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WOMEN'S PERCEPTIONS OF FATIGUE
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Major professor

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# WOMEN'S PERCEPTIONS OF FATIGUE AND QUALITY OF LIFE FOLLOWING BREAST CANCER SURGERY

By

Linda Sue Eckerson Abent

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ABSTRACT

WOMEN'S PERCEPTIONS OF FATIGUE AND
QUALITY OF LIFE FOLLOWING
BREAST CANCER SURGERY

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A descriptive, non-experimental, correlational study to describe the relationship between perceived fatigue and quality of life among a sample of 145 women at eight weeks following breast cancer surgery was analyzed, utilizing secondary data analysis from a larger, longitudinal community care cancer study. Data on study variables were obtained from a self-administered questionnaire and a telephone interview. To operationalize fatigue and quality of life, several instruments were used: the Symptom Experience Index, the Medical Outcomes Study Form Health Questionnaire Survey Form 36, the Center for Epidemiologic Studies Depression Scale, and demographical tool. The study was guided by the Fatigue Impact on the Dimension Quality of Life Model (Ferrell et al., 1996).

Data were analyzed using descriptive statistics and pairwise correlations. The findings of the study showed women perceive fatigue to be highly significant after breast cancer surgery. Women who reported fatigue perceive lower levels of quality of life, represented by more symptom severity, less physical functioning, less social functioning and an increase of depression.

To my husband, Steven, and our children

Eric and Sarah, *with love*

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# INTRODUCTION

## Problem

Fatigue, normally the body's protective mechanism that maintains balance between rest and activity, is one of the most frequently described and one of the most disturbing of the symptoms experienced by cancer patients (Glaus, 1993; Nail & Winningham, 1993; Given et al., 1993; Kurtz, Kurtz, Given, & Given, 1993). The physical and psychological changes the patient undergoes as part of the demands of the cancer disease and/or the cancer treatment, can induce acute fatigue in the initial period. If unrelieved, over the course of the illness, acute fatigue can become chronic fatigue, a totally overwhelming experience for cancer patients (Piper, 1991).

When fatigue becomes chronic, it can lose its protective function. Chronic fatigue frequently has a negative impact on the patient's quality of life. Ultimately, chronic fatigue can eventually lead to death.

It is imperative for primary care practitioners to understand the concept of fatigue, become aware of how much patients suffer from fatigue, and determine interventions that are effective in reducing the fatigue experienced by

their cancer patients (Richardson, 1995). This reduction of fatigue can result in the cancer patient's enhanced comfort, well-being, quality of life, and ability to heal from the disease.

Fatigue can strongly impact all dimensions of everyday life. Fatigue can change one's appearance, interfere with concentration, impair physical performance, and increase anxiety and irritability (Nail & Winningham, 1993). In the cancer patient, these changes are even more dramatic and disruptive. These alterations result in the patients' diminished ability to perform their normal role activities in life. This loss of role has a strong negative emotional impact on the person's sense of fulfillment, satisfaction with life, and self esteem (Ganz, Schag, & Cheng, 1990). In recent years, the attention of breast cancer research has been focused on early detection or aggressive treatment. There has been little attention given to the equally important aspect of quality of life (Ferrell et al., 1998).

Breast cancer is the leading cancer experienced by women in the United States today. Surgery is the primary treatment for breast cancer today. In many cases, surgery is followed with important adjuvant treatment, such as radiation and systemic therapies (American Cancer Society, 1997). Surgery and anesthesia add to the cancer patient's physiological and psychological stress level. The energy expended during this process may accelerate the patient's

entry and progression into the fatigue continuum more rapidly than other forms of cancer treatment.

Purpose

The purpose of this study is to describe the relationship between the perceptions of fatigue and quality of life in women who have undergone a surgical procedure for the removal of breast cancer at eight weeks after being discharged from the hospital. The quality of life dimensions included for this study are physical well-being, social well-being, and psychological well-being.

