th>
<th>Missing Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADL:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recall</td>
<td>452</td>
<td>1.04</td>
<td>.20</td>
<td>1.00</td>
<td>36</td>
</tr>
<tr>
<td>Wave I</td>
<td>451</td>
<td>1.07</td>
<td>.24</td>
<td>1.00</td>
<td>37</td>
</tr>
<tr>
<td>Wave II</td>
<td>441</td>
<td>1.04</td>
<td>.24</td>
<td>1.00</td>
<td>47</td>
</tr>
<tr>
<td>IADL:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recall</td>
<td>397</td>
<td>1.20</td>
<td>.59</td>
<td>1.00</td>
<td>91</td>
</tr>
<tr>
<td>Wave I</td>
<td>399</td>
<td>1.55</td>
<td>.89</td>
<td>1.00</td>
<td>89</td>
</tr>
<tr>
<td>Wave II</td>
<td>398</td>
<td>1.45</td>
<td>.91</td>
<td>1.00</td>
<td>90</td>
</tr>
<tr>
<td>Physical Function Subscale SF-36:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recall</td>
<td>421</td>
<td>2.60</td>
<td>.53</td>
<td>2.78</td>
<td>67</td>
</tr>
<tr>
<td>Wave I</td>
<td>419</td>
<td>2.24</td>
<td>.61</td>
<td>2.33</td>
<td>69</td>
</tr>
<tr>
<td>Wave II</td>
<td>463</td>
<td>1.61</td>
<td>.58</td>
<td>1.44</td>
<td>25</td>
</tr>
</tbody>
</table>

The means for the average severity score essentially show no change (1.47 in Wave I and 1.49 in Wave II). Finally, the summated symptom severity scores are 11.75 (S.D. = 9.74) at Wave II and 12.59 (S.D. = 8.91) at Wave I (see Table 4).
Table 4

Mean, Standard Deviation and Median for Reported Symptoms, Average Symptom Severity Scores, and Summated Symptom Severity Score

<table>
<thead>
<tr>
<th>Variable:</th>
<th>n</th>
<th>M</th>
<th>SD</th>
<th>Mdn</th>
<th>Missing Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reported Symptoms:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wave I</td>
<td>408</td>
<td>8.09</td>
<td>4.54</td>
<td>7.00</td>
<td>80</td>
</tr>
<tr>
<td>Wave II</td>
<td>435</td>
<td>7.33</td>
<td>4.74</td>
<td>7.00</td>
<td>53</td>
</tr>
<tr>
<td>Average Severity Scores:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wave I</td>
<td>405</td>
<td>1.47</td>
<td>0.39</td>
<td>1.43</td>
<td>83</td>
</tr>
<tr>
<td>Wave II</td>
<td>426</td>
<td>1.49</td>
<td>0.45</td>
<td>1.39</td>
<td>62</td>
</tr>
<tr>
<td>Summated Symptom/Severity Scores</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wave I</td>
<td>408</td>
<td>12.59</td>
<td>8.91</td>
<td>10.00</td>
<td>80</td>
</tr>
<tr>
<td>Wave II</td>
<td>435</td>
<td>11.75</td>
<td>9.74</td>
<td>9.00</td>
<td>53</td>
</tr>
</tbody>
</table>

The summated symptom severity score incorporates both the number of symptoms and the symptom severity rating. For these reasons, the summated symptom severity score was chosen for hypothesis testing. The measure of comorbid conditions is a simple count of 14 physical health problems the patient was asked about at Wave I. These included comorbid conditions like diabetes, arthritis, and heart conditions. Table 5 shows that three quarters of the cancer patients reported two or more such comorbid conditions with a sample mean of 2.71.
Table 5
Mean, Standard Deviation, Frequency and Percentage for Comorbid Conditions

<table>
<thead>
<tr>
<th>Comorbid Condition</th>
<th>n</th>
<th>%</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 2</td>
<td>101</td>
<td>24.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 &gt;</td>
<td>304</td>
<td>75.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>405</td>
<td>100.0*</td>
<td>2.71</td>
<td>1.70</td>
</tr>
<tr>
<td>*Missing Values</td>
<td>83</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The means, standard deviation, and median for depression (CES-D) are presented in Table 6 for two time periods (Wave I and Wave II). Following standard practice, all items were coded 0 (no depressive symptom) to 3 (strong depressive symptom). Thus, the possible range for the summated scale score is 0 to 60, with a score of 16+ usually indicating a greater risk of clinical depression. Clearly, mean scores of 10.95 in Wave I (S.D. = 7.73) and 9.91 in Wave II (S.D. = 7.69) and the frequency scores of 16 or greater (25.7% in Wave I and 19.2% in Wave II) indicate substantial presence of depressive symptomatology in this sample of cancer patients. The expected depression rate in elderly persons who live in the community is between 1 to 2% (Blazer, 1989, p. 164).

Reliability of Instruments

When applicable, Cronbach’s Alpha was employed to determine the reilability
Table 6
Mean, Standard Deviation and Median for Depression (CES-D)

<table>
<thead>
<tr>
<th>Depression Scores</th>
<th>%</th>
<th>M</th>
<th>SD</th>
<th>Mdn</th>
<th>Missing Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Wave I: (n=240)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-15</td>
<td>74.6</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16+</td>
<td>25.4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>100.0</td>
<td>10.95</td>
<td>7.73</td>
<td>10.00</td>
<td>248</td>
</tr>
</tbody>
</table>

| **Wave II: (n=229)** |    |    |     |     |               |
| 0-15               | 80.8 |    |     |     |               |
| 16+                | 19.2 |    |     |     |               |
| **Total**          | 100.0 | 9.91 | 7.69 | 8.00  | 259           |

of the scale variables, such as the activities of daily living, instrumental activities of
daily living, Physical Function Subscale of SF-36 and CES-D instruments. A
Cronbach's Alpha was not computed for symptom and symptom severity scores since
the instrument is not a classic scale measuring an underlying concept such as the
depression scale. There is no assumption that the presence or absence of all the listed
symptoms is internally consistent. Instead, symptoms may vary according to cancer
site and comorbid conditions, for instance (see Table 7).
Table 7

Cronbach’s Alpha for Activities of Daily Living, Instrumental Activities of Daily Living, Physical Function Subscale of SF-36 and the CES-D Instruments

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Alpha Recall</th>
<th>Alpha Wave I</th>
<th>Alpha Wave II</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADL</td>
<td>0.81</td>
<td>0.77</td>
<td>0.84</td>
</tr>
<tr>
<td>IADL</td>
<td>0.81</td>
<td>0.85</td>
<td>0.84</td>
</tr>
<tr>
<td>Physical Function</td>
<td>0.90</td>
<td>0.89</td>
<td>0.88</td>
</tr>
<tr>
<td>CES-D</td>
<td></td>
<td>0.89</td>
<td>0.89</td>
</tr>
</tbody>
</table>

Data Presentation for Hypothesis Testing

The research hypotheses and data will be presented in the following section. In general, statistical significance is observed at the conventional .05 level for alpha.

All the hypothesis tested in this study involve: (a) the observance of over-time outcome measures (Baseline, Wave I or Wave II); (b) a focal between-group factor (like diagnosis, treatment, or living arrangement); and (c) covariant adjustments (including other independent factors that are not the focus of the hypothesis). For this reason, the results of the analysis are presented in the form of a “profile analysis”. A repeated-measures analysis of covariance thus shows group means for the focal between-group factor over-time. All displayed group means are already adjusted for between-group factor over time and for differences in the other factors or covariant.
Hypotheses I, II, and III

Hypothesis I

*Adults age 65 and older with a cancer diagnosis experience a progressive loss of physical functioning from baseline.*

Hypothesis II

*Adults age 65 and older with a cancer diagnosis experience a progressive loss of physical functioning from baseline associated with cancer site.*

Hypothesis III

*Adults age 65 and older with a cancer diagnosis experience a progressive loss of physical functioning from baseline associated with cancer treatment.*

Hypothesis I, II, and III posit a change in physical functioning over time associated with two between-group factors: cancer site and treatment. In the following two tables, the emphasis (Table 8) is first on the time profiles associated with cancer site (adjusted for treatment modalities). Then, the emphasis shifts to Table 9. In addition to the table entries, giving the adjusted means for each time between group combination, marginal means for time as the main within subjects effect and cancer site (or treatment) as the main between subjects effects are also provided. At the bottom of the table, the significance levels associated with all
Table 8

Repeated Measures Analysis of Variance of Adjusted Means Outcomes
Variable: Physical Function Score Factors: Primary Site and Wave (Recall, T1, T2) Covariate: Cancer Treatment

<table>
<thead>
<tr>
<th>Primary Site</th>
<th>n</th>
<th>Recall</th>
<th>Wave I</th>
<th>Wave II</th>
<th>Site Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast</td>
<td>108</td>
<td>2.60</td>
<td>2.21</td>
<td>1.57</td>
<td>2.13</td>
</tr>
<tr>
<td>Colon</td>
<td>63</td>
<td>2.72</td>
<td>2.40</td>
<td>1.54</td>
<td>2.22</td>
</tr>
<tr>
<td>Lung</td>
<td>92</td>
<td>2.58</td>
<td>2.27</td>
<td>1.57</td>
<td>2.14</td>
</tr>
<tr>
<td>Prostate</td>
<td>138</td>
<td>2.57</td>
<td>2.20</td>
<td>1.63</td>
<td>2.14</td>
</tr>
<tr>
<td>Total</td>
<td>401</td>
<td>2.62</td>
<td>2.27</td>
<td>1.57</td>
<td></td>
</tr>
</tbody>
</table>

Note:
Main Effects:
- Site-Effect (Between-Subject Factor)
- Time-Effect (Within-Subject Factor)
Interaction Effects:
- Time-By-Site Interaction (Within-Subject)
Contrasts:
- T1 (Recall to Wave I)
- T2 (Wave I to Wave II)
Time by Cancer Site:
- T1 (Recall to Wave I)
- T2 (Wave I to Wave II)

Significant Level:
- .082
- .000***
- .467
- .000***
- .006
- .634
- .359

* * * p < .000

of the measures, contrasts are added to test for significant effect in each time interval (Recall to Wave I or Wave I to Wave II). The results in Table 8 indicate first a significant decline in the physical functional score over time (p < .000). The adjusted marginal means at the bottom tell the story: a precipitous decline in functioning from
the time before diagnosis (2.62) to Wave II (1.57). As the contrasts for time indicate,

Table 9

Repeated Measures Analysis of Variance of Adjusted Means Outcome
Variable: Physical Function Score Factors: Adjusted Treatment and Wave (Recall, T1, T2) Covariate: Cancer Site

<table>
<thead>
<tr>
<th>Cancer Treatment</th>
<th>n</th>
<th>Recall</th>
<th>Wave I</th>
<th>Wave II</th>
<th>Treatment Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surgery Only</td>
<td>124</td>
<td>2.67</td>
<td>2.09</td>
<td>552</td>
<td>2.09</td>
</tr>
<tr>
<td>Chemo Only</td>
<td>6</td>
<td>2.50</td>
<td>2.25</td>
<td>1.72</td>
<td>2.16</td>
</tr>
<tr>
<td>Surgery &amp; Chemo</td>
<td>57</td>
<td>2.61</td>
<td>2.17</td>
<td>1.56</td>
<td>2.11</td>
</tr>
<tr>
<td>Surgery &amp; Radiation</td>
<td>100</td>
<td>2.64</td>
<td>2.44</td>
<td>1.55</td>
<td>2.21</td>
</tr>
<tr>
<td>Chemo &amp; Radiation</td>
<td>85</td>
<td>2.49</td>
<td>2.33</td>
<td>1.67</td>
<td>2.16</td>
</tr>
<tr>
<td>Surgery, Chemo, &amp; Radiation</td>
<td>28</td>
<td>2.59</td>
<td>2.26</td>
<td>1.75</td>
<td>2.20</td>
</tr>
<tr>
<td>Total</td>
<td>400</td>
<td>2.58</td>
<td>2.26</td>
<td>1.63</td>
<td></td>
</tr>
</tbody>
</table>

Note:
Factors:
Treatment-Effect (Between-Subject Factor) .005
Time-Effect (Within-Subject Factor) .000***
Interaction Effects:
Time-By-Treatment Interaction (Within-Subject) .008**

Contrasts:
T1 (Recall to Wave I) .000***
T2 (Wave I to Wave II) .000***

Time by Treatment:
T1 (Recall to Wave I) .000***
T2 (Wave I to Wave II) .255

**p < .01   *** p < .000
this drop is significant both between Recall and Wave I and between Wave I and Wave II. However, physical functioning does not seem to be influenced by a patient's primary cancer site. The main site effect shows no difference in the average functioning (averaged across time) between subjects of various cancer diagnosis. Neither is there a significant time by site interaction, meaning that the time paths of physical functioning, i.e. a substantial drop in functioning over the three waves, is common to all four groups defined by their sites.

