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THE RELATIONSHIP OF AGE AND COMORBIDITY WITH THE REPORTING OF CANCER SYMPTOMS BY ADULT PATIENTS WITH SOLID TUMORS

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Donna M. Lonsbury

has been accepted towards fulfillment of the requirements for

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## THE RELATIONSHIP OF AGE AND COMORBIDITY

## WITH THE REPORTING OF CANCER SYMPTOMS

## BY ADULT PATIENTS WITH SOLID TUMORS

By

Donna M. Lonsbury

A THESIS

## Submitted to

## Michigan State University

in partial fulfillment of the requirements

for the degree of

MASTER OF SCIENCE IN NURSING

College of Nursing

### ABSTRACT

# THE RELATIONSHIP OF AGE AND COMORBIDITY WITH THE REPORTING OF CANCER SYMPTOMS BY ADULT PATIENTS WITH SOLID TUMORS By

Donna M. Lonsbury

Understanding cancer symptoms remains an important issue in oncology care. The changing trends in the maturity of the population signal the appropriateness of planning for the future by understanding the phenomena surrounding cancer symptoms. This study is a secondary analysis of a larger study, "Family Home Care for Cancer Patients," by Dr. Barbara Given, R.N., Ph.D. (Principal Investigator), funded by The American Cancer Society, #PBR-32 and "Family Home Care for Cancer-A Community Based Model," ; The National Center for Nursing Research, #1-R01-NR01915. This study utilized a sample of 145 cancer patients and describes the cancer symptoms reported and how this was affected by age and comorbid conditions. Findings suggest that as individuals age, the number of comorbid conditions increases. When singular cancer symptoms and comorbid conditions were analyzed together, a number of cancer symptoms are reported. In addition, existing comorbid conditions may impact the number of symptoms reported by cancer patients.

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#### ACKNOWLEDGEMENTS

I wish to thank the chairperson of my thesis committee, Dr. Barbara Given, for her expertise, support and encouragement throughout the writing of this thesis. I also wish to thank the other members of my committee, Dr. Sharon King and Dr. Charles Given who had given their valuable feedback throughout the composition of this manuscript. Miss Sping Wang provided kind support and assistance with the data runs of this project. And, many thanks to Dale Kraemer who always answered one more statistical question.

I am extremely grateful to The American Cancer Society for their financial support for my education through a graduate scholarship.

A special thank you to all of my friends and family, especially Bruce Barnes who provided continued support throughout this endeavor. My deepest and most heartfelt thanks to my fiance, Ron Sayre, for his unending encouragement and patience throughout the writing of this manuscript.

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#### Introduction

Current literature on the cancer experience focuses on quality of life as a measure of an individual's representation of an acceptable level upon which to live life (Germino, 1987). An optimum quality of life is the outcome of successful management of symptoms by the patient and health care clinician (Ehlke, 1988). Providing health care to individuals with cancer includes treatment of actual symptoms experienced and prevention of potential symptoms (Smith, Holcombe, & Stullenbarger, 1994).

Symptoms can originate from a concurrent chronic disease, the cancer disease itself, or treatment modalities the patient is receiving. Interventions for the management of the individual's symptoms can be planned, executed and evaluated for effectiveness (Smith et al, 1994). This traditional line of reasoning assumes patients readily and accurately report the symptoms they experience. What issues and circumstances surround symptom reporting? Symptom management can only take place if the clinician knows the symptoms exist. Symptom underreporting, or even concealment in some populations may be a significant problem (Engelking, 1988; Dodd, 1984).

A symptom is described in the English language as any phenomena experienced by an individual that is a variation from normal function or sensation, and often indicates a disease state (Morris, 1976). When an individual is diagnosed with cancer or a chronic disease, the clinician monitors the patient for the presence or absence of common symptoms that may occur. A clinician completes a physical assessment for additional information, and sometimes includes diagnostic and laboratory testing to find the origin of the symptom (Thomas, 1981). Knowing the origin of the

symptom can direct the clinician toward diagnosing disease states, and also give indications of a worsening of disease. Symptoms can also indicate to the clinician that a certain treatment for disease may be difficult for the individual's body to tolerate. Nevertheless, whatever the origin, all symptoms indicate change within an individual's body that a health clinician may help alleviate in some manner.

The incidence of cancer in the population of the United States is estimated to be 1,208,000 for 1994. (American Cancer Society, 1994). The American Cancer Society also estimates that there are over eight million individuals living with cancer today in the United States (1994). Cancer is labeled a chronic disease due to present treatment that for the most part, can only delay progression of the disease. Cancer or its treatment often may cause multiple and varied types of symptoms throughout the course of the disease. This may be due in part to the types of affected body organs. Furthermore, social pressures and stress related to the loss of function can make patients believe that they are having symptoms, which are actually manifestations of anxiety surrounding illness (Weintraub & Hagopian, 1990).

Comorbidity is a state in which an individual experiences one or more chronic diseases in addition to cancer (Manton, Wrigley, Cohen, & Woodbury, 1991). Manton et al (1991) points out that comorbidity presents a difficult dilemma. Cancer complications can affect the underlying chronic disease and visa versa. For example, a patient with cardiac disease receiving a drug for cancer that has cardiac side effects can experience symptoms of a worsening cardiac condition. This example illustrates the importance of recognizing and accounting for the effects of additional chronic diseases one might have in addition to cancer. The combined effect of chronic disease and a cancer diagnosis present significant issues given the high rate of cancer and therefore, are important to explore. Problems associated with this situation are cited as symptom identification and management. Specifically, the purpose of this study is to explore symptom reporting by adults of different age groups who have cancer and how chronic conditions may affect these individuals. This is a secondary study to explore two of these factors, age and comorbidity, and the impact upon reporting of cancer symptoms.

#### **Research Questions**

This study addresses the following research questions:

- 1. What is the relationship between the number of comorbid conditions and age?
- 2. What is the relationship between age and the number of cancer symptoms reported?
- 3. What is the relationship between the number of comorbid conditions and the number of cancer symptoms reported?

#### Study Relevance

The Oncology Nursing Society designates symptom management as a priority for nursing research (Cunningham, 1992). Given and Given (1988) cite determination of the effects of age on cancer care as a research priority aimed at the elderly population. Several journal articles and books describe multiple symptoms that patients experience and their potential management interventions. Two of the leading texts in cancer nursing care contain several chapters regarding common symptoms (Groenwald, Hansen-Frogge, Goodman, & Henke-Yarbro, 1992; Baird, McCorkle, & Grant, 1991). In Guidelines for Oncology Nursing Practice, sixty-seven topics are presented

to the nurse as potential areas of patient care and management. Germino declares the accurate reporting of symptoms to be one of the imperative items to successfully manage comfort issues (1987). Some journals suggest care for different age groups for instance, the elderly patient with cancer (Cohen & DeMaria, 1986).

Health care professionals require knowledge of the difficulties, or the factors in which a client might or might not report symptoms that may be occurring. Further, they need to know under what circumstances would more specific assessment questions be warranted to clearly bring out the patient's experience. Only then can the professional provide the social and professional environment and assessment which accurately investigates the cancer patient's experience. A description and explanation of the phenomena presented is required for understanding the scope of this study.

#### Theoretical Framework

#### **Conceptual Definition of the Study Variables**

#### Comorbidity

The first independent variable to be considered is comorbidity. Morbidity is defined as a "state of being diseased" (Thomas, 1981). In scientific arenas, morbidity is referred to as having a long term illness that interferes with one's every day life (Manton, 1986). Similarly, chronic disease is interpreted as any disease that comes on slowly and persists for a considerable length of time (Thomas, 1981). For the purpose of this investigation, the definition of comorbidity is the simultaneous occurrence of one or more chronic diseases in an individual with a diagnosis of a malignant solid tumor (cancer).

A review of oncology nursing literature on comorbidity reveals two themes. First, there is recognition that cancer in itself often causes a morbidity state. Thomas and Dodd (1992) published a nursing model of cancer morbidity which includes three different categories of variables. Physiologic and pathophysiologic, functional status, and psychological variables are believed to affect an overall picture of morbidity in the cancer patient. In this particular study, there was no mention of any other concurrent disease state in the variables or demographic data set presented (Thomas & Dodd, 1992).

Secondly, there is a more recent literature trend that includes chronic disease as moderator phenomena that affects individuals with cancer. Lindsey, Larson, Dodd and Brecht (1994) cited 81.4% of the 45 study subjects with cancer as also having another disease condition. These conditions were arthritis, hypertension, heart disease, chronic respiratory conditions (asthma, emphysema, or chronic bronchitis), stomach or intestinal disorder, thyroid condition, or diabetes, anemia or glaucoma. They concluded that there were no significant differences found between the subjects with and without a comorbid state on other variables compared to the small group who did not have another chronic disease. However, the results of the study are tempered by the fact that the population of subjects with comorbidity was small and may need replication.

When examining potential chronic diseases that can affect individuals, there are a vast array of possibilities. First, chronic degenerative disease is the most common cause of chronic morbidity picture. This is most prevalent in the greater than 85 age range (Manton, 1986). Diseases such as diabetes, emphysema, ischemic heart disease, senility, arthritis, cerebral vascular disease and hip fractures are also categorized as comorbid, chronic diseases (Manton, 1986).

Declining physiologic processes, exposure to environmental hazards, and life-style choices have a great deal to do with increasing morbidity as one ages (Manton, 1986). Since cancer incidence is higher in older adults and presently people are living longer with cancer, it follows that a patient who is older is also more likely to have concurrent chronic diseases (Manton, 1991). In 1991, researchers described one-third of their study population over 75 years had two or more chronic diseases besides cancer (Bergman et al, 1991).

#### Cancer Symptoms

Cancer is a term that is applied to collectively describe a group of diseases in which abnormal cells grow at an uncontrolled rate in the body. (American Cancer Society, 1993). To the general public, cancer is a feared term that often conjures a picture of a deteriorating life filled with uncontrolled pain, nausea, and other unforeseen horrors. This is not so much a fear of the cancer disease itself, but the manifestations of the effects of the disease on the body: the cancer symptoms (Mor, 1987).

A symptom is a subjective sensation experienced by the individual alone (Thomas, 1981). Since the symptom is a human response to the occurrence of an untoward sensation, an individual can only describe, or report a symptom to the health care provider. The health care provider, most often a nurse, can assess symptomatology by eliciting specific information from the patient (Rhodes, 1987). Important information to be elicited from the patient includes symptom occurrence as well as the amount of symptom distress experienced (Rhodes, 1987). This type of data helps determine potential avenues of treatment management.

McCorkle (1987) details a list of thirteen potential symptoms that an individual with cancer might experience. The symptoms are sleep

difficulties, fatigue, skin changes, anorexia, nausea, vomiting, indigestion, diarrhea, constipation, sore throat, cough, difficulty swallowing, pain, and urinary frequency. Additional cancer symptoms documented by others are numbness and tingling of the hands and feet, headaches, taste changes, hair loss and shortness of breath (Larson, Lindsey, Dodd, Brecht & Packer, 1993; Weintraub & Hagopian, 1990; Nail, Jones, Greene, Schipper, & Jensen, 1988). Other authors cite the cancer symptoms most distressing to cancer patients as nausea, alopecia and fatigue (Love, Leventhal, Easterling, & Nerenz, 1989). Dodd points out that there are some side effects such as nausea and vomiting that have been studied frequently, and other symptoms that have little concern shown in cancer literature (1993). But clearly, symptoms are an important problematic area to explore with respect to patients who experience cancer.

#### Age

Miller and Keane describes age as the passage of time that occurs after one is born (1978). From birth to childhood through the adolescent years, a continual growth pattern occurs until adulthood. Then, alterations in physiology of major organ systems occur as age advances past early adulthood (Blesch, 1988). Only now as Americans are living longer scientists are studying the "frail elderly", the 75 and beyond age groups to predict health outcomes. Manton et al (1991) examined comorbidity patterns, found out that if morbidity rates of cardiovascular disease change due to lifestyle change, cancer will become the prevalent cause of death as larger numbers of the population age. He also points out the importance of monitoring cancer effects on chronic conditions for treatment recommendations and outcomes in the aged who are experiencing functional decline. Cohen and DeMaria (1986) describe management of the elderly with cancer as a delicate balancing act between the cancer with existing comorbid conditions, the physical effects of aging, functional abilities, psychological adaptation and social support systems.

Although cancer occurs in all age groups, the incidence of cancer is higher in middle age and continues to increase in older adults and the frail elderly (American Cancer Society, 1994). According to the Surveillance, Epidemiology and End Results (SEER) program, the probability of developing cancer increases as age increases (American Cancer Society, 1994). Therefore, for this particular study it remains an interesting element to the author to present age in succinct categories to possibly find more information related to age groups experiencing cancer as they progress through life.