While numerous studies have documented the occurrence of fatigue in patients receiving chemotherapy and/or radiation therapy for the treatment of breast cancer, few have studied and documented the earlier effects of surgery for the removal of breast cancer and fatigue. The focus of this study is to describe the perceptions of fatigue and quality of life within the postoperative stage of recovery.

By identifying the incidence of fatigue and other related symptoms reported by patients during recovery and convalescence from breast cancer surgery, primary care practitioners can work with their patients to assist them in setting realistic and attainable goals. When goals are directed at 1) reducing fatigue in its initial stages before becoming chronic, and 2) improving the patient's perception of well-being and quality of life, energy can then be reserved and directed towards the patient's healing process.

Research Question

The specific research question is "What is the relationship between women's perceptions of fatigue and quality of life following breast cancer surgery within eight weeks of hospital discharge?"

Conceptual Definition of Study Variables

Fatigue is "an unusual, abnormal, or excessive whole body tiredness disproportionate to, or unrelated to, activity or exertion" (Piper, 1993, p. 279). Fatigue may be acute or chronic in nature, based upon the duration of the symptom experience.

Quality of life is a person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to her/him (Ferrans, 1994). The individual's personal sense of well-being encompasses the physical, psychological, social, and spiritual dimensions of life (Ferrell, 1995). The physical, psychological, and social dimensions are the focus of this study, due to the limitations of the data set analyzed.

Breast cancer is the proliferation of abnormal, tumor cells within the breast tissue influenced by various hormones and growth factors (Fields & Koeller, 1992). Although breast cancer is the most common cancer experienced among women, it is only the second greatest contributor to cancer mortality in women of all ages, with lung cancer now

being the first greatest contributor (Murphy, Lawrence, & Lenhard, 1995).

Breast cancer surgical procedures included for this study are lumpectomy, radical mastectomy, and modified radical mastectomy. Breast biopsy with needle localization is not included.

Stage of breast cancer determines the type and extent of cancer, and is used to determine treatment options and predict and compare outcomes (Knobf, 1984). Women with Stage I or II breast cancers were included in this study.

Eight weeks after discharge from the hospital provides a useful time frame for this study. More than eight weeks after surgery, patients may be starting adjuvant therapies, such as chemotherapy and/or radiation therapy.

## CONCEPTUAL FRAMEWORK

### Fatigue Impact on the Dimension of Quality of Life Model

The Fatigue Impact on the Dimension of Quality of Life Model (Ferrell et al., 1996) was adapted to develop the conceptual model used to guide this study. The Fatigue/Quality of Life (QOL) model is a multidimensional model which demonstrates the influence of fatigue on the four dimensions of quality of life depicted in this model: physical well-being, psychological well-being, social well-being, and spiritual well-being (Figure 1). The Fatigue/QOL