By contrast, as the results in Table 9 show, treatment does affect physical functioning, both regardless of time (see main effect for treatment: \( p = <.005 \)) and over time (see time-by-treatment interaction: \( p < .008 \)). For instance, while patients under any treatment combination show declines in physical functioning, those who had surgery end up with the lowest functioning scores at Wave II.

Hypothesis IV

Adults age 65 and older who have two or more pre-existing comorbid conditions will report an increase in symptoms associated with cancer site and treatment when compared to those with one or no comorbid conditions.

This hypothesis is tested with the help of the total symptom severity score described earlier. Since symptom reports cannot be usefully ascertained about some specified past periods, the test is restricted to the two Wave I and Wave II measures. Table 10 shows the results with time profile for the two patient groups: those with
Table 10
Repeated Measures Analysis of Variance of Adjusted Means Outcome
Variable: Symptom Severity Experience Score Factors: Comorbid Conditions Covariates: Cancer Site and Treatment

<table>
<thead>
<tr>
<th>Comorbid Condition</th>
<th>n</th>
<th>Wave I</th>
<th>Wave II</th>
<th>Average by Comorbid Condition Grouping</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;2</td>
<td>88</td>
<td>9.22</td>
<td>9.60</td>
<td>9.41</td>
</tr>
<tr>
<td>2&gt;</td>
<td>271</td>
<td>13.01</td>
<td>11.79</td>
<td>12.44</td>
</tr>
<tr>
<td>Total</td>
<td>359</td>
<td>11.15</td>
<td>10.70</td>
<td></td>
</tr>
</tbody>
</table>

Note: Significant Level:
Factors:
Comorbid-Effect (Between-Subject Factor) .002***
Time-Effect (Within-Subject Factor) .005**
Interaction Effect:
Time-By-Comorbid (Within-Subject) .075

one or no reported comorbid conditions versus those with two or more. All reported means are adjusted for both treatment and primary cancer site differences. As expected, the results confirm large differences in the symptom severity reports of patients with few compared to patients with several comorbid conditions (see the significant between subjects effects). However, the over-time effects are ambiguous: the adjusted sample means suggest a decline in symptom severity among patients with high levels of comorbid conditions (albeit a decline from a very high level) and an increase in reported symptom severity for patients with one or no comorbid
conditions (although this increase occurs at a much lower level). This apparent interaction may just be the result of sampling fluctuation as suggested by the non-significant time-by-grouping.

**Hypothesis V**

*Adults age 65 and older who have two or more pre-existing comorbid conditions will report a greater of loss of physical functioning associated with cancer site and treatment than those with one or no comorbid conditions.*

There is a between-subjects effect associated with the comorbid condition grouping: cancer patients with fewer comorbid conditions show higher average physical functioning scores when time is disregarded. However, there is a significant time by comorbid condition grouping interaction.

In particular, the decline in physical functioning is greater in the patient group with initially fewer comorbid conditions (from 2.77 to 1.43) compared to the patient group with two or more comorbid conditions (2.56 to 1.62). These results hold, after adjusting for possible differences in diagnosis (breast, prostate, lung or colon cancer) and treatment modality. A closer look at the contrasts reveal that the accelerated decline in physical functioning among the patients with one or no comorbid condition only occurs between Wave I and Wave II (see Table 11).

**Hypothesis VI**

*Adults age 65 and older with a cancer diagnosis, and two or more comorbid*
Table 11

Repeated Measures Analysis of Variance of Adjusted Means Outcome
Variable: Physical Function Score Factors: Comorbid Conditions
and Wave (T1, T2) Covariates: Cancer Site and Treatment

<table>
<thead>
<tr>
<th>Comorbid Condition</th>
<th>n</th>
<th>Recall</th>
<th>Wave I</th>
<th>Wave II</th>
<th>Average by Comorbid Condition Grouping</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;2</td>
<td>93</td>
<td>2.77</td>
<td>2.40</td>
<td>1.43</td>
<td>2.20</td>
</tr>
<tr>
<td>2&gt;</td>
<td>290</td>
<td>2.56</td>
<td>2.22</td>
<td>1.62</td>
<td>2.14</td>
</tr>
<tr>
<td>Total</td>
<td>383</td>
<td>2.67</td>
<td>2.31</td>
<td>1.53</td>
<td></td>
</tr>
</tbody>
</table>

Note:

Main Effects
Comorbid-Effect (Between-Subject Factor) .021 *
Time-Effect (Within-Subject Factor) .000 ***

Interaction Effects:
Time-By-Comorbid (Within-Subject) .000 ***

Contrasts:
T1 (Recall to Wave I) .000 ***
T2 (Wave I to Wave II) .004 ***

Time by Comorbidity:
T1 (Recall to Wave I) .565
T2 (Wave I to Wave II) .003 ***

** p = .01 *** p < .000
* p = .05

Conditions, have higher scores on the CES-D when compared to those with one or no comorbid conditions.

Table 12 contains all adjusted CES-D means for all of the time comorbid condition groupings. The significance tests associated with the table reveal that none
of the apparent patterns in CES-D score are statistically significant. There are probably two reasons for this finding. The analysis was run on only 195 cases, because the CES-D measures were obtained through self-administered booklets sent to the patients. This resulted in much lower response rates than those for the telephone survey measures. In addition, the CES-D scores exhibit substantial individual variation among the cancer patients (see Table 6). Both factors lead to large standard errors reducing the possibility of finding significant differences.

Table 12

Repeated Measures Analysis of Variance of Adjusted Means Outcome
Variable: Depression (CES-D) Scores Factors: Comorbid Conditions Covariates: Cancer Site and Treatment

<table>
<thead>
<tr>
<th>Comorbid Condition</th>
<th>n</th>
<th>Wave I</th>
<th>Wave II</th>
<th>Average by Comorbid Condition Grouping</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;2</td>
<td>51</td>
<td>9.33</td>
<td>8.27</td>
<td>8.80</td>
</tr>
<tr>
<td>2&gt;</td>
<td>144</td>
<td>11.03</td>
<td>9.94</td>
<td>10.49</td>
</tr>
<tr>
<td>Total</td>
<td>195</td>
<td>10.18</td>
<td>9.11</td>
<td></td>
</tr>
</tbody>
</table>

Note:
Main Effect:
- Comorbid-Effect (Between-Subject Factor) .140
- Time-Effect (Within-Subject Factor) .915

Interaction Effect:
- Time-By-Comorbid (Within-Subject) .972
  *p < .05

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between groups or over time. As a result, Hypothesis VI cannot be confirmed statistically. The results presented in Table 12 are adjusted for cancer site and treatment.

**Hypothesis VII**

*Adults age 65 and older who live alone, experience a greater increase in symptoms associated with cancer treatment, when compared to those who do not live alone.*

**Hypothesis VIII**

*Adults age 65 and older who live alone, experience a greater loss of baseline physical functioning associated with cancer treatment when compared to those who do not live alone.*

The following analyses for Hypothesis VII and VIII compare the time paths of symptom severity and physical functioning for patients who do or do not live with a designated caregiver. They are all adjusted for treatment, diagnosis (breast, prostate, lung or colon cancer), and the number of comorbid conditions.

Table 13 again offers a suggestive descriptive pattern, but differences between the two residence patterns and over-time are not strong enough to be statistically significant. Thus, we cannot conclude that the symptom experience of patients is influenced by whether or not they live together with a caregiver.
### Table 13
Repeated Measures Analysis of Variance of Adjusted Means Outcome Variable: Symptom Experience Score
Factors: Living Arrangements
Covariates: Cancer Site, Treatment, Number of Comorbid Conditions

<table>
<thead>
<tr>
<th>Living Arrangement</th>
<th>n</th>
<th>Wave I</th>
<th>Wave II</th>
<th>Average by Living Arrangement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lives with Others</td>
<td>273</td>
<td>11.80</td>
<td>10.91</td>
<td>11.36</td>
</tr>
<tr>
<td>Lives Alone</td>
<td>87</td>
<td>13.08</td>
<td>12.30</td>
<td>12.69</td>
</tr>
<tr>
<td>Total</td>
<td>360</td>
<td>12.44</td>
<td>11.61</td>
<td></td>
</tr>
</tbody>
</table>

**Note:**

**Main Effects:**

- Living Arrangement-Effect (Between-Subject Factor) .163
- Time-Effect (Within-Subject Factor) .744

**Interaction Effect:**

- Time-By-Living Arrangement (Within-Subject) .904

Although the means in Table 14 do not suggest a systematic difference in physical functioning of patients living with or without a caregiver, the significant mean (between group) effect does suggest a pattern. Patients who live alone do appear to be functioning at a slightly higher level. However, the lack of a time-by-living arrangement interaction does not suggest that patients living alone experience an accelerated loss of functioning. Patients in both living arrangement groups seem to experience the same rate of deterioration in their functioning.
### Table 14
Repeatec Measures Analysis of Variance of Adjusted Means Outcome Variable: Physical Functioning Score Factors: Living Arrangement and Wave (Recall, T1, T2) Covariates: Cancer Site, Treatment, Number of Comorbid Conditions

<table>
<thead>
<tr>
<th>Living Arrangement</th>
<th>Recall</th>
<th>Wave I</th>
<th>Wave II</th>
<th>Average by Living Arrangement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lives with Others</td>
<td>293</td>
<td>2.61</td>
<td>2.26</td>
<td>2.15</td>
</tr>
<tr>
<td>Lives Alone</td>
<td>90</td>
<td>2.63</td>
<td>2.30</td>
<td>2.17</td>
</tr>
<tr>
<td>Total</td>
<td>383</td>
<td>2.62</td>
<td>2.28</td>
<td></td>
</tr>
</tbody>
</table>

**Note:**
Main Effects:
- Living Arrangement-Effect (Between-Subject Factor) \( .001^{***} \)
- Time-Effect (Within-Subject Factor) \( .000^{***} \)

Interaction Effect:
- Time-By-Living Arrangement Interaction (Within-Subject) \( .835 \)

Contrast:
- T1 (Recall to Wave I) \( .000^{***} \)
- T2 (Wave I to Wave II) \( .000^{***} \)

Time by Living Arrangement:
- T1 (Recall to Wave I) \( .682 \)
- T2 (Wave I to Wave II) \( .622 \)

*** \( p < .000 \)

Tests for Hypotheses

A Repeated Measures Analysis of Covariance was computed to test for the differences between means for the study variables and to determine statistical significance for each research hypothesis.
The research hypotheses are stated and are followed by the findings of this study in relation to the hypotheses. A brief discussion of study findings in relation to expected relationships is presented.

Hypothesis I

*Adults age 65 and older with a cancer diagnosis experience a progressive loss of physical functioning from baseline.*

The research hypothesis was accepted. The main effect (time) was significant (p = .000). There was a change over time in physical functioning for the sample as a whole.

The findings are not consistent with other research. Kurtz et al. (1993, p. 279) found there were no significant differences in loss of physical functioning between Wave I and Wave II, when controlling for age and comorbid conditions. Satariano et al. (1990, p. M9) found that there was no evidence of a generalized loss of physical functioning among older women with incident breast cancer three months following diagnosis.

Hypothesis II

*Adults age 65 and older with a cancer diagnosis experience a progressive loss of physical functioning from baseline associated with cancer site.*

The research hypothesis was rejected. The site-effect (p = .082) and the time-by-site interaction (p = .467) were not significant. There was no difference between
physical functioning and cancer site (breast, prostate, lung and colon cancer).