Through review of the phenomena of age, comorbidity and cancer symptoms, it is evident that these concepts do become intertwined and there is difficulty separating their existence in life today. Review of literature will document researchers' past studies which illustrate the importance of age, comorbidity and cancer symptoms and the impact of these on the individual with cancer.

#### Introduction of the Model for Symptom Management

A theory is a group of concepts that explain phenomena and predict the relationships between the concepts (Polit & Hungler, 1991). A scientist explains phenomena by utilizing a theoretical framework that will guide thoughts and work in an organized way. The nursing profession as a science is presently developing and testing theories to explain phenomena as part of the foundation for practice.

This particular investigation will introduce and utilize a new schematic, conceptual model for symptom management developed by the

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University of California, San Francisco School of Nursing Symptom Management Faculty Group (1994). This is not yet theory because the concepts of this model are still being tested to show the deductive system of relationships that make up theory (Polit & Hungler, 1991).

The "Model for Symptom Management" attempts to direct patient care by examination of the many facets of symptoms (University of California Faculty Group, 1994) (see Appendix A). The traditional medical model focuses on symptoms primarily as manifestations of disease, and the diagnosis and cure of disease that causes the symptoms. In chronic disease, cure is not always possible therefore, one must find a new paradigm in which to approach and manage symptoms (University of California Faculty Group, 1994).

The conceptual model of symptom management emphasizes three interrelated dimensions. These are the symptom experience, symptom management strategies and symptom outcomes. Symptom experience refers primarily to the patient's subjective thoughts. These include the perception of the symptom, the judgement regarding the symptom such as the cause and severity, and the individual's emotional and behavioral response to the symptom.

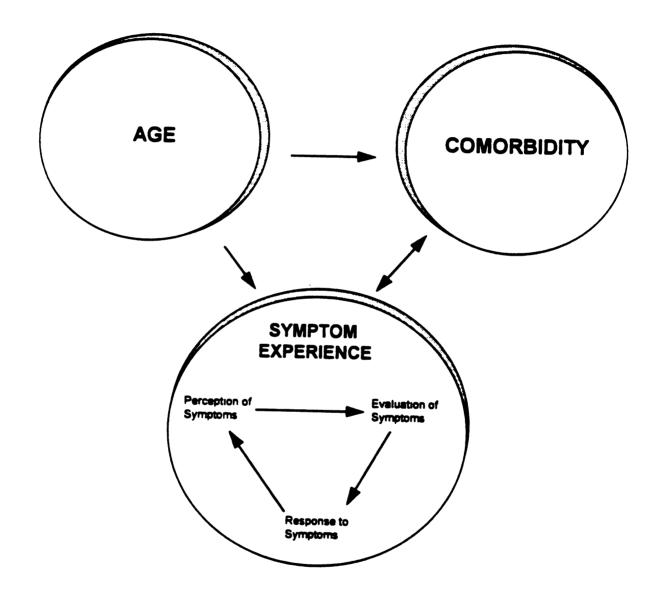
There are several variables, actually three categories of biopsychosocial factors that affect perception of a symptom (see Appendix A for the original unmodified model). Personal variables include age, financial status and other demographics. There are also psychological, sociological and physiological factors. Environmental variables that affect perception of symptoms include physical (home), social network and cultural background. Health/illness variables are risk factors (smoking, etc.), present health status, and present (comorbid) diseases. The Model for Symptom Management (University of California Faculty Group, 1994) points out that it is the perception and evaluation of the symptoms by the individual that motivates them to act on relieving the symptom. This includes activating the health care system and reporting the symptom. As an example for this particular manuscript a younger adult in good physical health might perceive that a symptom would restrict them from work, decreasing accompanying cash flow. Further, a symptom might restrict an active lifestyle in their own age culture and pose a threat to otherwise good health. These perceived threats to one's integrity and life may cause one to report the symptom, or try self-care strategies so that it might be relieved.

The dimension of the model entitled, symptom management strategies is aimed toward a goal of ameliorating or delaying a negative symptom outcome. Symptom management strategies include self care strategies of the patient and family social network. It also includes strategies initiated by nurses, physicians, including biomedical interventions.

Finally, the model's third dimension is labeled as the symptom outcomes. This centers on the status of the symptom. Variables affecting the symptom status are indicators that are bi-directionally related to the symptom status and may positively or negatively affect the final symptom outcome. This particular model of symptom management does appear to present all of the factors, or facets of the symptom experience in an individual.

When applying an overall picture of the symptom model to the phenomena presented in this investigation, one can easily integrate the concepts for this study. Age is a physiological factor of the patient's symptom perception as illustrated in Figure 1 (an independent variable).

Figure 1: Modified Conceptual Model for Symptom Management (University of California, Faculty Group, 1994)



Another factor that contributes to the symptom experience is comorbidity (an independent variable). Therefore, the independent variables under study, age and comorbidity are viewed as factors that contribute to a patient's symptom experience. This relationship is shown by directional arrows in the model. It is the sum total of the individual's symptom experience that influences the response to the symptom and therefore, the self-care practice of reporting of the symptom (dependent variable) to the health care provider. Do the number of comorbid conditions affect the perception of the symptoms enough to report them and further, is there a difference in reporting because of age? These questions must be answered to accurately assess cancer patients' symptoms.

#### **Review of Literature**

#### Cancer Symptoms

Symptom occurrence continues to be a concern and often a frustration for clinicians and patients alike. Although technologies in pharmaceuticals and procedures to date do decrease or alleviate some symptoms, science has not yet formulated any specific treatment that will alleviate any symptom in every case. Due to the complexity of the manifestations of symptoms arising from cancer disease and treatment, clinicians and researchers alike continue to publish their descriptions, interventions and research findings in an attempt to unravel the difficulties and find answers.

In 1994, Smith, Holcombe and Stullenbarger presented the research to date describing and summarizing specialized nursing symptom intervention effectiveness through meta-analysis (Smith, Holcombe, & Stullenbarger, 1994). The authors refrain from making recommendations regarding interventions due to the shortcomings of the research process. There are not enough studies about any particular symptom to allow for any substantial conclusions. Previous research lacks sociodemographic and disease site, stage and treatment characteristic examination to explain variability of the results. Few studies utilized nursing theory as a foundation. Within the collection of interventions studied, the effectiveness varied and was not consistent. The authors strongly point out that symptom management stands as a high priority of oncology nursing, the publication of such information is not reflected in the literature.

Another collation of nursing research on symptoms produced by cancer chemotherapy was presented by Dodd in the <u>Annual Review of</u> <u>Nursing Research</u> (1993). This particular review focuses primarily on gastrointestinal symptoms, interventions, and critiques of past studies.

Dodd pointed out several problems with studies regarding cancer symptoms to date. Studies lack of quality control of interventions over time, sample populations were too small and lacked randomization and control groups. Suggestions for further symptom management research focused on the pediatric and aged population with cost containment in mind. Recommendations for advancing a symptom intervention scientific knowledge base included single blind data collection and research building upon the previous completed studies.

Recent literature that describes the number of cancer symptoms experienced by an individual varies. A study by Youngblood and colleagues (1994) (n = 91) report a mean of 11 symptoms (S.D. 8; range 0 - 37) reported by patients using a self-administered instrument. The age range of the individuals was 19-84 (mean 55.9; S.D. 10.9).

In a study by Dodd (1982), patients also reported a high rate of cancer symptoms, an average of 7.69. In this investigation, comorbid conditions were reported in the demographics according to anatomical system affected, but were not discussed in relationship to the symptom reporting.

In a study of breast cancer patients (n = 107) receiving chemotherapy, Ehlke (1988) reported a mean of 2.32 symptoms. The age range reported in this study was 28-78 years with a mean of 52.57 (S.D. 11.63). Greene, Nail, Fieler, Dudgeon and Jones (1994) completed a longitudinal study on breast cancer patients (n = 86) receiving chemotherapy. The number of symptoms ranged from 3.2 to 4.9. Neither study measured nor discussed comorbidity issues.

An important foundation of this present investigation is published outcome of data inquiry from the original study principal investigator, Barbara Given. Given, Given and Stommel (1994) studied the impact of age, treatment, and symptoms on the physical and mental health of patients (n = 111) age 55 and older with cancer. The number of patient symptoms varied with the type of treatment they received. Patients reported a mean of 4.1 symptoms (S.D. = 2.8). Patients receiving chemotherapy reported a mean of 4.28 symptoms (no S.D. reported), those receiving radiation therapy reported a mean of 2.8 symptoms (no S.D. reported). Patients without current treatment modalities reported 2.8 symptoms. These reported symptoms were from data collected from adults fifty years or older in a sample population. The researchers reported that age, gender, or changes in treatment were not significant in predicting changes in patient's symptoms over time. They did find in this older population that with the increased number of symptoms reported by patients, the more likely they experienced decline in physical function (Given et al., 1994).

There is no definitive rationale for the range of the research results on the number of symptoms reported. There appears to be an older versus younger cancer patient difference in perception of symptoms. The issue here is the fact that research must continue to assess patterns of symptomatology until relationships become clear and reproducible in research.

Information on the most prevalent types of symptoms reported by Donnelly and Walsh (1994) were pain 82%, fatigue 67%, weakness 64%, anorexia 64%, greater than 10% weight loss 60%, lack of energy 59%, dry mouth 55%, constipation 51%, and dyspnea 51%. These findings of common symptoms were consistent in the results obtained by Given, Given and Stommel (1994), Sarna (1993) and Youngblood et al. (1994). Sarna also reported that those patients with a high level of symptom distress also had concurrent respiratory disease, were predominantly low income, had chemotherapy as treatment and had recurrent disease.

When investigating the phenomena of age with respect to symptomatology, one must consider the work of Engelking, that describes the geriatric population as not reporting symptoms regularly (1988). Potential reasons for decreased symptom reporting in elderly are their increase in delay in seeking medical advice, difficulty articulating symptoms and decreased perceived value in identifying and resolving health problems. Sparse financial reserves to pay for health care and attribution of signs and symptoms of cancer to old age are also reasons cited to withhold symptom reporting. Although all of the above reasons are described, they are not

directly studied by the author or individually cited by reference (Engelking, 1988).

Ganz, Schag and Henrich (1985) describe two symptoms, nausea and pain. The authors reported their findings according to the subject's perceived intensity of the nausea and pain. There were clear differences in the intensity of symptoms reported. The older population reported markedly less intensity than the younger population. The authors did admit that this study may not be entirely accurate because only the data from male subjects was utilized due to the very small number of females recruited. They suggest that one might look at data from an age perspective and potential gender differences in the cancer population. No level of significance was given for the reported results (Ganz, Schag, & Henrich, 1985).

Instruments to capture types of symptoms and specific qualifiers to accurately describe the symptom experience have been developed by several oncology researchers and clinical care providers. In a descriptive article on review of the instruments and measurement of symptom distress published in 1987, there were twelve instruments cited (McCorkle, 1987). Items or potential symptoms of inquiry ranged from ten to fifty-three. Most instruments are self-administered; some include observations from trained interviewers. Other researchers utilize written reports by patients in the form of diaries completed at home as they experience symptoms (Nail, Jones, Greene, Schipper & Jensen, 1988; Greene et al., 1994; Larson et al, 1993; Dodd, 1982; Dodd, 1983). This technique is believed to be more reliable because a patient's distress severity is often difficult to recall (Larson, 1993; Love et al, 1990). The McCorkle Symptom Distress Scale (SDS) was developed in 1976 by McCorkle and remains a popular instrument for gathering data on symptoms. The SDS was utilized as a reference in the 1988 original study by Given and Given. As an extensive literature review progressed, Given and Given (1988) included several more potential side effects to widen and accurately capture the scope of symptom data collection.

This study is a secondary analysis of the Given and Given research (1988). The symptom data collection for this analysis focuses on nine of twenty-three symptoms that Given and Given studied in their original research. This is discussed in greater detail in the methods section of this manuscript.

#### Comorbidity

The process of aging is manifested by a slow physiological decline of all organ systems. This decline is viewed by the scientific community as a natural process (Cohen, 1994; Smith-Blesch, 1988). Chronic disease and multiple comorbid conditions developed during the aging process are an abnormal occurrence but seem to emerge so often that they appear commonplace. For instance, a common comorbid condition is hypertension, which can easily span several decades of life (Larson, Linsey, Dodd, Brecht & Packer, 1993).