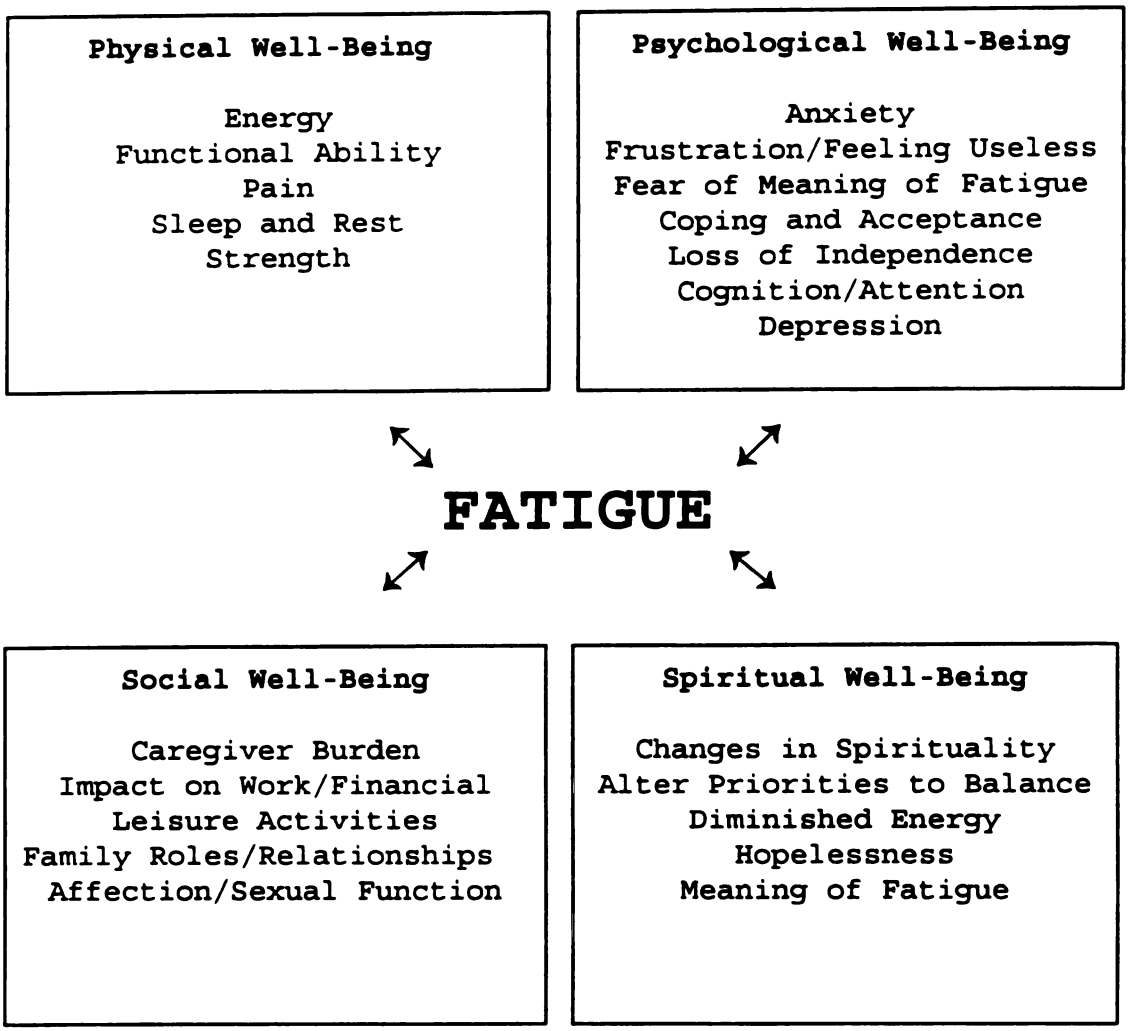


Figure 1. Fatigue Impacts the Dimensions of Quality of Life. (Ferrell, Grant, Dean, Funk & Ly, 1996).

model is an adaptation of Ferrell's earlier conceptual model Pain Impact on the Dimension of Quality of Life (QOL).

The Pain/QOL model is a multidimensional model which demonstrates the influence of pain on the four dimensions of quality of life: physical well-being, psychological well-being, social well-being and spiritual well-being. The

Pain/QOL model was developed using outcome data from Ferrell's previous research with cancer patients which explored the experience of pain and it's relationship to quality of life.

Through a decade of research with cancer patients, Ferrell and colleagues have found pain to be a major influence on overall quality of life (Ferrell, 1995). The symptom of fatigue also consistently appeared in these studies. In 1996, Ferrell and her colleagues adapted the Pain/QOL to create the Fatigue/QOL model (Ferrell et al., 1996).