The results for the study sample indicated that there was no significant difference between cancer site and physical functioning. The findings are not consistent with other research. Kurtz et al. (1993, p. 278) found significant differences in average loss of physical functioning scores by cancer site (p = .002). However, Given et al. (1994, p. 2135) found that there was no significant effect of the cancer primary site on physical functioning, symptoms, and mental health.

**Hypothesis III**

*Adults age 65 and older with a cancer diagnosis experience a progressive loss of physical functioning from baseline associated with cancer treatment.*

The research hypothesis was accepted. The time-effect (p = .000), treatment-effect (p = .01), and the time-by-treatment (p = .01) were significant. There were statistically significant differences between physical functioning and treatment modality surgery, chemotherapy, radiation or a combination).

These findings are not consistent with other research. Given et al. (1994, p. 2135) found that age, gender, and treatment modality accounted for less than 10 percent of the variation in patient's symptoms, functioning, or level of depression.

**Hypothesis IV**

*Adults age 65 and older who have two or more pre-existing comorbid conditions report an increase in symptoms associated with cancer site and treatment*
when compared to those with one or no comorbid conditions.

The research hypothesis was rejected. The time-effect ($p = .005$) and the comorbid-effect ($p = .002$) were significant. The time-by-comorbid interaction was not significant; therefore, there was no difference in symptom experience by comorbid conditions.

The findings are not consistent with other research. Kurtz et al. (1993, p. 227) found that comorbid conditions were not significantly correlated with symptoms at Wave I, but was significant at Wave II.

Hypothesis V

Adults age 65 and older who have two or more pre-existing comorbid conditions report a greater loss of physical functioning associated with cancer site and treatment when compared to those with one or no comorbid conditions.

The research hypothesis was rejected. The time-effect ($p = .005$), time-by-comorbid effect ($p = .000$) and the time-by-comorbid interaction ($p = .000$) were significant. The decline in physical functioning was greater in the patient group with initially fewer comorbid conditions compared to the patient group with two or more comorbid conditions.

The findings are consistent with other research. Kurtz et al. (1993, p. 277) found that comorbid conditions were significantly correlated with loss of physical functioning for the under 60 age group. Mor et al. (1992, p. 346) found that cancer patients with a significant number of comorbid conditions were more likely to have
an increase in need for help with physical functioning. The need for assistance was concentrated around personal care and transportation rather than household management tasks.

**Hypothesis VI**

*Adults age 65 and older with a cancer diagnosis and two or more comorbid conditions attain higher depression scores on the CES-D scale when compared to those with one or no comorbid conditions.*

The research hypothesis was rejected. The data indicated that the time-effect ($p = .005$) and the comorbid-effect ($p = .002$) were significant. However, the time-by-comorbid interaction was not significant. There was no statistically significant difference between the depression scores and comorbid conditions. However, the hypothesis could not be confirmed statistically, due to the low response rates and the substantial individual variation noted in the large standard deviations in depression among cancer patients.

The findings are not consistent with other research. Little research has been done in the area of depression and comorbid conditions. Given et al. (1994, p. 2136) studied the impact of cancer symptoms and depression. There was a statistically significant relationship for the patient group receiving active cancer treatment and depression scores ($p < .003$). Kurtz et al. (1995, p. 842) found that cancer patient immobility and symptom distress were highly correlated with levels of depression.
Hypothesis VII

Adults age 65 and older who live alone experience an increase in symptoms associated with cancer site and treatment when compared to those who do not live alone.

The research hypothesis was rejected. The data indicated that the time-effect, living-arrangement-effect and the time-by-living arrangement interaction were not significant. There was no statistically significant evidence that patient symptom experience was influenced by whether they lived alone or with a caregiver. No research was found which addressed living arrangements for cancer patients and their symptom experience.

Hypothesis VIII

Adults age 65 and older who live alone experience a greater loss of baseline physical functioning associated with cancer treatment when compared to those who do not live alone.

The research hypothesis was rejected. The data indicated that the time-effect was significant (p = .000). However, the site-effect and the time-by-site interaction were not statistically significant. There were no statistically significant differences between physical functioning based upon living arrangements.
Although the means in Table 14 suggest a systematic difference in physical functioning of patients living with or without a caregiver, the significant means (between-group) effect suggest a pattern that persons who live alone appear to be functioning at a slightly higher level.

The research is sparse in the area of cancer patient living arrangements and their physical functioning. Jones et al. (1989, p. 560) found that physical functioning was a better predictor of re-hospitalization than living arrangements. Mamon et al. (1992, p. 170) noted that the number of treatments and activity limitations were consistent predictors of unmet needs. Mor, et al. (1992, p. 837) found that married patients appeared to be at decreased risk for acquiring the need for help with personal care and household tasks. Mor noted that married men did not tend to attribute help from their spouses to illness-related needs, but to gender roles.

In conclusion, the differences in the findings for this study sample when compared to other research may be attributed to (a) sampling fluctuation, (b) data not staged, and (c) age truncated sample which makes it difficult to identify a clear attribution from symptom to cause.

The data for this sample of age 65 and older cancer patients indicates a significant loss of physical functioning from the three month Recall obtained at the time of diagnosis through Wave II. Cancer site had no effect on physical functioning. However, cancer patients under any treatment combination showed a decline in physical functioning. There was no difference in symptom experience and depression scores based upon the number of patient's comorbid conditions. However, 20 percent
of the sample had a score of 16 or greater on the CES-D instrument. This finding indicates a substantial presence of depressive symptomatology in this sample of cancer patients. Patients with fewer than two comorbid conditions had a significant decline in physical functioning compared to those with two or more comorbid conditions.

There was no difference in symptom experience or loss of physical functioning based upon living arrangements. The between-group effect suggested a pattern that persons who live alone appear to be functioning at a slightly higher level.

Summary

A description of the study sample in relation to sociodemographic, clinical characteristics, and tests to determine the validity of the instruments has been presented.

A Repeated Measures Analysis of Variance and Covariance was computed for each of the eight research hypotheses to determine statistical significance. Two research hypotheses were accepted and six research hypotheses were not accepted.

A discussion of these findings and their implications for public administration, health planners policy and future research will be presented in Chapter V.
CHAPTER V

CONCLUSIONS AND RECOMMENDATIONS

Summary of Findings

The purpose of this study was to explore self-reported needs of the oncology patient aged 65 and older, diagnosed with one of four types of cancer. The needs of the patients were identified at three observation points during the initial course of treatment. The first observation was a patient retrospective self-report concerning her or his physical functioning three months prior to the diagnosis. The second observation (Wave I) occurred as soon as possible following surgery, or before the patient began chemotherapy or radiation. The third observation (Wave II) occurred 14 weeks following the initial surgery, for those patients having no adjuvant therapy. For those receiving other therapies, the interviews varied by the individual and occurred in the midst of their cycle of chemotherapy or at the end of radiation. Some of the patients did not respond to all the interview questions. Perhaps these omissions were due to illness, timing of the interview, or not seizing the moment when the patient was well enough to participate.

Quality of Life was defined as the three domains of functional status: (1) physical, (2) social, and (3) mental domain. The physical domain was measured through the use of two modified instruments. Functional deficits were measured by
the Physical Functioning Subscale of the SF-36, and the patient's symptom experience was measured using the Symptom Experience Index. The social domain was measured by determining the patient's living arrangement. The mental domain was measured by using the depression (CES-D) scale.

In summary, this study focused on outcomes for incident in cancer patients aged 65 and older during the active treatment phase of their illness. The findings indicate that active treatment places the patient in jeopardy of a downward trajectory due to loss of physical functioning. The loss of physical functioning places the individual at risk to lose both personal and financial independence on one hand, and the potential aggravation of that loss through placement into an alternative care setting. Not only does the loss of function jeopardize the individual’s quality of life but it places a greater burden on the cost of health care.

Descriptors of the Study Sample

Sociodemographic Characteristics

This section will present a summary of the sociodemographic characteristics of the study sample and comparison of these characteristics to those of other research findings.

Age

The mean age of the study participants was 72.4 years with a range of 64 to 95
years. Two-thirds of the sample were the young-old who were aged 64-69 and 70-74 years.

The elderly population varies from state to state Michigan is one of nine states that has more than one million persons aged 65 and older (Hobbs, 1995, p. 53). According to Michigan 1994 Cancer Incidence and Mortality (Michigan Department of Public Health, 1994, p. 24), one-half (51.9%) of Michigan cancer cases occurred among people in the 55 to 74 age group. The study sample mean age of 72.4 years is consistent with the 1994 Michigan data. The greatest number of Michigan cancer cases occurred among people in the 70 to 74 age group.

The median age for all Michigan residents diagnosed with cancer decreased from 68 years in 1993 to 67.5 years of age in 1994. Cancer rates increased with advancing age until they peaked among persons 75 to 79 years of age. The lower rate among the oldest age group may be a result of a decline in identification and treatment among the old-old (Michigan Department of Public Health, 1994, pp. 25-26). These findings were consistent with McGill & Paul (1993, p. 1210) whose mean age for persons with cancer was 71.6 years with a range of 65 to 86 years.

Gender

Of the 488 participants, 53.3% were male and 46.7% were female. The gender makeup was similar to that of samples studied by previous researchers who examined loss of functioning among cancer patients (Kurtz et al., 1993, p. 277 and
The highest number of cancer cases in Michigan for 1994 among Caucasian females occurred in the 70 to 74 age group, while the highest number of cases for Caucasian males occurred among those aged 65 to 69. The peak rates for African-American males and African-American females occurred among persons 70 to 74 years of age and 80 to 84 years of age respectively (Michigan Department of Public Health, 1994, p. 26).

**Race/Ethnicity**

Over nine-tenths of the study participants (93.0%) were Caucasian. Of the others studied, 6.4% were African-American, 0.4% were Hispanic, and 0.2% were Native American. The individual’s in this study sample racially represent the ethnic make-up of the State of Michigan at this time period.

The cancer incident rates for African-American females in Michigan was the lowest rate observed among the four age-gender groups for 1994. The cancer rate for Caucasian females and Caucasian males were 0.2 % and 35.8 % greater, respectively, than the rate for African-American females. The incident rate for African-American males was 88.5 % greater than the rate for African-American females and was 38.8 % greater than the rate for Caucasian males. This rank of age-gender grouping is similar to previous years, with the exception that prior to 1991, the rates for African-American females tended to be higher than the rates for Caucasian females (Michigan Department of Public Health, 1994, p. 25).
Marital Status

Two-thirds of the study participants were married (65.1%). The remaining sample consisted of 25.2% widowed, 7.5% divorced or separated, and 2.2% never married. These findings were consistent with one other investigator. Satariano et al. (1990, p. M5) reported that 62% of their sample, ages 55-64, were married. Satariano noted a change in demographics with increased age. Of those ages 75-84, 69.6% were previously married, compared to 21.6% who were married.

Living Arrangements

Three-quarters of the sample, 76.2%, were living with another individual; the remaining sample lived alone. Satariano et al. (1990, p. M5) reported that more than three-quarters of the sample, ages 55-64, lived with another individual. Sataraino noted a change in demographics with marital status. Approximately 62% of the participants aged 65-74 lived with someone; 43% of the sample ages 75-84 lived with another person. Sama, et al., (1993, p. 484) found that 11% of the sample lived alone.

Educational Background

Slightly less than one-third (30.2%) of the sample did not complete high school. Of the remaining two-thirds, 30.4% completed high school and 39.4% of the sample had greater than a high school education. The sample was similar to Sataraino et al. (1990, p. M5), except that there was a higher percentage of college education in
the present sample. Sataraino and colleagues found that slightly over one-third (37.7%) of the sample had completed high school and less than one-third of the sample had more than a high school education.

In summary, the study sample was predominantly male, and the participants’ age ranged from 64 to 95 years, with a mean age of 72.4 years. More than half of the sample were married, had more than a high school education, and were predominantly Caucasian. Subjects in the study were similar in age to patients in one other study. Few studies have focused on patients age 65 and older and their functional status during the treatment phase of incident cancer.