Since publishing results in <u>JAMA</u>, a large study describing medical outcomes of care has established itself as a standard of research (Stewart, Greenfield, Hays, Wells, Rogers, Berry, McGlynn, & Ware, 1989). This particular study investigated numerous variables including characteristics of comorbidity in adults (excluding cancer). The results on comorbidity poignantly described signs or symptoms of the effects and complications subjects experienced. For instance, if a patient had a myocardial infarction, complications such as angina, congestive heart failure or cardiac arrhythmia were documented. Fifty-four percent of the 9385 subjects had at least one chronic disease. Twenty-nine percent of the sample population experienced two or more comorbid conditions (Stewart et al., 1989).

The nine most common patient or physician reported chronic conditions were hypertension, arthritis, diabetes, chronic lung problems, gastrointestinal disorders, back problems, angina, congestive heart failure, and myocardial infarction. An important conclusion of this study is that chronic conditions do affect general health and that these effects vary. For many of the comorbid conditions, study results conclude that the condition does affect overall functioning and perception of well-being in patients (Stewart et al., 1989).

There are some recent oncology based studies which include comorbidity as a variable. One looks at age and comorbidity with breast cancer treatment choice and survival (Bergman, Dekker, VanKerkhoff, Peterse, VanDongen & VanLeeuwen, 1991). The age range for this study was 55 and above. Comorbidity was categorized as none, mild (for one condition), and severe for two or more conditions. One third of the patients over seventy-four years reported two or more comorbid conditions. The most common comorbid diseases by this research group were hypertension, cardiovascular diseases and respiratory diseases. The authors demonstrated an age-related trend in comorbid conditions. They reported the age range from 55-64 years as having 26% with one comorbid condition, and 2% with more than one comorbidity. Ages 65 to 74, 21% of subjects had one comorbidity, 18% with more than one comorbidity. And, ages greater than 75 had 27% with one comorbid condition and 35% of subjects with more than one comorbidity. Another impressive finding

was that comorbidities cited at the time of a cancer diagnosis did not impact the prognosis of the cancer disease survival (Bergman et al., 1991). Frequently, individuals with comorbid conditions did not receive recommended standard therapy (Bergman et al., 1991; Satariano, 1992).

Another describes a model for breast cancer screening for elderly women aged sixty-five to eighty-five plus with and without comorbid conditions (Mandelblatt, Wheat, Monane, Moshief, Hollenberg & Tang, 1992). This study of comorbidity included subjects with no comorbidity, subjects with hypertension, and subjects with congestive heart failure. Findings showed that screening for breast cancer in women with other comorbid conditions was useful in extending survival times of the individual diagnosed with breast cancer (Mandelblatt et al., 1992)

The importance of examining individuals with comorbid conditions in addition to the diagnosis of cancer is important for the projection of future health care needs, especially in this aging society. In previous retrospective studies by Manton (1986) the relationship of age and morbidity rates were analyzed. He pointed out that past scientific estimates of age and life expectancy only investigate specific disease states as independently affecting one's health and life, not as a complex situation producing a combined effect (Manton, 1986).

After review of the literature, the measurement of comorbidity takes on a different perspective. Historically, measures of comorbidity in evaluating outcomes was pursued in 1974 primarily with diabetic patients (Kaplan & Feinstein, 1994). Since that time there has been more of a trend toward illness severity scales containing multiple indicators that collectively produce a total score, such as the Duke Severity of Illness Checklist for Measurement of Severity and Comorbidity (Parkerson, Broadhead, & Tse, 1993).

The Medical Outcomes Study described earlier as a benchmark research project utilized a simple listing of comorbid conditions. These comorbid conditions were cited by the physician provider and patient alike for gathering incidence information on comorbidity. This simple listing provided the study with valuable information for analysis (Stewart et al., 1989). In this particular study, fifteen common chronic conditions were presented in a self-administered questionnaire to the cancer caregiver. Each of the comorbidities had a yes or no response There also were blank areas to write in any other condition not mentioned.

#### Age

The subject of age can very well be daunting when one thinks globally of the definition alone. But, the subject of age and the cancer research literature describing an individual's response to the disease during a specific time in life is a distinct course. With a large cross-section of the population aging, it is imperative that the clinician and researcher examine the comparison of not only the young adults but the middle aged adults, the mature adults and elderly (Given & Given, 1989).

Prior cancer research often describes age in limited categories as either above or below sixty-five years. For example, Satariano (1992) reported that patients under sixty-five years tend to repeatedly report emotional distress as compared to older individuals). Ganz, Schag and Henrich (1985) also described older patients (>65 years) with varied cancer diagnoses as having less physical symptomatology and psychological distress than younger patients (<65 years). Similar results are cited in another study, finding younger patients experiencing greater

decompensated mental health than older individuals with severe postsurgical impairments and symptoms (Vinokur, Threatt, Vinokur-Kaplan & Satariano, 1990).

In 1989, McMillan considered the relationship between age and intensity of cancer-related symptoms. The symptoms specifically studied were nausea, vomiting and pain. Age was operationalized by the younger adults less than 55 years, and the older adults, 55 years or greater. Subjects diagnosed with either breast or lung cancer were studied for nausea and/or vomiting. Pain data were obtained from subjects with various cancers. Instruments utilized by the authors were tested and reported reliable and valid. This was a secondary study and although the original study was referenced, demographic data was not discussed. Also, gender of the subjects was not discussed which the previous study pointed out might make a difference. McMillan (1989) also described that younger subjects reported a higher intensity of nausea and vomiting than older subjects. Further, McMillian reported that in regard to pain, the older subjects reported less intensity than younger patients. The final conclusion the author cautioned the reader was that older adults may report lower symptom intensity and there presently was no way to actually measure exactly what they feel.

Another frequent theme found with age in cancer literature is the automatic, less intense treatment adjustment for those adults who happen to be in the latter decades of life. Bergman et al (1991) explored age, treatment choice and survival in breast cancer patients. Bergman reports that there is an assumption that either the elderly may not survive rigorous treatment or would probably die from another disease before the benefits of treatment were experienced. Bergman retrospectively analyzed the breast

cancer treatment of women 55-64 years, 65-74 years and 75 + years old, and concluded that age (75 +) alone rather than comorbid conditions determined whether a patient received non-standard treatment (1991).

Another study presented in the <u>Oncology Nursing Forum</u> focused on the data attempting to conclude age related recommendations of radiation treatment regimens for lung cancer. The authors collected data on age (greater than 65 years and less than 65 years), concurrent illnesses and "problems experienced" (Larson, Lindsey, Dodd, Brecht & Packer, 1993). Interestingly, in the less than 65 age group, subjects reported 2.8 side effects (S.D. = 1.3), whereas the greater than 65 years reported 3.4 side effects (S.D. = 2.1). This particular study was very explicit on all demographics and data regarding all variables studied. The investigators were very prudent regarding the applicability of the conclusions to other groups. They concluded that due to their subject numbers, it was difficult to make any statement regarding age and treatment outcomes.

In caring for the individual with cancer, it is important to anticipate the perceptions, responses and patient evaluation of different age groups with regard to the "symptom experience" and how this might influence symptom reporting. This would also assist in an accurate assessment of symptoms according to age groups and their potential effect on comorbid states. And, according to the severity of symptoms experienced by individuals of age groups, a health care provider could plan for interventions appropriate for the physiological state of the patient. This analysis intended to initially break age into decades, to study individual's experiences more closely, but due to sample size, the categories of age were extended for appropriate statistical measurement.

#### **Research Design**

A descriptive, retrospective approach served as the research design for this study. Cancer symptomatology was examined, including the relationships of age and comorbidity as independent variables. This study is a secondary analysis of data collected from "Family Home Care for Cancer --A Community-Based Model," by Principal Investigator, Barbara Given, Ph.D., R.N., F.A.A.N. (1988), funded by grants *#* 1-RO1-NRO1915 by the National Center for Nursing Research; and grant *#*PBR-32, "Family Homecare for Cancer Patients," funded by the American Cancer Society. Data were gathered by an initial screening telephone call, a 30-40 minute telephone interview that followed the screening, and a self-administered questionnaire given to cancer patients by mail. Although the original study investigated data on a longitudinal basis, this research will focus on the data accumulated on four separate contacts with the subjects.

The initial telephone patient screening tool occurred within two weeks after receiving the interest post card from the potential subject, this obtained some demographic information that included the subject's age. The first telephone interview initiated one month after the screening interview collected additional demographic information along with other instrument information pertinent to the original study objectives. The first patient self-administered, mailed questionnaire contained symptom experience data. And finally, a sixth month telephone interview gathered comorbidity information answered by the patient caregiver.

The following hypotheses were addressed:

 Older patients will report more comorbid conditions than younger patients.

- 2. Younger patients will report more cancer symptoms than older patients.
- There will be a positive relationship between the number of comorbid conditions and the number of cancer symptoms reported.

#### Sample

The sampling method for this study was a non-probability convenience sampling. Subjects were recruited from six Michigan community based cancer treatment centers by research staff. Potential participants were given a brief written description of the study and a postcard to return to the research staff if they were interested. Some subjects who were clearly interested in participating in the study did read and sign the consent on site. Physician providers of the treatment centers were informed on the proposed study and agreed to the patient recruitment request.

Criteria for subject selection included: Age 20 or older, diagnosed (within three months) recently with cancer or experiencing cancer recurrence, specifically with a solid tumor, and all currently receiving some type of treatment. Subjects also had to have a family member as the primary caregiver of the cancer patient. For this secondary study, data from 145 cancer patients recruited were utilized. All subjects completed an informed consent document which presented issues of voluntary admission, confidentiality and anonymity (see Appendix B).

#### **Data Collection Procedures**

Patients who had signed a participation consent were contacted by telephone by research staff. The initial contact objective was to complete screening questions that included demographics such as age, diagnosis and treatment, for determination of study eligibility. Graduate students in health careers were utilized for the screening interviews. They received two, eight hour sessions of training with research staff member. This training included a manual of written formal procedures they were to follow. Interviewers were given a script-type format for the screening interview of subjects to keep data consistent and unbiased. There were also monitoring sessions in which a staff person would listen to conversations with subjects to monitor for potential biased responses.

If subjects met eligibility requirements, self-administered questionnaires were mailed to their residence with a stamped, selfaddressed envelope included. Subsequently, the data were compiled from the information returned.

#### Instrumentation

Subject demographic information was obtained via telephone interview in the initial screening with the caregiver of the cancer patient. This included age, gender, marital status, education, and income. Also during this interview, cancer disease characteristics were obtained. Information was elicited on the primary cancer site, the time of either the new cancer diagnosis or cancer recurrence and the current treatment modality. This was recorded as site of cancer, the month and year of the cancer diagnosis and type of treatment currently being received.

Comorbidity data were addressed in a telephone interview of the caregiver six months after the telephone interview. Comorbidity was assessed by presenting a list of fifteen common chronic conditions. Respondents were also given the option to state "other" chronic conditions that were not on the list (see Appendix D) Stewart, Greenfield and Hayes (1989) report from a large study sample research project that stands as a

standard for medical research, that chronic conditions can adequately be assessed from research subjects by obtaining simple counts such as these.

Construct validity of potential comorbidity states was originally obtained by Given and Given (1988) by adapting "Older American Resources and Services Instrument" (OARS). The OARS instrument in itself has been tested and for reliability and validity (Fillenbaum & Smyer, 1981). Kurtz, Kurtz, Given, and Given (1988) reported an alpha of .47 for this particular scale in the original study. The important information for this analysis is the relationship of the number of reported comorbid conditions. Since these are lists of words instead of sentence statements or questions, internal consistancy cannot be judged. The validity with this type of scale can only be tested via checking with the subject's medical record for accuracy or test-retest method.

The patient's symptom experience was assessed by a scale presentation of the presence or absence of nine potential cancer symptoms. In the original study of Given (1988), "Family Home Care for Cancer--A Community-Based Model," the study subjects were presented with twentythree possible symptoms. These twenty-three symptoms were derived from the work of McCorkle (1986), and Dodd (1983) (see Appendix D).

To decrease the magnitude of information for the purpose of this study, nine symptoms (out of a total of twenty-three symptoms presented in the original study) were chosen for this analysis. These symptoms were found to reflect the combined symptom literature as the most common symptoms experienced by cancer patients. These symptoms were fatigue, pain, dry mouth, shortness of breath, trouble sleeping, nausea, poor appetite, cough, and vomiting. The symptoms experienced by subjects could possibly be the result of cancer disease, treatment, or encountered as a result of various chronic diseases. Occurrence of the symptom was measured by indicating "yes" or "no," if each specific symptom had been experienced in the last two weeks.