The predominance of Caucasian subjects is consistent with three other studies that used race as a descriptor. This study sample contained more males than reported in previous studies of cancer populations. The increased male population for this study may be attributed to one-third of the sample having a diagnosis of prostate cancer.

More than three-quarters of the study participants lived with a companion; more than half of the study participants were married. The marital status of the sample is similar to the study reported by Sataraino and Associates (1990). However, Sataraino noted a change in marital status as one ages. Educational background for the study sample was slightly higher than reported by Sataraino et al., (1990, p. M5). Except for a slightly higher male population, the sociodemographic characteristics and educational level are comparable to other studies.
Clinical Characteristics

Primary Site of Cancer

One-third (33.3%) of the sample was diagnosed with prostate cancer, 27.6% had breast cancer, 22.4% had lung cancer, and the remaining 16.7% had colon cancer (see Table 2).

The age-adjusted incidence of reported cancer was 388.6 cases per 100,000 in 1994 (Michigan Department of Public Health, 1994, p.25) compared to 408.7 cases per 100,000 Michigan population in 1993 (Michigan Department of Public Health, 1993, p.21).

Prostate cancer was the most frequently diagnosed cancer among Michigan residents in 1993 (8,199 cases, 18.9%) and in 1994 (6,930 cases, 16.6%). The use of the Prostate Surface Antigen (PSA) blood test as an early screening tool may be attributed to the increase in diagnosis of prostate cancer. Cancer of the lung and bronchus was the second most frequently diagnosed cancer in 1993 (6,410 cases, 16.4%) and remained the same for 1994 (6,259 cases, 14.5%). Cancer of the breast was the third most frequent cancer in 1993 (6,138 cases, 14.2%) and in 1994 (6,044 cases, 14.5%). Colon cancer was the fourth most frequently diagnosed cancer in 1993 (3,522 cases, 8.1%) and in 1994 (3,543 cases, 8.5%) according to the Michigan Department of Public Health (1993, pp. 27-29; 1994, pp. 32-33).

The study findings are similar to 1993 and 1994 Michigan incidence rates in relative frequencies except for breast and lung cancer. Prostate cancer was the most
frequently diagnosed cancer in this sample, followed by breast, lung and colon.

Although prostate, lung, breast and colon cancer remain the four most frequently
diagnosed forms of cancer, the incident rates have declined.

The study findings differ from those of other researchers. Kurtz, et al., (1993, p. 277) noted the relative frequencies of various cancer sites: breast (22.6%), lung (19%), colo-rectal (22.7%) and urinary/reproductive (22.7%). Given et al. (1994, p. 2131) also reported relative frequencies of various cancer sites: breast (27%), gastrointestinal/colon (29%), bladder, gynecologic and prostate (21%), and lung (14%).

Treatment Modalities

Surgery (31.3%) was the primary treatment for the study sample. A combination of surgery and radiation therapy was second (24.4%), a combination of chemotherapy and radiation therapy was third (20.7%). The remaining treatment modalities, as Table 2 indicates, were surgery and chemotherapy (13.6%), a combination of surgery, radiation, and chemotherapy (6.7%), chemotherapy only (1.8%), and radiation therapy only (0.2%). Only one investigator (Given et al., 1994, p. 2131) reported treatment in relation to age and physical and mental health. The investigator noted that 86 percent of the study sample received both a combination of chemotherapy and another treatment modality.

The study findings are not surprising. Surgery remains the most common treatment for all types of cancers. However, in the last half of this century surgical
techniques have had great advances in pre-, intra, and post-operative care (Patterson, 1992, p.145). The development of pre-operative staging of the cancer and a multidisciplinary management, including radiation oncologist, medical oncologist, nurses and social workers, have improved the quality of life for persons diagnosed with cancer.

According to Patterson (1992, p.145), age bias is still a concern in the treatment of cancers in older adults. Even when comorbid conditions have been taken into account in older persons, the treatment is frequently inadequate. With the projected growth rate of the elderly population, the increase in chronic diseases such as cancer will continue to rise. Appropriate treatment and the factors that influence the surgeon's decision to operate should be a focus for research and education.

Activities of Daily Living (ADL)

The possible answers to the questionnaire used in this study range from 1 to 4; indicating complete independence (=1) or heavy physical dependence on others (=4). The mean ADL scores ranged from a low of 1.04 at Recall to a high of 1.07 at Wave I. The majority of the sample were able to bathe, dress, feed, toilet and transfer without assistance during cancer treatment.

Instrumental Activities of Daily Living (IADL)

The possible answers range from 1 to 4; with one indicating living independently to four requiring total help. The mean IADL score ranged from a low
of 1.20 at Recall to a high of 1.55 at Wave I. Although there was a slight increase from recall of physical functioning three months prior to the cancer diagnosis to Wave I in both ADL’s and IADL’s, most of the cancer patients did not experience a substantial limitation. However, the findings indicated that there was a slight increase in patient need for assistance with an instrumental activity of daily living task from Recall to Wave I (see Table 3).

The increase in need may be attributed to assistance with transportation, light housework, laundry, shopping and cooking during cancer treatment. These findings are consistent with Mor, et al., (1991, p. 833) who noted that 60 percent of the cancer patients in their study required assistance with an instrumental activity of daily living task.

The study sample was predominately the young-old and most did not experience substantial limitations. These findings are consistent with Hobbs (1994). Hobbs (1994, p. 53) noted that among the total population, the young-old aged 65 to 74 differ in functional ability when compared to the old-old who are aged 85 years and older. Nine percent of the 65 to 69 age group require personal assistance when compared to 50% of those aged 85 years and older who needed assistance with one or more activities of daily living.

**Physical Function**

The possible answers range from one (limited a lot) to three (not limited). The mean scores for the Physical Functioning Subscale ranged from a low of 2.60 at
Recall indicating very little limitation to a high of 1.61 at Wave II indicating limitations. The change in means for vigorous functioning indicates that the Physical Functioning Subscale of SF-36 instrument may be more sensitive to physical limitation for patients diagnosed with cancer than the ADL and IADL measures.

These findings are consistent with other research. Given et al. (1994, p. 2133) noted that most patients were independent in lower order functioning. However, half of the patients were unable to walk several blocks, and had trouble bending, lifting and stooping.

**Comorbid Conditions**

Three-quarters of the cancer patients reported two or more comorbid conditions with a sample mean of 2.71. These findings differ from other studies. Stewart et al. (1989, p. 909) found that 29 percent of the sample had two or more conditions. Kurtz et al. (1993, p. 279) noted that the average comorbid condition for their sample was 1.11; however, for those aged 60 and older, the comorbid mean was 2.13.

Hoffman and Rice (1996, p.28) reported the 1987 incident rates of comorbid conditions in non-institutionalized Americans for all age groups. Fifty-six percent of the population had one or no chronic conditions while 44% had two or more chronic conditions. The rates for comorbid conditions change with age. Fifty-one percent of those aged 45 to 64 have two or more comorbid conditions. For those aged 65 years and older the population rate increases to 69% compared to 75% for this study. The
study sample appears to be “sicker” than the non-institutionalized elderly noted by Hoffman and Rice.

**Reported Symptoms**

Reported symptoms on a scale from 1 to 37 ranged from a mean of 8.09 (S.D. = 4.74) at Wave I to 7.33 (S.D. = 4.74) at Wave II. These sample findings were not consistent with other research. Kurtz et al. (1993, p. 277) noted that the mean number of symptoms on a scale from 0 to 27, for Wave I, was 6.59 (S.D. 4.80); Wave II was 4.91 (S.D. = 4.20). Given et al. (1994, p. 2131) noted that the mean sample symptom experience was 4.00 (S.D. = 2.8) for those patients who survived six months. For the patients who did not survive, the mean symptom experience score was 5.3 (S.D. = 2.2).

**Summated Symptom Severity**

The summated symptom severity was determined by multiplying the number of symptoms by their respective severity ratings. The summated symptom severity scores are 12.59 (S.D. = 8.91) at Wave I and 11.75 (S.D. = 9.74) at Wave II. Both the reported symptoms and the summated symptom severity declined from Wave I to Wave II.

The symptoms and their accompanying severity appeared to diminish in intensity after the initial cancer therapy for this sample. However, there was a pattern which indicated that patients who were “healthier” experienced a higher intensity of
symptoms than those who had more chronic conditions. Patients who have physical limitations may have developed a higher tolerance to the symptoms than those who were "healthy" prior to the cancer treatment.

**Depressive Symptoms**

Based upon the CES-D scale, the mean scores for types of distress accompanying depressive symptoms were 10.95 (S.D. = 7.73) for Wave I and 9.91 (S.D. = 7.69) for Wave II. The CES-D scores of 16 or more for the sample were 25.7% for Wave I and 19.2% for Wave II. The large standard deviation for the depressive symptoms indicates a substantial presence of depressive symptomatology in this sample of cancer patients. However, only forty percent of the sample answered the CES-D instrument.

The presence of depressive symptoms for this sample can be attributed to the loss of physical functioning, dependency on others, and symptoms associated with the disease and cancer treatment. The physical changes associated with cancer treatment, adjustment to the diagnosis of cancer, and the deficits and losses associated with aging can be overwhelming and intensify a *crisis state* for the patient diagnosed with cancer.

The high mean scores and standard deviations indicate that the person diagnosed with cancer may be experiencing a *crisis state*. A crisis state is defined as an obstacle to important life goals that is, for a time, insurmountable through the utilization of customary methods of problem solving (Clemen-Stone, Eigsti, and

Eventually some kind of adaptation is achieved. The decrease in the mean scores from Wave I to Wave II indicates that adaptation behaviors may have begun.

The study findings were slightly lower than Given et al. (1994, p.2131). Given found that the mean depression score was 12.2 (S.D. = 8.0) for patients who survived six months. For patients who did not survive six months, the mean depression scores were 15.3 (S.D. = 7.4).

In summary, one-third of the study sample was diagnosed with prostate cancer. Prostate cancer was the most frequently diagnosed cancer among Michigan residents in 1994. The majority of the sample either had surgery alone or in combination with another treatment modality. One other study (Given et al., 1994), found that chemotherapy was the predominant therapy of choice. The majority of the sample had little change in their activities and instrumental activities of daily living. However, there was a significant decline in their ability to perform vigorous activity after cancer treatment. Similar findings were noted by Given et al. (1994).

Both the symptom experience and depressive symptoms were lower for the study sample than the research by Given et al. (1994). However, with 20 percent of the sample indicating CES-D scores 16 or greater, the data indicates a substantial presence of depressive symptomatology in this sample of cancer patients that may be attributed to a crisis state triggered by the diagnosis and treatment of cancer.

Three-quarters of the study sample had more than two comorbid conditions. This finding is consistent with other research for individuals aged 65 and older.
(Stewart et al., 1989 and Kurtz et al., 1993). However, this sample appeared “sicker” than the normal non-institutionalized older adult (Hobbs, 1995, p. 53).

Clinical characteristics, except for site, treatment of cancer, and vigorous functioning are comparable with other research. A preponderance of research has focused on patient functional limitation changes through the ADL and IADL measures. The loss of vigorous physical functioning, as measured by the Physical Function Subscale of the SF-36, may indicate that the SF-36 is a more sensitive instrument for detecting changes in physical functioning for cancer patients aged 65 and older.

Conclusions

There are several conclusions that can be derived from this study. They are described below.

Sociodemographic Characteristics

The sample consisted predominantly of the young elderly. The mean age was 72.4 years. This data is consistent with Parker et al. (1996, p.13) who noted that persons aged 60 to 79 have the highest probability for developing invasive cancers for all sites.

The sample mirrors the 1994 Michigan Cancer Incidence and Mortality report that stated prostate cancer was the most frequently diagnosed cancer for that year. The greatest number of cancer cases occurred among people in the 70 to 74 age group.
in Michigan in 1994.

Males were 53.3% of the sample. This is not surprising, since persons diagnosed with prostate cancer constituted one-third of the sample. According to Balducci (1992, p.5) prostate cancer is the second most common cause of cancer in American males and after age 80, 50% of all men have Stage A1 cancer.