Construct validity was established by literature review of previous notable cancer researchers, Dodd (1983), and McCorkle (1988). This instrument was utilized in three previous studies with Alzheimer's patients, elderly patients and cancer patients. The alpha for this scale was reported as .75 (Kurtz, et al., 1988) in the original research.

Additional information gathered regarding the symptom experience specified the severity of each symptom. Although this data is not part of the research questions, it is included to quantify the patient's experience as a additional query item for the author. Symptom severity was measured for each of the symptoms in the original study by Given (1988). The subjects were instructed to rate the symptom's severity by check mark for each of the symptoms. The ratings listed for the subjects to choose from were mild, moderate, or severe symptom severity by a check mark in a box (none = 0, mild = 1, moderate = 2, severe = 3).

### **Operational Definitions**

Age, a independent variable, is defined as the number of years of life of each subject since birth. Age of cancer patients are categorized in groups according to appropriate significant numbers of subjects for statistical calculations. This variable is addressed in item 10 of the screening telephone interview (see Appendix C).

Comorbidity, another independent variable, is defined as specific chronic health conditions that an individual may exhibit in addition to the

diagnosis of cancer. These specific chronic health conditions are arthritis, glaucoma/cataracts, emphysema/chronic bronchitis, high blood pressure, heart trouble, diabetes, stomach/intestinal/gall bladder problems, stroke, Parkinson's disease, nervous disorders, broken hip, memory problems, prostate trouble, and female problems (such as diseases of the ovaries or uterus). The comorbid conditions are indicated as either presence or absence of the conditions in a yes or no format. More than one comorbid condition may coexist within an individual. This variable is addressed as item 40 in the one month telephone interview script (see Appendix D).

Cancer symptoms, the dependent variable(s), are defined as specific manifestations of subjective experiences by the patient that are known common side effects of cancer disease or the cancer treatment. Specific common symptoms studied in this analysis are pain, trouble sleeping, fatigue, shortness of breath, cough, dry mouth, nausea, vomiting and poor appetite. Subjects indicated each symptom presented in the survey that they particularly experienced as a check mark indicating "yes" or "no". This variable is addressed in the patient self-administered questionnaire (see Appendix E).

Severity of symptoms was measured by subjects choosing mild, moderate, or severe, as a rank of the intensity of their symptom experience. If the individual did not experience a specific symptom, the item was left blank.

The demographic variables of gender, marital status, education, and income are defined categorically. Primary cancer sites are listed as colon, lung, breast, lymphoma, gastrointestinal, gynecological, brain, Hodgkins, and other. Current cancer treatment includes options as chemotherapy,

surgery, oral chemotherapy, hormonal modalities, combined therapy above and, "other".

All of the above concept measurements of age, comorbidity and symptomatology were tested by the original researchers in previous studies of "Caregivers Responses to Managing Elderly Patients at Home" (1987) NIA #1R01 AG06584; Impact of Alzheimer's Disease on Family Caregivers" (1989) #1 R01 MH4176601; and "Family Home Care for Cancer--A Community-Based Model," funded by the National Center for Nursing Research, grant #1-R01-NR01915; and grant #PBR-32, "Family Homecare for Cancer Patients," funded by the American Cancer Society.

### Scoring

Age information was obtained by screening interview with the caregiver. The date was entered by project staff into the statistical software and placed into the appropriate category.

Comorbidities were scored by absence "yes" (1), or presence ""no"
(2) of each of the fifteen chronic conditions presented in the six month telephone interview. The total possible conditions were fifteen.

On the original self-administered questionnaire, patients were presented with twenty-three symptoms and asked to indicate (yes or no) if they had experienced each of the symptoms in the last two weeks. Cancer symptoms were scored by absence "no" (1), or presence "yes" next to each of the symptoms. Since nine of the original twenty-three symptoms are being studied in this analysis, the total possible number of symptoms is nine. If the symptom was experienced, the patient was instructed to rate the severity of each symptom my indicating mild, moderate, or severe. Symptom severity was scored by mild (1), moderate (2), or severe (3) in the self-administered questionnaire.

### Data Analysis

The research design was a retrospective, descriptive, secondary analysis. There was no randomization or control group.

Demographic information of the sample population was summarized by descriptive statistics. Frequency distributions and percentages were calculated for age categories (along with mean), gender, marital status, education, income categories (including mean), cancer diagnosis, new or recurrent disease diagnosis, and current treatment. Initially, all comorbid conditions and symptoms were also evaluated by frequency distributions and percentages.

- Hypothesis # 1: A Spearman's correlation coefficient was used to determine the relationship between age and number of comorbid conditions reported.
- Hypothesis # 2: A Spearman's correlation coefficient was used to determine the relationship between age and the number of cancer symptoms reported.
- 3. Hypothesis # 3: A Spearman's correlation coefficient was used to determine the relationship between comorbid conditions and the number of symptoms reported. In addition, a multiple linear regression analysis was performed between number of comorbid conditions, a single symptom (as an independent variable) and the number of symptoms occurring with each condition (excluding the symptom utilized as the independent variable).

Although it was not addressed in the research question, Spearman's correlation coefficient analyzed the subject's cancer symptom severity by age group to determine relationships and document the subjective feelings

of the subjects. Many cancer researchers including Ruth McCorkle, state that it is very important to look at symptom severity or distress when examining cancer symptoms to more fully understand the effect on the patient (1987).

# Assumptions of the Study

Assumptions of the study included the following:

- Measurement of cancer symptoms at one particular point in the disease trajectory can be utilized to describe the cancer experience of an individual.
- 2. Subjects with cancer report symptoms accurately on a selfadministered questionnaire.
- 3. Comorbid conditions affect an individual's body in some inherent manner.

# Limitations of the Study

Limitations of the study included the following:

- 1. Since this is a non-randomized sample, conclusions to the general population cannot be inferred.
- This is secondary data utilized from a singular collection point in time. The symptom experience trajectory can cause an increase or decrease in symptoms over time, therefore this data may not reflect the entire cancer experience.
- Studying types of comorbidity with specific types of cancer diagnosis and analyzing trends of symptoms would produce so many results that any emerging relationships would not be significant due to the sample size limitations.

- Younger age groups experience fewer comorbid conditions than older age groups, which might possibly cause under representation of this population.
- 5. Since individuals subjectively perceive symptoms differently, some symptoms may not be reported accurately.
- 6. Symptom data were from self report only and not interpreted information gathered by health care professionals.

### Protection of Human Subjects

The human subjects' rights of confidentiality and privacy were maintained during this research analysis. In the original study, identification code numbers were assigned to each subject and data were entered into the computer statistical software. All data was coded and analyzed without any identifying subject names being available to this researcher. Only scored data entered into the statistical program was utilized for this analysis. Approval from the University Committee on Research Involving Human Subjects (UCHRIS) for this research study was received (see Appendix F).

### Findings

The sample to be described consisted of 145 patients from the original study. Data analyzed here were gathered from several interactions with the subjects. The subjects completed an initial screening interview, a 30-40 minute telephone interview, a self-administered questionnaire returned in the mail by the subjects and a six month telephone interview.

Mean age of the sample was 57.8, range 30-81 (S.D. = 11.81). Gender distribution of the sample revealed 71 (48.9%) were male and 74 (51%) were female. Many of the subjects were married (n = 125; 86%). The subjects' average annual household income was \$32,575.19 (S.D. = \$16,502). Table 1 summarizes the demographic characteristics of the sample. Education data were not collected at this particular time in the original study. In summary, gender and household income were evenly distributed across the sample, while age and marital status were not evenly distributed.

### Table 1

| Characteristics  | n   | %    |  |
|------------------|-----|------|--|
| Age              |     |      |  |
| 20-35            | 10  | 6.9  |  |
| 36-50            | 24  | 16.6 |  |
| 51-65            | 72  | 49.7 |  |
| 66+              | 39  | 26.9 |  |
| Sex              |     |      |  |
| Male             | 71  | 49   |  |
| Female           | 74  | 51   |  |
| Marital Status   |     |      |  |
| Single           | 6   | 4.1  |  |
| Married          | 125 | 86.2 |  |
| Divorced         | 3   | 2.1  |  |
| Widowed          | 11  | 7.6  |  |
| Household Income |     |      |  |
| \$7,500-17,499   | 20  | 13.8 |  |
| 17,500-27,499    | 34  | 23.4 |  |
| 27,500-37,499    | 22  | 15.1 |  |
| 37,500-47,499    | 27  | 18.6 |  |
| 47,500-60,000    | 30  | 20.7 |  |
| Missing          | 12  | 8.3  |  |

Sociodemographic Characteristics of the Sample (n=145)

A one way analysis of variance (ANOVA) between demographic information and the variables of number of cancer symptoms, number of comorbid conditions, and severity of symptoms were completed. The ANOVA examines the ranges of variability within the demographic groups (e.g. female ranges of reported symptoms) and the means between the groups (e.g. mean number of female vs. mean number of male symptoms reported). This test breaks down the subject responses for the researcher to see how subjects' responses affect the analysis outcome. A significant relationship (p = 0.04) was found between patient sex and the number of reported cancer symptoms. Men reported a mean of 3.9 symptoms (S.D. = 2.3) as compared to women, who reported a mean of 3.1 symptoms (S.D. = 2.5) (see Table 2).

Table 2

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| ANOVA: The Effect of | Gender on a | Symptoms | Reported |
|----------------------|-------------|----------|----------|
|----------------------|-------------|----------|----------|

| Variation    | DF       | 32     | MS                | F        | Sia  |
|--------------|----------|--------|-------------------|----------|------|
| Within group | 143      | 814.52 | 5.70              | <u>~</u> |      |
| Gender       | 1        | 23.52  | 23.52             | 4.13     | 0.04 |
|              |          |        | Symptoms Reported |          |      |
| Sex          | <u>n</u> |        | Μ                 |          | SD   |
| Male         | 71       |        | 3.87              |          | 2.30 |
| Female       | 74       |        | 3.07              |          | 2.46 |

Although the marital status frequencies indicated that the majority (n = 125; 86.6%) of the subjects were married, a one way analysis of variance (ANOVA) between marital status and the number of patient reported symptoms was not significant (p = 0.5672) (see Table 3).

A significant relationship (p = 0.012) also existed between reported symptoms and income. The correlation value inferred a negative relationship (r = -0.2183). As income decreased, the number of symptoms reported increased.

| Variation      | DE  | <u>32</u> | MS                | E    | Sig   |
|----------------|-----|-----------|-------------------|------|-------|
| Within group   | 143 | 836.12    | 5.85              |      |       |
| Marital status | 1   | 1.93      | 1.92              | 0.33 | 0.567 |
|                |     |           | Symptoms Reported |      |       |
| Marital Status | n   |           | M                 |      | SD    |
| Married        | 125 |           | 3.41              |      | 3.30  |
| Not married    | 20  |           | 3.75              |      | 3.05  |

ANOVA: The Effect of Marital Status on Symptoms Reported

The effect of the primary site of cancer was not significant in predicting the number of symptoms reported (p = 0.0834). Table 4 demonstrates this and displays the mean number of symptoms per primary site, which may be interesting to the oncology clinician.