The sample was predominantly caucasian and two-thirds had a high school or post high school education. Sixty-five percent of the sample was married and 76% lived with another person. Eisenberg and associates (1984, p.17) noted that the majority of elderly adults still live with spouses.

Clinical Characteristics

Surgery was the main treatment for the sample, followed by surgery and radiation. According to Balducci (1992, p.6), surgery is not contraindicated for advanced age. However, the amount of comorbid factors is an indicator of potential contraindications for major surgery.

Most of the cancer patients did not experience substantial limitations in activities of daily living. The majority of the sample who were receiving active treatment for cancer could bathe, dress, transfer and toilet without assistance or minimum assistance. According to Hobbs (1993, p.53), 4.5 million elderly persons needed assistance with one or more activities of daily living. Nine percent of persons aged 65 to 69 years require personal assistance. The percentage increased to 50% for those aged 85 and older who require personal assistance. This data is consistent with
the study's findings. The mean age of the sample was 72.4 years.

There was a slight increase in limitations for the instrumental activities of daily living during the active treatment phase. This can be attributed to the need for transportation or light housework, such as cooking and cleaning, following surgery and/or during active cancer treatment.

There may be a gender bias with the activity of daily living and instrumental activities of daily living measures. Half of the sample were male and married. According to Hobbs (1993, p.53) women were more likely to need assistance than men in the area of general household chores. This may be attributed to females traditionally assuming the role of household manager and caregiver.

There was a significant decline in vigorous physical functioning such as walking more than one block or going up and down a flight of stairs during active cancer treatment as measured by the Physical Functioning Subscale of SF-36. The decline in vigorous physical functioning may be attributed to surgery and the effects of cancer treatment. The Physical Functioning Subscale of the SF-36 may be a more sensitive tool in determining the quality of life for cancer patients during the active treatment phase than the ADL and IADL instruments.

Patient symptoms were measured as a composite score. The number of symptoms decreased from Wave I to Wave II during the treatment phase while the symptom severity essentially remained unchanged.
Hypothesis Testing

**Hypotheses I, II, III**

The time-effect for physical functioning was significant (p = .000) for breast, colon, lung and prostate cancer. However, physical functioning did not seem to be influenced by the patient's primary cancer site.

Treatment did affect physical functioning for this sample. Both time and time-by-treatment were significant. While patients under any treatment combination demonstrated a decline in physical functioning, those who had surgery had the lowest physical functioning score at Wave II.

**Hypothesis IV**

There were large differences in the symptom severity reports of patients with one or no comorbid conditions compared to patients with two or more comorbid conditions. The comorbid effect (between-subject factor) was significant. The over-time effects were ambiguous. The adjusted sample means suggest a decline in symptom severity for patients with two or more comorbid conditions and an increase in symptom severity for patients with one or no comorbid conditions. This apparent interaction may only be a sampling fluctuation as the nonsignificant time-by-grouping suggests. A crisis state may diminish a person's ability to cope with symptoms, and the cancer patient may experience the symptoms at a greater intensity than those who have adapted to multiple symptoms due to living with chronic diseases.
Hypothesis V

Three-quarters of the cancer patients reported two or more comorbid conditions. The sample mean was 2.71. Interestingly, the persons with less than two comorbid conditions experienced a precipitous decline in physical functioning compared to those with two or more comorbid conditions. The accelerated decline in physical functioning among the patients with one or no comorbid conditions only occurs between Wave I and Wave II. This may be attributed to persons who have two or more chronic conditions experienced physical limitations and have learned to cope with these changes. Persons who consider themselves “healthy” may not have developed these coping behaviors.

The ramifications of a sudden physical decline in persons with one or no comorbid conditions are tremendous, for the patient, health professional, and health policy makers. This is a shift from the paradigm that has focused resources primarily on those who have major health care needs or disabilities. The person who experiences a sudden change in self-definition from “healthy” to “sick” appears to need special preparation in coping with his or her illness. It is possible that the recovery of the “healthy” person could have been unintentionally hindered because health professionals and their families did not understand the special needs of this patient. Health professionals must understand that, to coin a phrase: “the healthier they are, the harder they fall”. Accordingly, health professionals need to provide physiological and psychological support for both the “healthy” patient and their
family when they first experience illness and being “chronically” ill.

**Hypothesis VI**

The sample had a substantial presence of depressive symptomatology (19-25%) when compared to the elderly in the community (1-2%). This finding indicates that there is a need for monitoring cancer patients for signs and symptoms of depression and using preventative counseling to deal with the crisis of being diagnosed and treated for cancer. Depressive symptomatology can affect a person’s well-being and quality of life and may be linked to the decline in physical functioning as well as the cancer diagnosis.

**Hypothesis VII**

There is a suggestive descriptive pattern between symptom experience and where one resides. The mean scores indicate that those who live alone experience a greater symptom severity than those who live with others. However, the difference between the two resident patterns could not be statistically confirmed.

**Hypothesis VIII**

There did not appear to be a systematic difference in physical functioning of patients living with or without a caregiver. However, the between-group effect suggests a pattern that patients who live alone appear to be functioning at a slightly higher level, or they may be more independent. A change in physical functioning
may be an indicator for either seeking additional in-home assistance or to a change of residence when they become disabled or more physically impaired.

Living arrangements did not suggest that there was an accelerated loss of physical functioning among patients who live alone, due to the lack of time-by-living arrangement interaction. Interestingly, patients in both living arrangements seem to experience the same rate of deterioration.

Unanticipated Findings

The following findings were not anticipated at the onset of this research study.

1. Activities of daily living (ADL) and instrumental activities of daily living (IADL) were not as sensitive as the Physical Function Subscale of SF-36 in measuring loss of physical functioning for this sample. Hoffman and Rice (1996, p.24) refer to ADL and IADL measures as descriptors for chronic conditions and their subsequent limitations. The study findings indicated that the Physical Functioning Subscale of the SF-36 instrument should be included when determining loss of physical functioning for cancer patients. All three measures should be used in combination to determine a person's physical functioning.

2. Cancer patients with one or no comorbid conditions experienced a precipitous decline in physical functioning when compared to those with two or more comorbid conditions. It is possible that persons who have two or more chronic conditions have developed coping skills to accept one more limitation. The “healthy” older adult with one or no comorbid conditions has not yet developed these coping
behaviors.

3. The CES-D frequency scores (25.7% Wave I and 19.2% Wave II) indicated a substantial presence of depressive symptomatology when compared to 1 to 2% in the community elderly. Although the depressive symptoms decreased from Wave I to Wave II, they were still significant. This may be attributed to being diagnosed with cancer and the subsequent treatment.

4. It was anticipated that persons who were frail, with more than two comorbid conditions, would have experienced a greater decline in physical function when compared to those who were “healthy”. The data indicated the direct opposite during the initial treatment phase. “Healthier” persons experienced greater physical decline. “The healthier they are, the harder they fall”

Limitations of the Study

Limitations of the study include the following:

1. The patients participating in the study were selected from those diagnosed with one of four specific cancers; therefore, the results may be unique and not generalizable to individuals with other types of cancer.

2. The patients were not randomly selected; therefore, this reduces the potential generalizability of the study.

3. History or events external to the cancer treatment may affect internal validity.
4. Maturation or processes that occur within the patient during the cancer
treatment may affect internal validity.

5. Data for the stage of cancer for the study sample were not available.

6. The low response rate for completion of the depression (CES-D)
instrument is attributed to the patient completing the self-administered booklet. The
booklet was sent to the patient one week after the telephone interview. Forty percent
of the sample answered the CES-D instrument.

Recommendations and Conclusions

Implications for public policy and future research based upon the results of
this study will be presented in the following section with a focus on the Quality of
Life conceptual framework adapted for this dissertation. Conclusions derived from
this study are included in this section with a discussion of the findings.

Implications Related to the Conceptual Framework

Quality of life for this study was interpreted as a composite of factors. The
quality of life variables include physical, social and mental functioning. The study
used a longitudinal design, comparing three observation points, for the aged 65 and
older cancer patient. The model was disease-specific, and the purpose was to detect
differences in the three domains of functional status.

The findings for this study are consistent with other research related to quality
of life and cancer patients. Mor (1987, p. 2046) found that the strongest correlate
with quality of life for the older adult was function. Grant et al. (1990, p. 260) indicated that quality of life was an outcome variable for cancer treatment. Ware (1984, p.2317) conceptualized a disease impact model that considered how individuals experienced disease, treatment and changes in health over time.

Quality of Life, as it pertains to the study's conceptual model, was examined in the following three domains of functional status.

**Physical Domain**

Treatment appeared to have the greatest impact on the loss of physical functioning. However, cancer patients with one or no comorbid conditions appeared to have a greater decline in physical functioning than those with two or more comorbid conditions.

A person who has been diagnosed with cancer, with one or no comorbid conditions, may consider the diagnosis and treatment a catastrophic life event. A person in “good health” may not have developed gradual adaptation coping behaviors. Any change in physical function may be perceived as a dramatic physical decline.

A person who has lived with chronic disabilities and has developed gradual adaptation coping behaviors, also experiences a decline in physical functioning due to the cancer diagnosis and treatment. However, the decline is not perceived as dramatic. The physical limitations imposed by other chronic conditions are additive, and adaptation coping techniques have been developed. For the person with multiple comorbid conditions, cancer may be considered just another ailment.
Activities of daily living and instrumental activities of daily living appeared to remain consistent throughout the observation time, although there was a slight increase in means from Recall to Wave I for both ADL's and IADL's. The most need for assistance appeared to be with needs of instrumental activities of daily living. Patients were generally able to bathe, dress, eat, toilet and transfer. However, assistance was needed for transportation, cooking, shopping, laundry and light housework.

The greatest impact in physical functioning occurred with vigorous activity such as climbing stairs, walking more than one block, lifting and bending. There was an appreciable decline from Recall to Wave II. The decline in vigorous activity may be attributed to surgery as the primary treatment or a combination of treatment modalities.

There was no statistical difference between symptom experience and the number of comorbid conditions. There were large differences in symptom severity of patients with fewer comorbid conditions compared to those with several comorbid conditions. The adjusted sample means suggest a decline in symptom severity among patients with high levels of comorbid conditions (albeit a decline from very high levels) and an increase in reported symptom severity for patients with one or no comorbid conditions.

The crisis state that may have occurred when the cancer patient experienced the decline in physical functioning for those with one or no comorbid conditions may also have occurred in how the patient perceived the symptom experience. The
“healthy” older adult may not have adapted to the physical limitations and symptom experience associated with a chronic condition as those who have had multiple chronic conditions. One symptom for the previously “healthy” person may be disabling compared to someone who daily experiences symptoms due to other chronic diseases. “The healthier they are, the harder they fall”.

**Mental Domain**

Depression scores were not statistically significant. There was no statistical difference between Wave I and Wave II; yet, depressive symptomatology was present. Twenty percent of the study sample appeared to have depressive symptomatology. This finding indicates the importance of monitoring cancer patients age 65 and older for signs and symptoms of depression and offering prophylactic counseling to deal with the disease and its ramifications. Prophylactic counseling’s goal should be to maintain or improve the biopsychosocial homeostasis and assist the cancer patient with adaptation. The general health provider should monitor, treat the symptoms of depression, or refer the person to a mental health specialist if the symptoms persist. Typical symptoms include isolation, loss of interest, trouble sleeping, feeling both sad and blue or down in the dumps, and thinking of death or suicide.

**Social Domain**

There appeared to be no difference between the patient’s living arrangements,
symptom experience and physical functioning. However, there was a pattern indicating that those who lived alone were functioning at a higher level, when compared to those who lived with another person. Patients in both living arrangement groups seemed to experience the same rate of deterioration in their functioning.

It is possible that those who lived alone have developed a supportive community, such as family and friends. Other reasons include that they might be more independent by nature or they may have an earlier stage of cancer (data that this study did not include).

In summary, a repeated measures analysis of variance was used to test the hypotheses. The study's findings remain consistent with the conceptual framework. The physical domain had the greatest impact on quality of life for this sample of cancer patients aged 65 and older.