Table 4

| Variation        | DE  | SS     | MS   | E        | Sig    |
|------------------|-----|--------|------|----------|--------|
| Within groups    | 135 | 750.45 | 5.56 | <u>d</u> |        |
| Cancer diagnosis | 9   | 87.59  | 9.73 | 1.75     | 0.0834 |
|                  |     |        |      |          |        |
| Diagnosis        | ם   | Μ      | SD   | Min.     | Max.   |
|                  |     |        |      |          |        |
| Bladder          | 2   | 2.00   | 0.00 | 2.00     | 2.00   |
| Breast           | 40  | 3.17   | 2.33 | 0.00     | 9.00   |
| Colon            | 24  | 3.25   | 2.31 | 0.00     | 9.00   |
| Gastrointestinal | 11  | 4.91   | 2.17 | 2.00     | 8.00   |
| Gynecological    | 9   | 3.33   | 3.04 | 0.00     | 8.00   |
| Lung             | 17  | 5.00   | 2.26 | 0.00     | 9.00   |
| Prostate         | 10  | 2.80   | 1.99 | 0.00     | 6.00   |
| Lymphoma         | 19  | 3.00   | 2.43 | 0.00     | 9.00   |
| Head / Neck      | 1   | 5.00   |      |          | 0.00   |
| Other            | 12  | 2.83   | 2.55 | 0.00     | 7.00   |

# ANOVA: The Effect of the Primary Site of Cancer on Number of Symptoms Reported

# Table 5

# Disease Characteristics of the Sample (n=145)

| Characteristic                  | <u>n</u> | <u>%</u> |
|---------------------------------|----------|----------|
| Symptoms reported               |          |          |
| Fatigue                         | 102      | 70.3     |
| Trouble sleeping                | 77       | 53.1     |
| Pain                            | 70       | 48.3     |
| Cough                           | 57       | 39.3     |
| Dry mouth                       | 48       | 33.1     |
| Shortness of breath             | 41       | 28.3     |
| Poor appetite                   | 42       | 39.3     |
| Nausea                          | 40       | 27.6     |
| Vomiting                        | 25       | 17.2     |
| Comorbid conditions             |          |          |
| Arthritis                       | 55       | 38.2     |
| High blood pressure             | 31       | 21.4     |
| Heart trouble                   | 28       | 19.3     |
| Stomach, intestinal or gall     |          |          |
| bladder problems                | 21       | 14.5     |
| Glaucoma or cataracts           | 20       | 13.9     |
| Diabetes                        | 16       | 11.0     |
| Kidney disease or urinary       |          |          |
| tract problems                  | 13       | 9.0      |
| Emphysema or chronic bronchitis | 12       | 8.3      |
| Memory problems                 | 10       | 7.0      |
| Prostate trouble                | 9        | 6.2      |
| Female problems (disease of     |          |          |
| ovary or uterus)                | 5        | 3.4      |
| Nervous disorders               | 4        | 2.8      |
| Stroke                          | 2        | 1.4      |
| Parkinson's disease             | 1        | 0.7      |
| Broken hip                      | 1        | 0.7      |

A little over one-half of the subjects (55%) were diagnosed with breast, colon, or lung cancer (Table 5). Of the sample, 85 (58.6%) were new diagnoses and 57 (39.3%) were experiencing cancer recurrence. The analysis of variance between the disease status (new diagnosis versus cancer recurrence) and the number of cancer symptoms reported was significant (p = 0.051) (Table 6).

Table 6

----

| ANOVA: The Effect of Disease Status on | Number of |
|--|-----------|
| Symptoms Reported                      |           |

| Variation      | DE  | SS     | MS                | E    | Sia   |
|----------------|-----|--------|-------------------|------|-------|
| Within group   | 140 | 773.41 | 5.52              |      |       |
| Disease status | 1   | 21.23  | 21.23             | 3.84 | 0.051 |
|                |     |        | Symptoms Reported |      |       |
| Disease status | ם   |        | Μ                 |      | SD    |
| New diagnosis  | 85  |        | 3.10              |      | 2.21  |
| Recurrence of  |     |        |                   |      |       |
| cancer         | 57  |        | 3.89              |      | 2.55  |

The number of the patients who had received cancer treatment in the last three months was 99 (68.3%). Chemotherapy was the predominant cancer treatment in this sample (n = 81). Table 8 summarizes these disease characteristics. The analysis of variance between the cancer treatment (occurring within the last three months) and the number of cancer symptoms reported was significant (p = .051) (Table 7).

# Table 7

ANOVA: The Effect of Cancer Treatment in the Last Three Months on Number of Symptoms Reported

| Variation     | DE  | <u>55</u> | MS                | E    | <u>Sia</u> |
|---------------|-----|-----------|-------------------|------|------------|
| Within group  | 143 | 816.09    | 5.71              |      |            |
| Received      |     |           |                   |      |            |
| treatment     | 1   | 21.95     | 21.95             | 3.85 | 0.051      |
| Treatment     |     |           | Symptoms Reported |      |            |
| status        | n   |           | Μ                 |      | SD         |
| Treatment in  |     |           |                   |      |            |
| last 3 months | 99  |           | 3.73              |      | 2.44       |
| No treatment  |     |           |                   |      |            |
| last 3 months | 46  |           | 2.89              |      | 2.28       |

The most frequent cancer symptom reported was fatigue (n = 102; 70.3%). The second and third most frequent cancer symptoms reported were trouble sleeping (n = 77; 53.1%) and pain (n = 70; 48.3%) (see Table 5). In this sample of 145 subjects, the mean number of symptoms experienced was 3.46 (S.D. = 2.41, range 0-9).

Subjects' collective scoring of the severity of their symptoms demonstrated that fatigue and poor appetite were ranked most often as moderate in severity, (n = 102) 38.1% and (n = 42) 15.9%, respectively. The most common degree of severity chosen among the remaining seven symptoms was given a mild ranking by the subjects. Further inquiry into the level of severity was performed by the Mantel-Haenszel test for linear association of each symptom by age group to examine some possible associations (i.e. hypothesis 2). There was no significant correlation between age groups and perceived symptom severity for each individual

| Characteristic                        | n  | <u>%</u> |
|---------------------------------------|----|----------|
| Primary site of cancer                |    |          |
| Bladder                               | 2  | 1.4      |
| Breast                                | 40 | 27.6     |
| Colon                                 | 24 | 16.6     |
| Gastrointestinal                      | 11 | 7.6      |
| Gynecological                         | 9  | 6.2      |
| Lung                                  | 17 | 11.7     |
| Prostate                              | 10 | 6.9      |
| Lymphoma                              | 19 | 13.1     |
| Head / Neck                           | 1  | 0.7      |
| Other                                 | 12 | 8.3      |
| Cancer disease status                 |    |          |
| New diagnosis                         | 85 | 58.6     |
| Recurrent cancer                      | 57 | 39.3     |
| Missing                               | 3  | 2.1      |
| Cancer treatment within last 3 months |    |          |
| Chemotherapy                          | 81 | 55.9     |
| Surgery                               | 1  | 0.7      |
| Hormonal modalities                   | 16 | 11.0     |
| Radiation therapy                     | 13 | 9.0      |
| Other                                 | 4  | 2.8      |

symptom. No other tests were performed with severity since it was not the primary purpose of this investigation.

The most common comorbid conditions reported in the sample were arthritis (n = 55, 38.2%), high blood pressure (n = 31, 21.4%), and heart trouble (n = 28, 19.3%). See Table 5 for frequencies on all fifteen comorbid conditions. The mean number of comorbid conditions reported

per subject were 1.57 (S.D. = 1.51, range 0-9). The ANOVA for the number of comorbid conditions by subject gender was not significant. The mean number of comorbid conditions for female subjects was 1.5 (S.D. = 1.57). The mean number for male comorbid conditions was slightly higher, 1.7 (S.D. = 1.45).

### Analysis of Research Questions

Question #1. What is the relationship between the number of comorbid conditions and age?

There was a significant, positive correlation between the number of comorbid conditions and subjects' age (r = 0.4517, p < .0005). As subjects' age increased, the number of comorbid conditions increased (see Table 9).

Question #2. What is the relationship between age and the number of cancer symptoms reported?

There is no significant relationship between cancer subjects' age and the number of cancer symptoms reported (r = 0.1106, p = 0.180) (see Table 9).

### Table 9

# Spearman's Correlations: Hypotheses Results

|               | ח   | Ĺ    | Sig     |
|---------------|-----|------|---------|
| Hypothesis #1 | 145 | 0.45 | <0.0005 |
| Hypothesis #2 | 145 | 0.11 | 0.1800  |
| Hypothesis #3 | 145 | 0.22 | 0.0090  |

Question #3. Is there a relationship between the number of comorbid conditions and the number of cancer symptoms reported?

There was a significant positive correlation between the number of comorbid conditions and the number of cancer symptoms reported (r = 0.2163, p = 0.009) (see Table 9). Therefore, the more comorbid conditions the subjects exhibited, the more cancer symptoms they experienced.

To further understand the relationship between comorbidity and the reporting of cancer symptoms, multiple linear regression was used. The multiple linear regression technique utilizes two or more independent variables to predict the value of the dependent variable. The regression vields an R squared which is a measure of the closeness, or strength, of the relationship (Ingram & Monks, 1992). When the independent variables of the number of comorbid conditions and each symptom were assessed in a model predicting the number of symptoms reported (excluding the symptom used as the independent variable), two patterns emerged. A positive significant relationship occurs when selected singular symptoms were combined with the number of comorbid conditions to predict the number of symptoms reported by the subjects (see Table 10). These symptoms were fatigue, pain, nausea, vomiting, cough and shortness of breath as judged by models retaining a comorbidity significance of < .5. It should be noted that each regression stands alone when looking at the sample. For instance, when fatigue is entered as an independent variable, this is a comparison of subjects with fatigue versus those without fatigue. Also, the six symptoms that were positively correlated cannot be judged as equal measures since they are each part of unique models containing different independent and dependent variables.

| Symptom          | B²      | Symptom Sig. | Comorbidity Sig. |
|------------------|---------|--------------|------------------|
| Nausea           | 0.27904 | < 0.0005     | 0.0013           |
| Poor appetite    | 0.26683 | < 0.0005     | 0.6563           |
| Pain             | 0.20493 | < 0.0005     | 0.0201           |
| Cough            | 0.22085 | < 0.0005     | 0.0408           |
| Short of breath  | 0.19688 | < 0.0005     | 0.0436           |
| Trouble sleeping | 0.19244 | < 0.0005     | 0.0628           |
| Fatigue          | 0.18669 | < 0.0005     | 0.0266           |
| Vomiting         | 0.19372 | < 0.0005     | 0.0143           |
| Dry mouth        | 0.13456 | < 0.0005     | 0.0827           |

Multiple Linear Regression: Number of Comorbid Conditions and Each Symptom's Impact on Number of Symptoms Reported

An alternate pattern exists with the remaining symptoms of trouble sleeping, poor appetite, and dry mouth. The number of comorbid conditions combined with these single symptoms was not significant in predicting the number of symptoms. This means that models that contain comorbidity and these specific symptoms do not appear to determine the number of reported cancer symptoms.

### Discussion

The findings confirm previous studies and also bring about some interesting information regarding comorbidity, age and symptom experience in the cancer patient. This particular analysis is unique because comorbidity related to the individual with cancer is analyzed in more depth than previous studies. It is analyzed here as a possible factor impacting the number of cancer symptoms reported. Since this is not true experimental design, the findings can only be attributed to this particular group of cancer patients and not to the general population of oncology patients. The frequency of specific cancer symptoms reported by the sample subjects followed the literature closely (Greene et al., 1994; Nail et al., 1991; Weintraub & Hagopian, 1990; Love et al., 1992; McCorkle & Young, 1978). Fatigue was the most commonly occurring symptom in the sample, followed by trouble sleeping. According to the literature, fatigue and pain appear to be the top two symptoms reported by cancer patients (Donnelly & Walsh, 1994; Youngblood et al., 1994; Sarna, 1993; Dodd et al., 1991; Ehlke, 1988;). Pain in this analysis was ranked third which could be due to the distribution of cancer diagnoses in the sample, stage of the cancer, or management of the pain. The remaining symptoms of cough, shortness of breath, nausea and dry mouth all occurred in numbers similarly described by related literature. This sample therefore, is similar to previous literature, which assists in lending credibility to the findings.

The subject demographics and the cancer disease and treatment information revealed interesting findings. Gender frequencies data revealed similar distribution of male and female subjects. The findings also indicated that the male subjects consistently reported close to one more symptom than the female subjects. Cancer symptom literature does consistently report frequencies of research subject gender, but does not publish differences in male and female symptom reporting. If the primary site of cancer were significant in this analysis with the number of cancer symptoms reported, the above result might be due to possibly fewer symptoms in the female breast cancer patients which were 27.6% (n = 40) of the subjects. The relationship of primary site of cancer should therefore be studied further with larger samples.

Much of the literature describing gender characteristics has uneven groups represented (McCorkle, Benoliel, Donaldson, Georgiadou, Moinpour & Goodell, 1989; Nail et. al, 1991) and more recently has focused on breast cancer description (Green et. al, 1994; Ehlke, 1988). Therefore, one must be cautious with conclusions from gender specific results with symptom reporting, as this does not accurately describe the combined male and female cancer experience.

Subjects' income was evenly distributed in the sample. There was a significant negative relationship between income and number of symptoms reported. This data reveals that as income decreases, symptoms increase. This might suggest that income and the ability to pay for health services and treatment measures may affect symptom control and adequate access to the health system. Low income subjects may represent those without jobs and no subsequent health care coverage. If one does not have health care coverage, one may delay seeking medical care, therefore diseases including cancer may progress and cause symptoms. Also, if an individual does not have prescription payment coverage for symptom control interventions, they may choose not to buy drugs over food and rent.

Additionally, this population might have other competing demands and stressors that are interfering with symptom control measures. Family intergenerational illnesses and subsequent ADL needs may compete with needs of an individual with cancer. Literature demonstrating the same results with patient income and symptoms reported is scant. This may be due to inadequate demographic data collection in literature or the deletion of analysis of variance as noted by Smith et al. (1994). Sarna (1993) does report that high symptom distress is associated with low income. As mentioned by Smith et al. (1994), information analyzed with demographic data and cancer disease characteristics are missing in literature and future research must include this information.