There was a significant decline in the physical functioning scores over time. The drop was significant both between Recall and Wave I and between Wave I and Wave II. The adjusted marginal means indicated a precipitous decline in physical functioning from the time before diagnosis to Wave II. Those who had surgery had the lowest functioning scores at Wave II. By contrast, treatment did affect physical functioning, both regardless of time and over time. There was an accelerated decline in physical functioning among those patients with one or no comorbid conditions only between Wave I and Wave II. This indicates that the initial treatment of cancer for persons considered "healthy" with one or no comorbid conditions prior to diagnosis
experienced a greater decline in physical functioning than those who had to adjust to other health problems prior to the treatment of cancer.

The adjusted symptom severity mean suggested a decline in symptom severity among patients with high levels of comorbid conditions (albeit a decline from very high levels) and an increase in reported symptom severity for patients with one or no comorbid conditions. This increase may be a result of sampling fluctuation as the time-by-comorbid condition grouping suggests, or an indication that those who were previously considered “healthy” experience symptoms more profoundly than those with multiple comorbid conditions. Persons with multiple chronic conditions may have developed adaptive behaviors not developed in healthier adults.

Therefore, physical functioning, as measured by Physical Function Subscale of the SF-36, was a better predictor of functional limitation than symptom severity for this sample of cancer patients. There was some indication that persons who were previously “healthy” had higher symptom severity scores during treatment. “The healthier they are, the harder they fall”.

The mental and social domains were not statistically significant predictors of functional limitation during the active cancer treatment phase of illness. However, twenty percent of the sample have a score in the CES-D of sixteen or greater indicating depressive symptomatology. Early detection and screening of depression for cancer patients should be part of the treatment regimen.

Patients in both living arrangements seemed to experience the same rate of physical deterioration over time. However, persons who live alone were functioning
at a higher level. Community resources for both those living alone and for the
caregiver and patient in either living arrangement should be considered. Physical
decline for the person living alone is a cause for uprooting or institutionalization.
Physical decline for the person living with another causes wear and tear on the
caregiver. In either scenario, physical decline diminishes quality of life. Financial
and community resources should be available to maintain or improve function when
feasible.

The data implies that health providers need to monitor functional outcomes
during initial cancer treatment for all patients. Physical, mental and social
functioning, which includes assessment of activities of daily living, instrumental
activities of daily living, vigorous physical functioning, and depression, should occur
before, during and after medical interventions for cancer. Medical management
should include a care plan that addresses maintenance or improvement of functional
status including anticipatory grieving to help people who are dealing with the crisis of
the disease. Quality of Life outcome indicators are essential in clinical decision
making to prevent or minimize a decline in physical, mental and social functioning
and thus avert costly supportive resources or institutionalization.

Implications for Public Policy

The research findings that can be inferred from this study encompass issues
pertaining to Medicare reform that may well be introduced in the 105th Congress.
What Medicare will look like in the next few years and how Medicare will be funded
are questions that are germane to these research results.

The rapid increase in the number of people eligible for the Medicare program, combined with the increase in medical costs, will lead to a significant depletion of the Medicare Trust Fund within the next ten years if no preventive measures are taken. Gradually the federal government has opened the door for managed care for the Medicare population. It is anticipated that the 105th Congress will continue to experiment with, and encourage the use of, managed care principles to restrain cost growth.

When health practitioners understand the opportunity offered by Medicare Risk plans, there will be a rapid increase in the expansion of these programs. Medical risk is defined as a contract between a health maintenance organization and the Health Care Financing Administration (HCFA) to provide services to Medicare beneficiaries. The health plan receives a fixed payment for the enrolled Medicare members and then must provide all services on an at-risk basis (Kongstvedt, 1996, p.1001). As the Medicare Risk plan matures, and takes on the cost of medical care for a defined population, it will be essential that it more effectively meets the needs of the senior population. The focus of care shifts from disease management to health prevention. Disease specific outcome indicators will be imperative to maintain or prevent functional decline.

The 104th Congress considered several legislative proposals that would have significantly affected the growth of Medicare Risk plans. The proposals included changes in HCFA payment methodology, fixed growth of Medicare funding, and
licensing of provider sponsored networks.

Legislation has been reintroduced by Representatives Bill Thomas (Republican), Michael Bilirakis (Republican) and Ben Cardin (Democrat), HR15, to add preventative Medicare benefits for diabetes, and breast, cervical, prostate and colon cancer. The purpose of preventative health care, according to Representative Thomas, is to improve health and quality of life and lower health costs for seniors (American Hospital Association News, January 20, 1997, p.3).

In addition to the federal initiatives, which focus on controlling health care costs through Medicare Risk programs, several federal waivers to states for Medicaid have been initiated. Waivers that would allow large state-wide approaches that include benefits, services, eligibility, payment and/or delivery services have either been proposed or initiated in some states. Limited scale waivers have also been proposed that require enrollment in a managed care plan. Many of the proposals that have been introduced into Congress include home and community based services for the elderly (Ross, 1994, p.1).

Conventional thought currently considers Medicaid a publicly sponsored Medigap policy for the state's dual-eligible and disabled. In some states, Medicaid is 20 percent of aggregate state expenditures, and growing at three times the rate of other state program categories. Because of the consistent growth in Medicaid expenditures, many states, including Michigan, have developed Medicaid Managed Care initiatives for long-term care.
Senator Russell Feingold (Democrat) introduced Bill Number S.58 entitled "Modification of the Estate Recovery Provision of the Medicaid Program Provision," on January 21, 1997 to the Senate Committee on Finance. The purpose of the bill is to modify estate recovery provisions of the medicaid program to give states the option to recover the cost of home and community based services for those aged 55 and older according to The Long Term Care Campaign Six Month Strategy Plan (Eagen, 1997, p. 1).

These initiatives involve community-based waivers that utilize federal funding. The program offers services not covered under the state's Medicaid plan and broadens the terms of Medicaid income eligibility.

The focus of the federal and state initiatives has been on providing programs and services that allow older adults and the disabled to continue living at home. Caring for seniors at home is approximately half the cost of caring for them in an alternate care site, such as a skilled nursing facility. According to Ross, (1994, p.1) long-term health care spending was estimated in 1993 to cost $79.2 billion, $20.6 billion of which was for home and community-based services. It is estimated that these expenditures will more than double by 2020 under current spending patterns.

Programs such as disease-state management or medical management models for patients have focused on providing a comprehensive approach to caring for a patient through prevention, managing the disease, and containing costs (Kaplan & Gill, 1996, p. 1). The goal of disease-state management is to anticipate the needs of patients before they require costly hospital services.
The traditional medical model treats the symptoms of the disease, not the problems associated with functional status, which include the physical, mental and social domains related to the disease. As the health paradigm has shifted toward health prevention models, several programs have made an impact on disease management. These programs include case management and outcomes management.

The results of this study have important implications for all three components of disease management. Congress authorized optional case management services under Medicaid in 1981. Currently, at least 40 states have developed case management programs (Satinsky, 1996, p. 12). The purpose of case management is to assess, plan, intervene, monitor and evaluate the social, medical, and economic needs of the patient (Satinsky, 1996, p. 13).

The findings of this research suggest cancer patients age 65 and older experience a loss of physical functioning during the active treatment phase. There is a precipitous decline in physical functioning from diagnosis to Wave II. Physical functioning did not seem to be influenced by the primary site of cancer, but treatment did affect physical functioning, regardless of time. In particular, the decline in physical functioning is greater among the patient group with initially fewer comorbid conditions when compared to the patient group with two or more comorbid conditions. In addition, patients either living alone or with another seemed to experience the same rate of deterioration in physical functioning.

Incorporating a case manager into the treatment plan for patients age 65 and older, who are experiencing active cancer treatment, may reduce the downward
trajectory of physical limitations in functioning. Providing financial and human resource support for outcomes management focusing on the three domains of functional status would assist the patient and caregiver during the treatment phase.

Case management support needs to be incorporated into the disease management model for any federal or state Medicare or Medicaid risk plan. Offering case management as a covered benefit would include medical and nursing care coordination, recipient support, and administrative support.

The purpose of case management is to intervene prior to a downward trajectory in the loss of the three domains of physical functioning. Intervention from a case manager could prevent costly hospital readmissions, ancillary service utilization and skilled nursing facility admissions. The case manager needs to monitor the functional status for early changes in vigorous activity including a deterioration in the ability to perform self-care tasks. Anticipatory grief counseling needs to be implemented when appropriate to help the cancer patient move through the crisis state and achieve at least the same level of psychological comfort he or she experienced before the cancer diagnosis and treatment (Kus, 1985, p. 279).

In the past, the focus of case management has been on patients who live alone with multiple comorbid conditions. The data from this study indicates that persons who are newly diagnosed with cancer, regardless of living arrangements and levels of comorbid conditions, should receive case management and crisis counseling. The findings suggest a precipitous decline in function for the previously “healthy” older adult. This finding may be attributed to a sudden change in health status for the
previously “healthy” person compared to a long-term compensation of diminishing
health for those with multiple comorbid conditions.

Additional findings from this study indicate that older adults who were living
with a designated care giver appeared to have more functional limitations than those
living alone. Federal and state initiatives should provide incentives for care givers to
provide care for the older adults in his or her own home. These incentives may
include income tax deductions, health aides during the day for the working caregiver,
adult day care, respite care, and assisted living benefits.

Inherent in developing case management as a covered Medicare/Medicaid
benefit, hospitals and integrated delivery systems must develop disease-specific
outcomes. The term outcomes management was coined by Paul Elwood in 1988
(Spath, 1996, p.3). The purpose of outcomes management is to describe the patient
experience and make rational medical care-related choices based upon more informed
insights on how these choices affect the patient’s life.

There are multiple components to outcomes management. Spath (1996, p.6)
noted that treatment outcomes should focus on quality of life issues related to the
patient’s ability to function during and after a medical intervention. These health-
related quality of life issues are being used as an outcome measure in clinical trials
and in research on Quality of Life.
Implications for Future Research

1. There are several implications for research that may be drawn from this study. Future research should continue to focus on outcomes and the relationship between age, cancer treatment, comorbid conditions, and the loss of physical functioning. Inclusion criteria incorporating the stage of cancer should be included in future studies, since the physical functioning of patients with metastatic cancer may differ from those without metastasis.

   Additional research should be instituted to determine if there is a relationship between depressive symptomatology, loss of physical functioning, the amount of comorbid conditions and the presence of crisis states during initial cancer treatment.

2. Additional research should be instituted using the Physical Function Subscale of the SF-36 to detect the loss of physical deterioration for cancer patients who are aged 65 and older. Continued research should be conducted to determine at what point activities of daily living and instrumental activities of daily living capture extreme physical deterioration during cancer treatment; and if there is a gender bias during initial treatment.

3. A longitudinal study should be instituted to monitor the effects of case management and disease management. The purpose is to determine effective interventions that reduce iatrogenic events such as loss of physical function and reduction in the cost of care during cancer treatment.

   Research should be undertaken to validate the components of the quality of
life conceptual model proposed by this study for patients aged 65 and older, and to
determine a feedback for change over time.

Summation

The purpose of this study was to determine whether there were changes in the
quality of life of cancer patients aged 65 and older following initial treatment for
cancer. A Quality of Life model was developed. Quality of Life was defined as those
variables that encompass functional status, including (a) physical, (b) social, and (c)
mental capacities.

This study analyzed data from a larger longitudinal data set and compared data
at three observation points. Change in functional status was measured through the
Physical Function Subscale of the SF-36, depression (CES-D) and a total symptom
severity instrument.

Data were analyzed using Repeated Measures Analysis of Variance and
Covariance. There was a significant decline in physical functioning over time (p < .000). Cancer treatment affected physical functioning regardless of time (p < .005) and over time (p < .008). The decline in physical functioning was greater among patients with fewer comorbid conditions when compared to the patient group with two or more comorbid conditions.

Cancer site had no effect on physical functioning. There was no statistical
difference in symptom experience and depression scores based upon the patient’s
number of comorbid conditions. However, the “healthier” patient experienced greater
symptom severity scores than patients with two or more comorbid conditions. This interaction may have been due to a sampling fluctuation or to a crisis state which may have affected a person's ability to cope.