The primary site of cancer frequencies in this sample is not evenly distributed. Breast, colon, and lung cancer accounted for the majority 58.6 % (n = 81) of the subjects studied (Table 4). It is recognized that this could have affected the findings of this study. Breast cancer alone was demonstrated in 27.6% (n = 40) of the sample and almost always represent females. This may be the result of the under-representation of cancer site. Further research is necessary with a heterogeneous sample with regard to cancer diagnosis to replicate the findings of this analysis.

Number of symptoms per primary site of cancer did approach significance in this analysis. Again here, the unequal representation of the subjects with a specific type of cancer may have affected the number of symptoms (see Table 4). Further research with a larger sample might prove to be significant. Oncology clinicians often focus on increased symptom reporting associated with aggressive treatment, disease progression to other organ systems, or end stage manifestations. It may be important to focus on the primary cancer site (with consideration to stage of cancer growth) and utilize preventive interventions if further studies can document certain symptoms occurring with certain cancers. Moreover, one might explore the primary cancer site with the disease characteristic of new and recurrent cancer diagnosis to observe the number of cancer symptoms reported.

Two-thirds of the sample subjects (n = 99) had indicated that they had received treatment for their cancer with in the last three months. The ANOVA of the subjects reporting a number of symptoms with and without treatment within the last three months was significant (p = .051) (see Table 7). The 99 subjects indicating recent treatment reported a mean of 3.72 symptoms (S.D. = 2.45). The 46 subjects without recent treatment

reported a mean of 2.89 symptoms (S.D. = 2.28). A clinician might expect (from practice experience) a wider spread of symptoms with treatment. These statistics do yield a difference, indicating increased symptoms with treatment. Comparing these numbers with the overall mean of symptoms reported in the sample 3.46 (S.D. = 2.41) it can clearly be interpreted that the patients receiving treatment and cancer recurrence are experiencing more symptoms. From the practicing clinician point of view, the subjects are experiencing and enduring symptoms for the purpose of suppression or cure of their disease. We must decrease the presentation of these symptoms.

To extend the discussion above, the number of reported symptoms was significant (p = .051) with the presence of new diagnosis versus recurrent cancer. The subjects indicating recurrent cancer reported a mean of 3.89 symptoms (S.D. = 2.54). The subjects indicating new diagnoses of cancer reported a mean of 3.1 symptoms (S.D. = 2.20). These findings suggest that subjects experiencing symptom recurrence have the highest number of symptoms as compared with the total sample symptom mean and those with recent treatment. Most often when cancer reoccurs, it does so by traveling to other organs or bone (depending upon the type of cancer). Depending upon where the cancer recurrence occurs, many sites in the body may be affected and the cancer patient may experience symptoms as the first manifestation of cancer recurrence.

The mean number of symptoms experienced by the sample was 3.46 (S.D. = 2.41). Although the literature as a whole reports a wide range of symptoms reported by cancer patients, the particular mean in this analysis is supported by the work of Ehlke (1988) and Greene et al. (1994). Nevertheless, this sample's range was 0 to 9. This potentially large range

of symptoms reported by any individual may reflect metastasis to other organs, recurrent disease, the lack of knowledge in the use of accessing health services or the difficulty or insufficiency of symptom management.

The relationship between age and the number of cancer symptoms reported was not significant. These results could have occurred because the sample size was too small, or because sixty-five percent of the sample was over 51 years old. It may be that older adults may not be reporting their symptoms. A potential reason for under-reporting symptoms may be adaptation to physical discomfort and symptoms. It may be possible that incurring years of chronic disease with varying severity may change one's expectations of the meaning of symptom severity and "feeling good". With consideration of this explanation, the data results would be less significant because they were less accurate.

Younger adults may be more sensitive to the feelings of organ dysfunction and report more symptoms. The literature describing the phenomenon of less symptom reporting by older adults is too numerous to discount, and needs to be replicated. Of course, the relationship that age does not effect symptom reporting could be a possible explanation that may be replicated by further studies.

More research is needed in the area of the mature adult's perception of symptoms and potential social reasons why they might not be reporting their cancer symptoms. It must be stated also though, that age may not influence the number of symptoms reported at all and more research is needed to sort out these questions.

The types of comorbid conditions reported by subjects in this sample coincided with the common comorbidities cited in the Medical Outcomes Study (Stewart et al., 1989) and in the work of Dodd et al (1994).

Arthritis, hypertension, cardiomyopathy, gastrointestinal disorders, diabetes and chronic lung problems were the prevalent comorbid conditions cited by this sample population (see Table 5). The findings of this study support the hypothesis and related literature that as age increases, the number of comorbid conditions also increase.

The relationship between the number of comorbid conditions and the number of reported cancer symptoms was significant. This supports the hypothesis that there is a direct relationship between the two variables. The more comorbid conditions a patient exhibits, the more cancer symptoms they will experience. Even though this relationship appears to reflect common sense to the clinician, it is important that this be documented. The oncology literature that has collected information on concurrent comorbid conditions are reported only as subject physical characteristics and has not directly linked them to the number of symptoms reported.

There are other factors that could also be influencing the number of reported symptoms. The comorbid conditions could be causing some of the symptoms. This could be termed a symptom overlap and it is recognized here that this is very possible, and even probable. Another factor that could be the origin or exacerbation of symptoms in the comorbid individual could be medication. Over the counter medication and the medication to control the comorbid conditions could also cause symptoms in any individual. These are factors that cannot be ruled out as extraneous variables affecting the number of symptoms experienced.

It should be noted that there was a disproportionate representation of subjects over 51 years old which might have affected the outcome when comorbidity was analyzed in the second and third hypothesis. One must consider though, that the population is aging and that this group of mature adults will soon be in the majority of the general population.

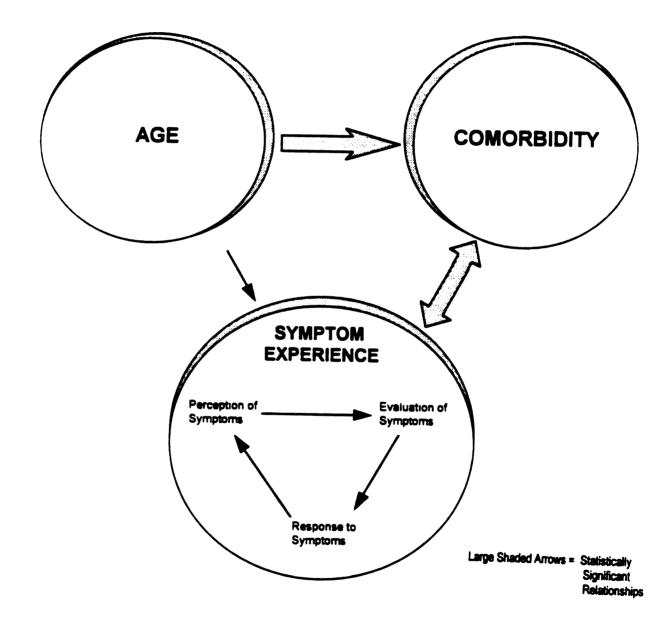
The multiple linear regression of the individual symptoms with the number of comorbid conditions predicting the number of cancer symptoms was performed to increase understanding of the potential interaction of variables. It is not clear exactly what the direction of the relationship is because this does not imply a cause and effect situation. What could be said though, is that if a patient walks into an office with for instance, nausea plus a number of comorbid conditions, it is predicted that they will experience an increased number of cancer symptoms. The analysis cannot predict the exact number of symptoms that will occur, but it does demonstrate a relationship of how certain symptoms might affect an individual with a comorbid condition. The only six symptoms (out of nine studied cancer symptoms) for which this holds true are fatigue, pain, nausea, vomiting, shortness of breath and cough. A possible reason for these results might be that many of these particular symptoms tend to subjectively affect all of body systems in some way by their inherent nature of discomfort and trauma to the body. It also is a possibility that if the body systems are traumatized by these symptoms, it could flare additional symptoms associated with the comorbid conditions. Furthermore, the chronic conditions themselves could be the primary cause of some symptom experience. For instance, nausea and vomiting can be caused by "stomach/intestinal/gallbladder problems" and shortness of breath can occur from emphysema alone. The work of Sarna (1993) reports the interaction of chronic respiratory disease with lung cancer. High symptom distress was statistically significant with the presence of concurrent respiratory disease and lung cancer in women (Sarna, 1993).

One way to have made the regression analysis stronger was to have also analyzed symptoms and symptoms reported (by spearman's correlation) as an outcome to see if any relationship existed that could be explained by the symptoms alone. This is an area for potential further research on symptoms.

A revised version of the modified conceptual model for symptom management depicts the outcome relationships of the variables studied in this research (see Figure 2). Age does predict the occurrence of the number of comorbid conditions. The number of comorbid conditions does predict the number of symptoms experienced. And presently, age does not affect the number of cancer symptoms experienced. Figure 2 illustrates the statistically significant relationships that were established by the analysis of this study.

Additional research is needed to adequately assess the potential differences that age might have on reporting symptoms. This includes the perception of severity of symptoms between younger and older cancer individuals with cancer. If one follows some of the direction of literature, one might conclude that an older adult may experience less sensitive perception of symptoms due to declining physiological systems. Also, an older adult may be hesitant to report symptoms that they believe may be due to aging. How much of symptom reporting has to do with an older adult's past history of adaptation to medical and surgical effects over time? Another viable explanation may be that age may not influence symptom reporting. This is another alternative that requires further replication to demonstrate this possible relationship.

Figure 2: Modified Model of Symptom Management (1994) (Revised) Significant Relationships of the Study



These data results have provided some insight into some of the possible experiences of cancer patients. Concurrent chronic conditions which occur often in the more mature patient, impact the number of cancer symptoms they experience. Furthermore, a patient with a number of comorbid conditions presenting with certain singular cancer symptoms might experience a number of cancer symptoms. Cancer patients with recurrent disease appear to experience more symptoms than someone with recent cancer treatment. And finally, the cancer symptoms are still present in this sample of patients, 3.4 symptoms on the average. More research and work is necessary to produce a better day to day quality of life for these individuals.

#### Implications for Advanced Practice Nursing

This research asserts many implications for the primary care advanced practice nurse caring for individuals experiencing cancer. Many clinicians already understand that cancer is a multi-faceted disease that has a multitude of biopsychosocial effects on an individual. The advanced practice nurse (APN) also understands that all individuals require excellent assessment skills to prevent, monitor and manage the many diseases, symptoms and complications. The APN in primary care is in the perfect position to counsel, teach and provide support to families experiencing cancer.

The information explored and studied in this research confirms that as adults age, chronic disease often occurs and this includes the diagnosis of cancer. The findings of this research provide a scientific flag for the awareness of the confounding effects of age and comorbid conditions on the cancer patient and the symptoms they may experience. This is important information to be shared with colleagues physician collaborators and policy makers that influence health care legislation.

This investigation confirmed the relationship that the trajectory of aging is associated with the development of comorbid conditions. Patients, specifically older adults in a primary care practice should be assessed by the APN for any potential signs of body system dysfunction on an ongoing basis. The APN develops relationships with older adults and their families over time in which trust and mutual respect are established . As the APN manages the health care of these patients, routine teaching to patients and families should include symptom presentation of potential chronic conditions and, when and how to contact the APN should be a primary focus.

More often today, individuals with cancer are managed by their primary care provider. The picture of the patient in a primary care practice may have a long history of chronic diseases. A slow growing diagnosed cancer may not be the primary focus of the APN in an older adult, and any younger adult experiencing multiple chronic diseases. It is appropriate to document all symptoms over time that appear to develop from the chronic diseases. If other symptoms develop, it then may be more clear which of the symptoms may be due to cancer. Nevertheless, symptoms do very often overlap and there may not be a clear origin. The APN still is obligated to teach self-care interventions to the family and patient, and provide other symptom interventions while still examining the possible origin of the symptom.

Counseling families experiencing cancer is an important aspect of the role of the APN. Listening to family concerns and providing information

regarding the normal anticipatory grieving process provides the family with validation that their feelings are normal.

Families may also experience fear with regard to future symptomatology the cancer patient may experience. The APN offers assurance that any future questions or concerns will be addressed promptly. The APN should continue to maintain contact with the cancer patient and family by regular follow-up office visits and frequent phone calls. Cancer has become a long term illness, and survival can extend beyond many years. Maintaining contact and rapport with the patient and family will provide them with security and support they will need throughout the disease trajectory.

The findings of this research suggest that cancer symptoms are still a problem with patients. The fact that the range of nine possible symptoms studied here could possibly exist in an individual at one time is troublesome. Often in the care of the cancer patient, only the most troublesome symptoms are evaluated by the health care provider. In the total care of the patient all symptoms should be addressed. The patient and family should be included in all interventions. According to the literature, keeping a diary of symptoms, self-care interventions and prescribed interventions and their effectiveness has been helpful in symptom management. Also as a resource there are many written pamphlets on various symptoms available from regional cancer centers that may help the family and patient understand the disease process and suggest sound self-care measures.

Patients with cancer often report fatigue to a clinician, especially during treatment with chemotherapy and radiation. This fatigue phenomenon is recognized as a difficult situation in which to suggest interventions. Again here, a symptom and self-care log might be helpful in establishing fatigue patterns in individual patients. With knowledge of predictable times of fatigue, the patient can successfully plan some daily activities. Fatigue is presently the subject of study for different professional nursing groups.

The experience of pain by patients should be occurring less and less, due to breakthroughs in pharmaceutical and alternative therapy research. The constellation of sustained release pain medication is growing, along with subcutaneous and intrathecal narcotic infusion for difficult pain cases. APNs can assist individuals to relieve pain by tenaciously monitoring these patients until their pain is relieved or minimal at the least. For difficult cases, referral to a acute pain clinic may be necessary.

To the APN, a clinician and patient advocate, the recommendation of symptom intervention and sequential evaluation of the cancer patient's status cannot be emphasized enough. Quality assurance activities of cancer practice need to focus on symptom control instead of accepting symptoms as part of the disease and treatment process.

Another model of health care may include an oncologist's treatment of patient's cancer only, and any other health care be provided by the primary provider. The APN can maintain contact with the patient and family during treatment to provide support and maintain continuity. During or after cancer treatment, the APN may observe exacerbation of minor organ dysfunction to the level of a comorbid condition and this may require management. Additionally, the APN may wish to collaborate with the oncologist for exchange of information regarding antineoplastic drugs the patient had received along with potential side effects.

This analysis cites high symptom occurrence with cancer treatment, and even more symptoms presenting in patients with recurrent cancer. Often symptoms occurring in these situations are acute. If symptom presentation is severe in the cancer patient (and is presently not an emergency) the APN may consider consulting with, or initiating a referral to an oncologist for more complicated management.

According to the data analysis, the relationship of the number of comorbid conditions was significant in predicting the number of symptoms reported. The more comorbid conditions a patient exhibits concurrently with their cancer, the more symptoms might probably require careful observation, intervention and evaluation over time. This information is extremely important for the APN, especially when one contemplates the health care system today and the kind of prevention of hospitalization (without sacrificing quality of care) that needs to occur.

A recommendation as a tool for monitoring symptoms of chronic disease and cancer patients' experience is the utilization of a symptom occurrence and severity instrument that has been placed in a flowsheet format. The severity scale can be a numbered scale from one to ten (one being slight discomfort, ten being worst possible). The flowsheet can then be compared with the instrument previously filled out by the patient and kept with the medical record. It would be important that this flowsheet be utilized with each patient contact. This assessment method might prove to be helpful in timely questioning of all possible symptoms. An instrument such as this might also document evaluation of the effect of interventions.

The findings of this study also suggest that if patients with a number of comorbid conditions present with any one of the six symptoms (nausea, vomiting, pain, shortness of breath, cough, or fatigue) exclusively, they might be experiencing or will experience a number of other symptoms. This suggests that the adult patient with chronic conditions along with a

diagnosis of cancer will need careful monitoring to avoid increased presentation of symptoms and severe complications. This may very well be the patient that may be costly to manage unless symptoms are watched closely.

The findings of this research accentuate the need for the APN to assess the lower income individual for potential barriers to symptom control that may be psychosocial in origin. Any patient in a primary care practice may be of low income and have difficulty financing specific symptom interventions. Potential barriers specific to cash resources might include prescription cost and coverage, transportation to clinics, appropriate knowledge base to access medical and community health services and selfcare interventions. Referral to community services such as senior services, public health, and American Cancer Society may be very helpful in these particular cases.

The APN should explore new technologies in other fields that may assist in monitoring these patients more closely. Computer software can be utilized to monitor patient acuity, patient contacts and use of the health care system, interventions, and outcomes.

The model for symptom management provides a useful framework for understanding the multitude of factors and dimensions of patients' symptoms. This model is definitely one in which the advanced practice nurse can refer to as a potential foundation of clinical practice. Presently, the physiological factor of age has not proven to affect symptom reporting. Further research will add credibility and strength to the model's concepts.

The United States Congress recognizes that people are still dying of cancer. It is asking what are health care professionals doing with the allocated funds to make a difference in quality of life of cancer patients (Levy, 1993). The essential information discovered within the results of this research calls on APN's to be the driving force to change cancer care as it presently exists. The role of the APN is the perfect place to begin making the difference and documenting outcomes for improved cancer care. Implications for Further Research

Additional research designs with random sampling, longitudinal design and larger sample populations would improve the clarity of the relationships between age, comorbidity and reporting cancer symptoms.

Studies exploring comorbid conditions and cancer with symptom reporting need to be repeated. A sample of subjects with one group of patients with comorbid conditions compared to one group of patients with comorbid conditions and concurrent cancer may further clarify symptom experience. Research with this focus may assist in understanding a possible overlap of symptoms that may be happening between symptoms occurring because of comorbid conditions and cancer alone.

Since adults with comorbid conditions often take many over the counter and prescription drugs to try to control the symptoms of their disease, it is important to explore how these drugs may interact to cause multiple side effects in an individual. This may be an additional extraneous factor to monitor in symptom studies also.

Ideally, more research should be completed on specific cancers and the comorbid conditions related to the same body system as presented by Sarna (1994). For instance, patients with gastric ulcerative disease and gastric cancer should be studied with personal demographics, disease characteristics and symptom presentation.

Speculation in the literature suggests that there might be different criteria in a more accurate assessment of cancer symptoms in the younger versus older individual (McMillan, 1989). Do younger age groups with the same cancer diagnosis and treatment experience similar cancer symptoms with similar severity? Does long term adaptation to chronic disease symptoms in the older adult change the way symptoms are perceived and reported? Do older adults have the expectation that symptoms will not completely be controlled? What role does age related declining physiology play in the perception of symptoms?

As stated earlier, the number of symptoms experienced by cancer patients is disturbing. Specific symptom information description on the 23 + cancer symptoms needs to be researched and published (Smith et al., 1994; Dodd, 1993). The frequency of symptoms and severity of symptoms for newly diagnosed cancer patients and recurrent cancer should be investigated.

The literature review in this manuscript described the research to date on symptom presentation and nursing interventions. Continued research on symptoms with a focus on sociodemographic information and disease characteristics (cancer stage, treatment etc.) data collection is mandatory to be able to understand and control discomfort associated with symptom presentation in cancer patients. A wealth of symptom intervention research is needed to guide and direct symptom control within the cancer nursing practice.

Specifically, sleep disturbance is common symptom reported by cancer patients. Anxiety and worry about the impact of the cancer on their future may impair rest in the cancer patient. Research on sleep physiology and sleep patterns in cancer patients might reveal insight into this problem.

Research utilizing an instrument for a standard measure for follow-up and evaluation of symptom presentation on a frequent basis is needed to monitor the effectiveness of interventions. Furthermore, standard, progressive and aggressive protocols need to be developed for populations experiencing specific symptoms.

The most helpful research that could take place to confirm the findings of this analysis would be to study and focus on a specific type of cancer, and comorbid conditions exhibited by the subjects and describe patterns of the number of symptoms.

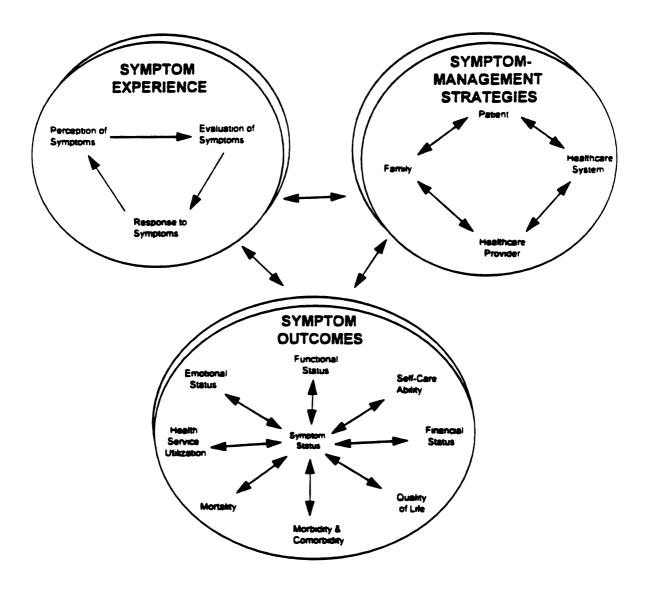
#### Summary

This study has addressed the relationships of age, the number of comorbid conditions and the number of reported cancer symptoms in adults. Age was found to positively correlate with the number of comorbid conditions. The number of comorbid conditions were positively correlated with the number of cancer symptoms reported. And, specific symptoms combined with the number of comorbid conditions appeared to predict the number of symptoms experienced. Demographic characteristics, comorbid conditions, type of cancer, and treatment issues were considered as potential factors affecting the phenomena studied.

Suggested changes in advanced nursing practice for oncology patients reflected the findings of this study. Specific nursing assessment and precise evaluation of symptom intervention effectiveness are strategies for beginning to correct the problem of continued symptom occurrence. Further research with true experimental design including larger samples is needed to predict specific relationships surrounding continued symptom reporting. Also, research with individuals with specific types of cancers and a number of comorbid conditions might further demonstrate the relationship to the number of cancer symptoms reported. APPENDICES

Original Conceptual Model For Symptom Management

(University of California, Faculty Group, 1994)



| Variables That Influence Perception of Symptom |             |                  |  |
|--|-------------|------------------|--|
| Person   | Environment | Health / Niness  |  |
| Demographic                                    | Physical    | Risk Factors     |  |
| Psychological                                  | Social      | Health Status    |  |
| Sociological<br>Physiological                  | Cultural    | Disease & Injury |  |

### Appendix B

## CONSENT FORM

The study in which we are asking you to participate is designed to learn more about the ways in which cancer affects the individual with cancer. Over the next 18 months, individuals will be asked to complete a questionnaire about your health status and symptoms. Each questionnaire will take approximately 20 minutes to complete. If you are willing to participate in the study, please read and sign the following statement.

- 1. I have freely consented to take part in a study of caregivers conducted by the College of Nursing and Department of Family Practice, College of Human Medicine, Michigan State University.
- 2. The study has been described to me and I understand what my participation will involve.
- 3. I understand that participation in this study is voluntary.
- 4. I understand that I can withdraw from the study at any time after originally agreeing to participate, and that withdrawal from the study will not affect the regular health care that I receive.
- 5. I understand that the results of the study will be treated in strict confidence and, should they be published, my name will remain anonymous. I understand that, within these restrictions, results of the study will be made available upon request.
- 6. I understand that no immediate benefits will result from taking part in this study, but am aware that my responses may add to the understanding of health care professionals.

| Signed Date |  |
|-------------|--|
|-------------|--|

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

Appendix C

# SCREENING CANCER CAREGIVER

| 4) | Sex of caregiver: Male (1) Female (2) 18  |
|----|---|
| 5) | What is your birthday: /// 19 20 21 22 23 24<br>Month/ Day/ Year  |
| 6) | What is your marital status? (CHECK ONE)  |
|    |   |
| 7) | What is your relationship to the person you provide care for?   |
|    | INTERVIEWER: Check caregiver's relationship to patient (e.g., if a daughter<br>is caring for her mother, check daughter/son.                              |
|    | spouse (1) 26<br>daughter/son (2)<br>daughter-in-law/son-in-law (3)<br>brother/sister (4)<br>brother-in-law/sister-in-law (5)<br>mother/father (6)<br>(7) |
| 8) | What is the marital status of the person for whom you provide care?<br>(CHECK ONE)  |

\_\_\_\_\_\_single (1) \_\_\_\_\_\_married (2) \_\_\_\_\_\_divorced (3) \_\_\_\_\_\_widowed (4) \_\_\_\_\_\_separated (5)