The ramifications of the sudden physical decline and intensity of symptom experience for the "healthier" patient are tremendous, both for the patient, the health professional, and health policy maker. This data suggests a shift from the paradigm that has focused resources primarily on those individuals who have major health needs or disabilities. Health professionals must understand that "the healthier they are, the harder they fall" Accordingly, health professionals need to provide physiological and psychological support to the "healthy" patient and their family when they first experience illness and being "chronically" ill.
Appendix A

Instruments
Sociodemographic Information For Cancer Patient

1. Sex of Patient: (check one) ___ Male (1) ___ Female (2)

2. What is your birth date? (write in) __/__/__ (month/day/year)

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

4. What is your race or ethnic background? (check one)
   ___ Caucasian/White (1)
   ___ African American/Black (2)
   ___ Mexican American/Hispanic/Chicano (3)
   ___ Native American/Alaskan (4)
   ___ Oriental/Asian/Pacific Islander (5)
   ___ Other (6) (specify _________________________)
   ___ NA/Refused (9)

5. What is your marital status? (check one)
   ___ Never married (1)
   ___ Married (2)
   ___ Divorced/Separated (3)
   ___ Widowed (4)
   ___ NA/Refused (9)

6. Who lives in your household with you? (check one)
   ___ No One—lives alone (1)
   ___ Spouse (2)
   ___ Other (3)
   ___ NA/Refused (4)
Physical Health Patient

1. Has a health care professional ever told you that you have high blood pressure or hypertension? (check one)
   ___ Yes (1)
   ___ No (2)
   ___ DK/NA/Refused (9)

2. Has a health care professional ever told you that you have diabetes?
   ___ Yes (1)
   ___ No (2)
   ___ DK/NA/Refused (9)

3. Has a health care professional ever told you that you have cancer or a malignant tumor, other than the cancer for which you are being treated? (check one)
   ___ Yes (1)
   ___ No (2)
   ___ DK/NA/Refused (9)

4. In which organ or part of your body did your (most recent) cancer start? (write in)____________________

5. Not including asthma, has a health care professional ever told you that you have chronic lung disease such as chronic bronchitis or emphysema? (check one)
   ___ Yes (1)
   ___ No (2)
   ___ DK/NA/Refused (9)

6. Has a health care professional ever told you that you had a heart attack, coronary heart disease, angina, congestive heart failure, or other heart problems? (check one)
   ___ Yes (1)
   ___ No (2)
   ___ OK/NA/Refused (9)

7. Has a health care professional ever told you that you had a stroke? (check one)
   ___ Yes (1)
   ___ No (2)
   ___ DK/NA/Refused (9)
8. Have you ever seen a health care professional for emotional, nervous, or psychiatric problems? (check one)
   ___ Yes (1)
   ___ No (2)
   ___ DK/NA/Refused (9)

8a. Have you had any of these problems in the last twelve 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 ever fractured your hip? (check one)
    ___ Yes (1)
    ___ No (2)
    ___ DK/NA/Refused (9)

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

11. During the last 12 months, have you lost any amount of urine beyond your control? (check one)
    ___ Yes (1)
    ___ No (2)
    ___ DK/NA/Refused (9)

12. With or without corrective lenses, would you consider your eyesight to be excellent, very good, good, fair, or poor? (check one)
    ___ Excellent (1)
    ___ Very good (2)
    ___ Good (3)
    ___ Fair (4)
    ___ Poor (5)
    ___ DK/NA/Refused (9)

13. Have you ever had cataract surgery? (check one)
    ___ Yes (1)
    ___ No (2)
14. With or without hearing aids, would you consider your hearing to be excellent, very good, good, fair, or poor? (check one)
   ___ Excellent (1)
   ___ Very good (2)
   ___ Good (3)
   ___ Fair (4)
   ___ Poor (5)
   ___ DK/NA/Refused (9)

15. Do you have any other major health problems which you haven't told me about? (check one)
   ___ Yes (1)
   ___ No (2)
   ___ DK/NA/Refused (9)
Patient Symptom Experience

The following is a list of symptoms that some people with cancer experience either from the illness or as a result of treatment. If you have not experienced the symptom in the past two weeks answer NO.

If you have experienced the symptom in the past two weeks, answer YES, then identify how severe this symptom was, indicating the severity of this symptom, either 1 = MILD, 2 = MODERATE, 3 = SEVERE.

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

<table>
<thead>
<tr>
<th>SYMPTOM</th>
<th>YES</th>
<th>NO</th>
<th>MILD</th>
<th>MODERATE</th>
<th>SEVERE</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(1)</td>
<td>(2)</td>
<td>(1)</td>
<td>(2)</td>
<td>(3)</td>
</tr>
<tr>
<td>Nausea</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Pain</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Trouble with sleep</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Fatigue</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Short of Breath</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Diarrhea</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Coordination problem</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Vomit</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Difficulty Concentrating</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Weak</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
A. Did you experience this symptom in the past two weeks? (circle one)

B. If yes, how severe is this symptom for you? (circle one if experienced)

<table>
<thead>
<tr>
<th>SYMPTOM</th>
<th>YES (1)</th>
<th>NO (1)</th>
<th>MILD (2)</th>
<th>MODERATE (2)</th>
<th>SEVERE (3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dizzy</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Numb/tingle/loss of feeling</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Poor appetite</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Weight loss</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Fever</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Cough</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Dry Mouth</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Constipation</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Freq. urination</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Dehydration</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Mouth Sores</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Itching</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Leak urine</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Urgent need to urinate</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Hot flashes</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Breast tender</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Wake up at night to urinate</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Difficult Swallow</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Sweats/night sweats</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Lack of sexual interest</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
A. Did you experience this symptom in the past two weeks? (circle one)

B. If yes, how severe is this symptom for you? (circle one if experienced)

<table>
<thead>
<tr>
<th>SYMPTOM</th>
<th>YES (1)</th>
<th>NO (2)</th>
<th>MILD (2)</th>
<th>MODERATE (2)</th>
<th>SEVERE (3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bleed/bruise</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Altered Taste</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Mood changes</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Vaginal dryness (women only)</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Arm Swell</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Limit arm movement</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Leg Swell</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
**Physical Functioning**

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

<table>
<thead>
<tr>
<th>Activity</th>
<th>3 months ago</th>
<th>Current</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mod. Act. move a table, bowl, play golf</td>
<td>3 2 1 3 2 1 1</td>
<td></td>
</tr>
<tr>
<td>Vigorous Activity: lift heavy object, play strenuous sports</td>
<td>3 2 1 3 2 1 1</td>
<td></td>
</tr>
<tr>
<td>Lift or carry groceries</td>
<td>3 2 1 3 2 1 1</td>
<td></td>
</tr>
<tr>
<td>Climb several flights of stairs</td>
<td>3 2 1 3 2 1 1</td>
<td></td>
</tr>
<tr>
<td>Climb one flight of stairs</td>
<td>3 2 1 3 2 1 1</td>
<td></td>
</tr>
<tr>
<td>Bend, kneel, stoop</td>
<td>3 2 1 3 2 1 1</td>
<td></td>
</tr>
<tr>
<td>Walk one block</td>
<td>3 2 1 3 2 1 1</td>
<td></td>
</tr>
<tr>
<td>Walk several blocks</td>
<td>3 2 1 3 2 1 1</td>
<td></td>
</tr>
<tr>
<td>Walk more than one mile</td>
<td>3 2 1 3 2 1 1</td>
<td></td>
</tr>
</tbody>
</table>
Activities of Daily Living

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 question regarding the activity.

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

1a. Three months ago, with regard to dressing, would you say...(check one)
   __ WERE INDEPENDENT (did not need help of another person in any part of this activity) (1)
   __ NEEDED SUPERVISION (2)
   __ NEEDED SOME PHYSICAL HELP (required physical help and the presence of another during all or part of this activity) (3)
   __ NEEDED TOTAL PHYSICAL HELP (needed another person to carry out this activity) (4)
   __ NEVER DRESSED (5)
   __ NA/REFUSED (9)

1b. Currently, with regard to dressing, would you say...(check one)
   __ WERE INDEPENDENT (did not need help of another person in any part of this activity) (1)
   __ NEEDED SUPERVISION (2)
   __ NEEDED SOME PHYSICAL HELP (required physical help and the presence of another during all or part of this activity) (3)
   __ NEEDED TOTAL PHYSICAL HELP (needed another person to carry out this activity) (4)
   __ NEVER DRESSED (5)
   __ NA/REFUSED (9)

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

2a. Three months ago, with regard to eating, would you say...(check one)
   __ WERE INDEPENDENT (did not need help of another person in any part of this activity) (1)
2b. Currently, with regard to eating, would you say...(check one)
  __WERE INDEPENDENT (did not need help of another person in any part
  of this activity (1)
  __NEEDED SUPERVISION (2)
  __NEEDED SOME PHYSICAL HELP (required physical help and the
  presence of another during all or part of this activity) (3)
  __NEEDED TOTAL PHYSICAL HELP (needed another person to carry
  out this activity) (4)
  __NA (5)
  __REFUSED (9)

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

3a. Three months ago, with regard to bathing, would you say...(check one)
  __WERE INDEPENDENT (did not need help of another person in any part
  of this activity (1)
  __NEEDED SUPERVISION (2)
  __NEEDED SOME PHYSICAL HELP (required physical help and the
  presence of another during all or part of this activity) (3)
  __NEEDED TOTAL PHYSICAL HELP (needed another person to carry
  out this activity) (4)
  __NA (5)
  __REFUSED (9)

3b. Currently, with regard to bathing, would you say...(check one)
  __WERE INDEPENDENT (did not need help of another person in any part
  of this activity (1)
  __NEEDED SUPERVISION (2)
  __NEEDED SOME PHYSICAL HELP (required physical help and the
  presence of another during all or part of this activity) (3)
4. **WALKING INSIDE THE HOUSE:** This category includes all upright movement on foot over the floor inside the house. **MUST MOVE AT LEAST FIVE FEET.** May use cane, walker, crutches, or handrail. Select the response that best describes your level of functioning for walking inside the house.

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

- __**WERE INDEPENDENT** (did not need help of another person in any part of this activity) (1)
- __**NEEDED SUPERVISION** (2)
- __**NEEDED SOME PHYSICAL HELP** (required physical help and the presence of another during all or part of this activity) (3)
- __**NEEDED TOTAL PHYSICAL HELP** (needed another person to carry out this activity) (4)
- __**NA** (5)
- __**REFUSED** (9)

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

- __**WERE INDEPENDENT** (did not need help of another person in any part of this activity) (1)
- __**NEEDED SUPERVISION** (2)
- __**NEEDED SOME PHYSICAL HELP** (required physical help and the presence of another during all or part of this activity) (3)
- __**NEEDED TOTAL PHYSICAL HELP** (needed another person to carry out this activity) (4)
- __**NA** (5)
- __**REFUSED** (9)

5. **TOILETING:** This category includes: getting to and from the toilet (or use of toileting equipment such as bedpan), removal and adjustment of clothing, positioning on toilet, cleaning of body parts, and replacement of clothing. This does not include assistance because of incontinence of bowel or bladder. Select the response that best describes your level of functioning for toileting.