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**Cancer Screening** Page 2

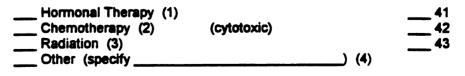
| What is the name of the person for whom you provide care?                                     |      |
|---|------|
| What is the birth date of the person for whom you provide care?                               |      |
|   | 2 33 |
| Are you the person who provides the most care for your relative?                              |      |
| Yes (1)No (2)   | 34   |
| INTERVIEWER: Terminate interview at this point. Go to the page<br>7 of the screening section. |      |
| Where is the primary site of your relative's cancer? (CHECK ONE)                              |      |
| Breast (02)   | 36   |
| Colon/Rectal (03)<br>Gastrointestinal (04)  |      |
| Gynecological (cervix, ovaries, uterus) (05)  |      |
| Lung (06)<br>Prostate (07)  |      |
| Lymphoma (08)   |      |
| Head and Neck (09) Other (specify) (00)   |      |
|   |      |
| What was the month year your relative was diagnosed with cancer?                              |      |

#### was diagnosed with cancer , y

**37 38 39 40** 

Month/ Year

What type of treatment is your relative currently receiving for their cancer? (CHECK ALL THAT APPLY) 14)



| 15) | Does your relative currently require assistance with: |
|-----|---|
| •   | •   |

| Pain management (medications or injections)                  | YES (1)  | NO (2) | _ 44            |
|--|----------|--------|-----------------|
| Nutritional Support (hyperalimentation sustagen, etc.)       | ,YES (1) | NO (2) | 45              |
| Tube feeding, (NG, Jejunostomy,<br>Gastrostomy, Doboff, etc) | YES (1)  | NO (2) | 46              |
| Drainage bags  | YES (1)  | NO (2) | 47              |
| Skin care  | YES (1)  | NO (2) | 48              |
| Mouth care   | YES (1)  | NO (2) | 49              |
| Lifting and turning  | YES (1)  | NO (2) | _ 50            |
| Ostomy care  | YES (1)  | NO (2) | 51              |
| Oxygen   | YES (1)  | NO (2) | 52              |
| Toileting  | YES (1)  | NO (2) | _ <sup>53</sup> |
| Dressing for wounds  | YES (1)  | NO (2) | 54              |
| Broviac/Hickman/Infusaport/<br>Portacath                     | YES (1)  | NO (2) | 55              |
| Decubiti care  | YES (1)  | NO (2) | _ 56            |
| Nausea and vomiting management                               | YES (1)  | NO (2) | 57              |
| Emotional distress   | YES (1)  | NO (2) | 58              |

# 16) Does your relative currently require assistance with: (CHECK A RESPONSE FOR EACH)

| Household Tasks (such as cleaning) | YES (1) | NO (2) | 59   |
|------------------------------------|---------|--------|------|
| Telephoning                        | YES (1) | NO (2) | 60   |
| Cooking                            | YES (1) | NO (2) | 61   |
| Laundry                            | YES (1) | NO (2) | 62   |
| Shopping                           | YES (1) | NO (2) | _ 63 |
| Transportation                     | YES (1) | NO (2) | 64   |

Cancer Screening Page 4

17) Is your relative currently experiencing difficulties with any of the following symptoms or problems: (CHECK A RESPONSE FOR EACH)

| Nausea                        | YES (1)NO (2) | 65       |
|-------------------------------|---------------|----------|
| Diarrhea                      | YES (1)NO (2) | 66       |
| Mouth sores                   | YES (1)NO (2) | 67       |
| Pain/frequency of urination   | YES (1)NO (2) | 68       |
| Coordination of movements     | YES (1)NO (2) | 69       |
| Mood swings or alterations    | YES (1)NO (2) | 70       |
| Poor Appetite (Anorexia)      | YES (1)NO (2) | 70       |
| Sleep disturbances (Insomnia) | YES (1)NO (2) | _        |
| Pain                          | YES (1)NO (2) | 72<br>72 |
| Mobility Limitations          | YES (1)NO (2) | 73       |
| Fatigue                       | , , , ,       | 74       |
| Constipation                  |               | 75       |
| Shortness of breath           |               | 76       |
| Vorniting                     | YES (1)NO (2) | _ 77     |
| Cough                         | YES (1)NO (2) | 78       |
| Colyn                         | YES (1)NO (2) | 79       |

- 18) What of the following best describes your relative's performance or activity status at this time? (CHECK ONE)
  - \_\_\_\_ No symptoms, fully active and able to carry out all daily activities without restrictions. (1)
  - Some symptoms, fully active and able to carry out light activities or sedentary activities (house or office work). (2)
  - Symptomatic, unable to carry out work activities and is in bed less than 50% of the day. (3)
  - Symptomatic, able to care for self, but in bed 50% or more during the day.
  - \_\_\_\_ Symptomatic, unable to care for self, bedridden. (5)

80

Cancer Screening Page 5

#### DURATION

| 19)            | How long have you been helping<br>Please answer in years and months.  | ? (NAME OF RELATIVE)   |
|----------------|---|--|
|                | (When did you begin caring for  | ?)   |
|                | yearsn  | nonths 81 82 83  |
| LIVING         | ARRANGEMENTS  |  |
| 20)            | Do you currently live with  | ? (NAME OF RELATIVE)   |
|                | YES (1)NO (2)   | NO: But help out daily (3) 84<br>If no, please get pt.<br>address      |
| IF ELIG        | SIBLE CONTINUE  | NOT ELIGIBLE, SEE PAGE 6   |
| <br> <br> <br> | INTERVIEWER: "Thank you for answering<br>you have shared with us, we would like to t<br>like to help with care and ask you to share<br>Would you be willing to participate in this ir | alk to you further about what it is with us some of your experiences." |
| <br>           |   |  |
|                | YES (1)   | NO (2)   |
| <br> <br>      | If YES, go to #22   | If NO, go to #24   |

21) I would like to schedule a time that one of the research staff interviewers might call you on the telephone and talk with you. This call will take approximately 45 minutes.

Which day of the week is better for you?

| What time of the day would be most convenient? _ |  |
|--|--|
|--|--|

The research staff will be sending you some information about the study and some questions we would like you to complete before we talk to you. DOUBLE CHECK SPELLING OF NAME AND ADDRESS FROM PAGE 1!

If you have questions or problems with the questionnaire the interviewer will be happy to help you when they call or you can reach them at 517/355-6526.

Sometimes we may be unable to contact you after trying for several weeks. Could you please give us the name and phone number of two people we could contact:

| First person:                         | Name<br>Phone<br>Relationship  |
|---------------------------------------|--|
| Second person:                        | Name<br>Phone<br>Relationship  |
| Tell caregiver we time for the interv | will be contacting them in about a month to set up a specific iew.                   |
|                                       | in knowing the reason people choose not to participate in you be willing to tell us? |
| REASON FOR RE                         | EFUSAL:  |
|                                       |  |
|                                       | Thank caregiver again for their participation.                                       |
| ELIGIBLE                              |  |
| INTERVIEWER:                          | CAREGIVER DOES NOT MEET CRITERIA   |
|                                       | ular study, we are obligated to have people participate who are                      |

providing the most care for their family member diagnosed with cancer. We realize you have needs and concerns. We acknowledge this and want you to

understand that we care about you and the experience you are going through.

# THANK YOU FOR TAKING TIME TO ANSWER THESE QUESTIONS.

٦

# Appendix D

# PHYSICAL HEALTH PATIENT (Answered by Caregiver)

Following are a list of illnesses. Please indicate if patient has been told by a health care professional that they <u>CURRENTLY HAVE THIS ILLNESS</u>. Place an "X" under "NO" if the have not been told they have this illness. We are interested in knowing the illnesses they have now in addition to cancer. (Check one for each condition patient has).

|    | (2) | 4<br>5<br>5<br>5<br>5<br>5 |
|----|-----|----------------------------|
|    |     | 5                          |
|    |     | 5<br>5<br>5                |
|    |     | 52                         |
|    |     | 5:                         |
|    |     | _                          |
|    |     | 54                         |
|    |     | _                          |
|    |     | 5                          |
|    |     | 56                         |
|    |     | 57                         |
|    |     | 58                         |
|    |     | 58                         |
|    |     | 60                         |
|    |     | 61                         |
|    |     | 62                         |
|    |     | 63                         |
| NO |     | 64                         |
|    |     | - 65                       |
| •  | NO  | NO                         |

## SYMPTOM EXPERIENCE

The following is a list of symptoms that <u>some</u> people with cancer experience either from the illness or as a result of treatment. If you have not experienced the symptom <u>in the</u> <u>past two weeks</u>, place an X under NO. If you have experienced the <u>symptom in the past</u> <u>two weeks</u>, place an X under YES, then place an X indicating the severity of this symptom, either MILD, MODERATE, or SEVERE.

|   | Did you ex<br>this sympt<br><u>past two w</u><br>(CHECK C | om in the <u>reeks</u> ? | How seve<br>you? (CH<br>EXPERIE<br>IF YES: |                 |               |                                 |
|---|---|--------------------------|--|-----------------|---------------|---------------------------------|
| Symptoms  | NO (1)  | YES (2)                  | Mild<br>(1)                                | Moderate<br>(2) | Severe<br>(3) | _                               |
| 1. Nausea   |   |                          |  |                 |               | 18 19                           |
| <b>2. Pain</b>  |   |                          |  |                 |               | $\overline{20}$ $\overline{21}$ |
| 3. Poor appetite                                      |   |                          |  |                 |               |                                 |
| 4. Weight loss  |   |                          |  | ++              |               | 22 23                           |
| 5. Trouble  |   |                          |  |                 |               | 24 25                           |
| sleeping  |   |                          |  | ļ               |               | 26 27                           |
| 6. Fatigue  |   |                          |  |                 |               | 28 29                           |
| 7. Difficulty<br>breathing/<br>shortness of<br>breath |   |                          |  |                 |               | 30 31                           |
| 8. Fever  |   |                          |  |                 |               |                                 |
| 9. Cough  |   |                          |  |                 |               | 32 33                           |
| 10. Dry mouth   |   |                          |  |                 |               | 34 35                           |
| -   |   |                          |  |                 |               | 36 37                           |
| 11. Constipation                                      |   |                          |  |                 |               | 38 39                           |
| 12. Diamhea   |   |                          |  |                 |               | 40 41                           |
| 13. Urinary<br>frequency                              |   |                          |  |                 |               | 42 43                           |
| 14. Coordination problems                             |   |                          |  |                 |               | 44 45                           |
| •   |   |                          |  |                 |               |                                 |
| 15. Vomiting  | L   |                          | L  |                 |               | 46 47                           |

Did you experience this symptom in the <u>past two weeks</u>? (CHECK ONE) How severe is this symptom for you? (CHECK ONE IF EXPERIENCED) IF YES: ..

| Symptoms   | NO (1) | YES (2) | Mild<br>(1) | Moderate<br>(2) | Severe<br>(3) | _                     |
|--|--------|---------|-------------|-----------------|---------------|-----------------------|
| 16. Difficulty concentrating                     |        |         |             |                 |               | 48 49                 |
| 17. Difficulty swallowing                        |        |         |             |                 |               | 50 51                 |
| 18. Dehydration                                  |        |         |             |                 |               | 52 53                 |
| 19. Weakness                                     |        |         |             |                 |               | 54 55                 |
| 20. Mouth sores                                  |        |         |             |                 |               | 56 57                 |
| 21. Confusion                                    |        |         |             |                 |               | 58 59                 |
| 22. Delirium/<br>Hallucinations                  |        |         |             |                 |               | <b>6</b> 0 <b>6</b> 1 |
| 23. Loss of<br>Feeling,<br>Numbness/<br>Tingling |        |         |             |                 |               | 62 63                 |

Appendix F

# MICHIGAN STATE

UNIVERSITY

March 14, 1995

TO: Donna M. Lonsbury 2328 Darrow Drive Ann Arbor, Mi. 48104-5204

 
 RE:
 IRB#:
 95-118

 TITLE:
 THE RELATIONSHIP OF AGE AND COMORBIDITY WITH THE REPORTING OF CANCER SYMPTOMS BY ADULT PATIENTS WITH SOLID TUMORS

 REVISION REQUESTED:
 N/A 2-H APPROVAL DATE:

 03/07/95

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 including any revision listed above.

**REMEMAL:** 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.



OFFICE OF RESEARCH AND GRADUATE

STUDIES

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)336-1171.

University Committee on Research Involving Human Subjects (UCRIHS) Michigan State University Michigan State University

PROBLEMS/ CHANGES :

225 Administration Building East Lansing Michigan 48824-1046 517/355-2180 FAX: 517/432-1171

Wright, Ph.D UCRIHS Chair DEW:pjm

cc: Barbara A. Given

MSU is an affirmative-action equal-opportunity institution

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