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

- __**WERE INDEPENDENT** (did not need help of another person in any part of this activity) (1)
5b. Currently, with regard to toileting, would you say...(check one)

- **WERE INDEPENDENT** (did not need help of another person in any part of this activity) (1)
- **NEEDED SUPERVISION** (2)
- **NEEDED SOME PHYSICAL HELP** (required physical help and the presence of another during all or part of this activity) (3)
- **NEEDED TOTAL PHYSICAL HELP** (needed another person to carry out this activity) (4)
- **NA** (5)
- **REFUSED** (9)

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

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

- **WERE INDEPENDENT** (did not need help of another person in any part of this activity) (1)
- **NEEDED SUPERVISION** (2)
- **NEEDED SOME PHYSICAL HELP** (required physical help and the presence of another during all or part of this activity) (3)
- **NEEDED TOTAL PHYSICAL HELP** (needed another person to carry out this activity) (4)
- **NA** (5)
- **REFUSED** (9)

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

- **WERE INDEPENDENT** (did not need help of another person in any part of this activity) (1)
- **NEEDED SUPERVISION** (2)
- **NEEDED SOME PHYSICAL HELP** (required physical help and the presence of another during all or part of this activity) (3)
7. TRANSPORTATION:

7a. Three months ago, with regard to getting places outside of walking distance, i.e., going to the doctor's or grocery shopping away from the neighborhood...(check one)
   ___ WERE INDEPENDENT (did not need help of another person in any part of this activity) (1)
   ___ NEEDED SUPERVISION (2)
   ___ NEEDED SOME PHYSICAL HELP (required physical help and the presence of another during all or part of this activity) (3)
   ___ NEEDED TOTAL PHYSICAL HELP (needed another person to carry out this activity) (4)
   ___ NA (5)
   ___ REFUSED (9)

7b. Currently, with regard to getting places outside of walking distance, i.e., going to the doctor's or grocery shopping away from the neighborhood...(check one)
   ___ WERE INDEPENDENT (did not need help of another person in any part of this activity) (1)
   ___ NEEDED SUPERVISION (2)
   ___ NEEDED SOME PHYSICAL HELP (required physical help and the presence of another during all or part of this activity) (3)
   ___ NEEDED TOTAL PHYSICAL HELP (needed another person to carry out this activity) (4)
   ___ NA (5)
   ___ REFUSED (9)

8. LAUNDRY

8a. Three months ago, with regard to laundry, would you... (check one)
   ___ WERE INDEPENDENT (did not need help of another person in any part of this activity) (1)
   ___ NEEDED SUPERVISION (2)
8b. Currently, with regard to laundry, would you... (check one)

- **WERE INDEPENDENT** (did not need help of another person in any part of this activity) (1)
- **NEEDED SUPERVISION** (2)
- **NEEDED SOME PHYSICAL HELP** (required physical help and the presence of another during all or part of this activity) (3)
- **NEEDED TOTAL PHYSICAL HELP** (needed another person to carry out this activity) (4)
- **NA** (5)
- **REFUSED** (9)

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

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

- **WERE INDEPENDENT** (did not need help of another person in any part of this activity) (1)
- **NEEDED SUPERVISION** (2)
- **NEEDED SOME PHYSICAL HELP** (required physical help and the presence of another during all or part of this activity) (3)
- **NEEDED TOTAL PHYSICAL HELP** (needed another person to carry out this activity) (4)
- **NA** (5)
- **REFUSED** (9)

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

- **WERE INDEPENDENT** (did not need help of another person in any part of this activity) (1)
- **NEEDED SUPERVISION** (2)
- **NEEDED SOME PHYSICAL HELP** (required physical help and the presence of another during all or part of this activity) (3)
- **NEEDED TOTAL PHYSICAL HELP** (needed another person to carry out this activity) (4)
- **NA** (5)
- **REFUSED** (9)
10. **HOUSEWORK**: This includes picking up, dusting, light cleaning, vacuuming, or doing dishes.

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

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

___ **NEEDED SUPERVISION** (2)

___ **NEEDED SOME PHYSICAL HELP** (required physical help and the presence of another during all or part of this activity) (3)

___ **NEEDED TOTAL PHYSICAL HELP** (needed another person to carry out this activity) (4)

___ NA (5)

___ REFUSED (9)

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

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

___ **NEEDED SUPERVISION** (2)

___ **NEEDED SOME PHYSICAL HELP** (required physical help and the presence of another during all or part of this activity) (3)

___ **NEEDED TOTAL PHYSICAL HELP** (needed another person to carry out this activity) (4)

___ NA (5)

___ REFUSED (9)

11. **COOKING AND PREPARING MEALS**:

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

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

___ **NEEDED SUPERVISION** (2)

___ **NEEDED SOME PHYSICAL HELP** (required physical help and the presence of another during all or part of this activity) (3)

___ **NEEDED TOTAL PHYSICAL HELP** (needed another person to carry out this activity) (4)

___ NA (5)

___ REFUSED (9)

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

___ **WERE INDEPENDENT** (did not need help of another person in any part of this activity) (1)
NEEDED SUPERVISION (2)
NEEDED SOME PHYSICAL HELP (required physical help and the presence of another during all or part of this activity) (3)
NEEDED TOTAL PHYSICAL HELP (needed another person to carry out this activity) (4)
NA (5)
REFUSED (9)
Depression (CES-D)

These questions ask about how you feel, and how things have been with you **within the past month**. For each question, read the statement then check the one answer that comes closest to the way you have been feeling during the past month. Do not spend too much time on any one statement.

<table>
<thead>
<tr>
<th>During the past month, how much of the time ...</th>
<th>Almost all of the time (3)</th>
<th>Most of the time (2)</th>
<th>Some of the time (1)</th>
<th>Rarely/none of the time (0)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Were you bothered by things that usually don't bother you?</td>
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<td>2. Have you not felt like eating; had a poor appetite?</td>
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<td>3. Have you felt that you could not shake off the blues, even with the help of family or friends?</td>
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<td>4. Have you felt that you were just as good as other people?</td>
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<td>5. Have you had trouble keeping your mind on what you were doing?</td>
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<tr>
<td>6. Have you felt depressed</td>
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</tbody>
</table>
During the past month, how much of the time ...

<table>
<thead>
<tr>
<th>Question</th>
<th>Almost all of the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>Rarely/none of the time</th>
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</thead>
<tbody>
<tr>
<td>7. Have you felt that everything you did was an effort?</td>
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<td>8. Have you felt hopeful about the future?</td>
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<td>9. Have you thought your life has been a failure?</td>
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<td>10. Have you felt fearful?</td>
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<td>11. Has your sleep been restless?</td>
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<td>12. Were you happy?</td>
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<td>13. Have you talked less than usual?</td>
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<tr>
<td>14. Have you felt lonely?</td>
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<td>15. Were people unfriendly?</td>
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<tr>
<td>16. Have you enjoyed life?</td>
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<tr>
<td>17. Have you had crying spells?</td>
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<td>18. Have you felt sad?</td>
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<tr>
<td>19. Have you felt that people disliked you?</td>
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<tr>
<td>20. Could you not get going?</td>
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</tbody>
</table>
Service Utilization

Now I want to ask you some questions about the doctors you have visited and the health services that you have used in the past three months or since you were first diagnosed with cancer.

1. In the past three months or since you were first diagnosed with cancer, have you visited a surgeon for your cancer? (check one)
   ___ Yes (1)
   ___ No (2)
   ___ DK/NA/Refused (9)

2. What was the date on which you had your surgery?
   —/-/-/-— (Month/Day/Year)

3. In the past three months or since you were first diagnosed with cancer, have you visited or are you scheduled to visit, a medical oncologist or an oncology group practice for your cancer treatment? (check one)
   ___ Yes, I have begun treatment on —/-/-/-— (Month/Day/Year) (1)
   ___ Yes, scheduled, but do not know if I need treatment (2)
   ___ Yes, scheduled to begin treatment on —/-/-/-— (Month/Day/Year) (3)
   ___ No, not scheduled to see an oncologist (4)
   ___ I don't know (8)
   ___ NA/Refused (9)

4. In the past three months or since you were first diagnosed with cancer, have you visited or are you scheduled to visit, a radiation therapist/ oncologist for your cancer treatment? (check one)
   ___ Yes, I have begun treatment on —/-/-/-— (Month/Day/Year) (1)
   ___ Yes, scheduled, but do not know if I need treatment (2)
   ___ Yes, scheduled to begin treatment on —/-/-/-— (Month/Day/Year) (3)
   ___ No, not scheduled to see an oncologist (4)
   ___ I don't know (8)
   ___ NA/Refused (9)
Appendix B

Human Subjects Approval
Western Michigan University
To: Kathleen Redding  
    Rosmary Zivic
From: Richard A. Wright, Chair  
    Human Subjects Institutional Review Board
Subject: HSIRB Project # 96-04-16
Date: June 19, 1996

This is to inform you that your project entitled "Self-Reported Needs After Acute Treatment for Oncology: Patients Aged 65 and Older," has been approved under the exempt category of research. This approval is based upon your proposal to use only secondary data, without identifiers, collected through a larger longitudinal study.

Your project is approved for a period of one year from the above date. If you should revise any procedures relative to human subjects or materials, you must resubmit those changes for review in order to retain approval. Should any untoward incidents or unanticipated adverse reactions occur with the subjects in the process of this study, you must suspend the study and notify me immediately. The HSIRB will then determine whether or not the study may continue.

Please be reminded that all research involving human subjects must be accomplished in full accord with the policies and procedures of Western Michigan University, as well as all applicable local, state and federal laws and regulations.

Thank you for your cooperation. If you have any questions, please do not hesitate to contact me.

Project Expiration Date: June 19, 1997
Appendix C

Human Subjects Approval
Michigan State University
The University Committee on Research Involving Human Subjects (UCRINS) 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 UCRINS approved this project including any revision listed above.

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

REVISIONS: UCRINS 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 UCRINS Chair, requesting revised approval and referencing the project's IRB # and title. Include in your request a description of the change and any revised instruments, consent forms or advertisements that are applicable.

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

If we can be of any future help, please do not hesitate to contact us at (517) 355-2180 or FAX (517) 336-1171.

Sincerely,

[Signature]
David E. Wright, Ph.D.
UCRINS Chair
June 6, 1995

To: Barbara A. Given
A230 Life Sciences

Re: IRB:
IRB#: 92-280
Title: FAMILY HOME CARE FOR CANCER—A COMMUNITY-BASED MODEL
Revision Requested: 06/25/95
Category: FULL REVIEW
Approval Date: 06/05/95

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

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

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

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

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

Sincerely,

David E. Wright, Ph.D.
UCRIHS Chair

DEW: kaa/lcp

Michigan State University
Office of Research and Graduate Studies
University Committee on Research Involving Human Subjects (UCRIHS)
Michigan State University
232 Administration Building
East Lansing, Michigan
48824-1046
517/355-2180
FAX: 517/352-1171

Michigan State University
EXCELLENCE IN ACTION
EQA is an affirmative-action, equal-opportunity institution

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Appendix D

Permission for Use of Longitudinal Data
Dear Dr. Kobrak:

Rose Zivic has met with us to discuss her communication with you about her dissertation and research plans. We are excited to have Rose work with us and our program of research related to supportive and continuing care for patients and their families who are living with cancer. We are willing to make available to Rose the data that she needs for her work. Since our research grant is in process, we will have our research team conduct all phases of the study and will make our staff members available to Rose to provide the assistance that she needs to complete the data analysis. In essence we will make all of the needed information available to her. I look forward to serving on her dissertation committee.

Since it is essential that doctoral students immerse themselves in the research process we hope that Rose can become actively involved in this large research project. Her role will be to develop a proposal for her dissertation that is in keeping with the specific aims of this project. She will develop the literature and a conceptual framework for her research problem. We anticipate that with the clinical background that she has she can be of assistance to develop the system to track the patients across the many transitions that occur in a cancer care episode. We would see that she would assist us in developing and piloting the process to be used to follow these families across one year. Rose will also be involved in developing the process needed to recruit subjects for the study. While the data is being collected Rose will be actively involved in the team meetings to discuss the implementation of the research plan and time line and assist us with the problem solving that is necessary should patient accrual be compromised in the area of selected conditions or minorities (a proper patient mix). Depending on the full plan of the research, Rose will be involved in the development of the analysis plan for the research questions related to her problem. Thus Rose should develop the skills needed for policy related health care services research through participation in our research project and her dissertation.

Learning how families care

*MSU is an Affirmative Action/Equal Opportunity Institution*
We anticipate that this will be a fruitful process for Rose and know her expertise will contribute to our research.

Please contact me if you have questions or need clarification. I look forward to working on this dissertation and program of research.

Sincerely,

Barbara A. Given, Ph.D., R.N., F.A.A.N.

BG:ke
BIBLIOGRAPHY


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Ware, J.E., Sherbourne, C.D. (1992). The MOS 36-Item Short-Form Health Survey (SF-36), Conceptual Framework and Item Selection. Medical Care, 30 (6), 473-481.


Zivic, R.C., (1995), *Post-Surgical Cancer Patient Attributes Related to Hospital Readmission Within one Month Post-Discharge.* Unpublished manuscript, Western Michigan University at Kalamazoo