Dimension of Physical Well-Being

Based on the Ferrell et al. (1996) Fatigue/QOL model, the dimension of physical well-being in relationship to fatigue includes the components of energy, functional ability, pain, sleep and rest, and strength. When fatigue was present, patients found it interfered with their ability to carry out the physical functions of daily life, job, and role, and forced them to be focused on themselves. Since fatigue is often one of the symptoms experienced by many patients before being diagnosed with cancer, fatigue can continue to be a meaningful physical sign, within the domain of physical well-being, indicating a possible recurrence of the cancer.

Dimension of Psychological Well-Being

The dimension of psychological well-being, as it

relates to fatigue in this model, encompasses anxiety, frustration/feeling useless, fear of the meaning of fatigue, coping and acceptance, loss of independence, cognition/ attention, and depression. Fatigue is associated with psychological symptoms, results in psychological effects, and decreases the overall energy level needed to balance aspects of life and cope with the disease. Ferrell et al. (1996) found that many times healthcare providers and family members did not take fatigue seriously or consider it a life-threatening problem.

Dimension of Social Well-Being

The social well-being dimension in the Fatigue/QOL model includes the factors of caregiver burden, work/ financial impact, leisure activities, family roles and relationships, and affection/sexual function. Patients in Ferrell's 1996 study described many examples of how fatigue limited their energy level and their ability to participate in many of their usual social activities with their families and friends, and also their work and enjoyment. Cancer psychological symptoms, results in psychological effects, and decreases the overall energy level needed to balance aspects of life and cope with the disease. Ferrell et al. (1996) found that many times healthcare providers and patients have reported a decreased concern for trivial matters and a heightened appreciation for family and friends (Ferrans, 1994). The social well-being of cancer patients

and support from family and friends can be very important for cancer patients in maintaining their quality of life throughout cancer treatment and recovery.

Dimension of Spiritual Well-Being

Spiritual well-being in the Fatigue/QOL model encompasses changes in spirituality, altered priorities to balance diminished energy, hopelessness, and meaning of fatigue. For some patients in their study, Ferrell and colleagues found fatigue to have a positive effect on their spirituality by imposing quiet time which they used for contemplation and reflection. Others resented the fatigue for wasting valuable time. Because of the fatigue, these patients found they reprioritized their precious time and reserved their energy for focusing on the most important aspects of their lives, commonly family and relationships.

In summary, Ferrell and colleagues have found fatigue to be a major force that affects all dimensions of quality of life rather than just being an isolated symptom (Ferrell et al., 1996). Patients report that physical symptoms are far more distressing than even receiving the diagnosis of cancer (Ferrell, 1996). Fatigue is not only a physical symptom, but an *experience* which can permeate the multiple dimensions of an individual's quality of life (Irvine et al., 1991; Richardson, 1995; Nail & Winningham, 1995). The Fatigue/QOL conceptual model can be adapted and used to guide clinical practice and reduce the distressing effects

of fatigue in all aspects of patients' quality of life.

Adaptation of Fatigue Impact on the Dimension of Quality of Life Model

The Fatigue Impact on the Dimension Quality of Life Model (Ferrell et al., 1996) was modified for use in guiding this study of women's perceptions of fatigue and quality of life after breast cancer surgery. The use of secondary data in this study limits the variables available to represent the QOL dimensions in the Ferrell et al. (1996) model of fatigue and how it impacts QOL. In Figure 2, the adapted model depicts fatigue as not only a symptom, but a concept that influences three of the four central dimensions of quality of life defined by Ferrell et al., in the Fatigue/QOL Model.

In this study, the QOL dimension of physical well-being is represented by the variables symptoms and functional ability. Social well-being, another QOL dimension, is represented by the variable social functioning. The variable depression represents the third QOL dimension in this study. Spiritual well-being, the fourth QOL dimension in the Ferrell et al. (1996) study, was not clearly represented by appropriate data from the larger data set. For this reason, the effects of fatigue are shown only for the QOL dimensions identified in the Ferrell et al. (1996) Fatigue/QOL Model of physical, social, and psychological well-being in the adapted model used to guide this study.

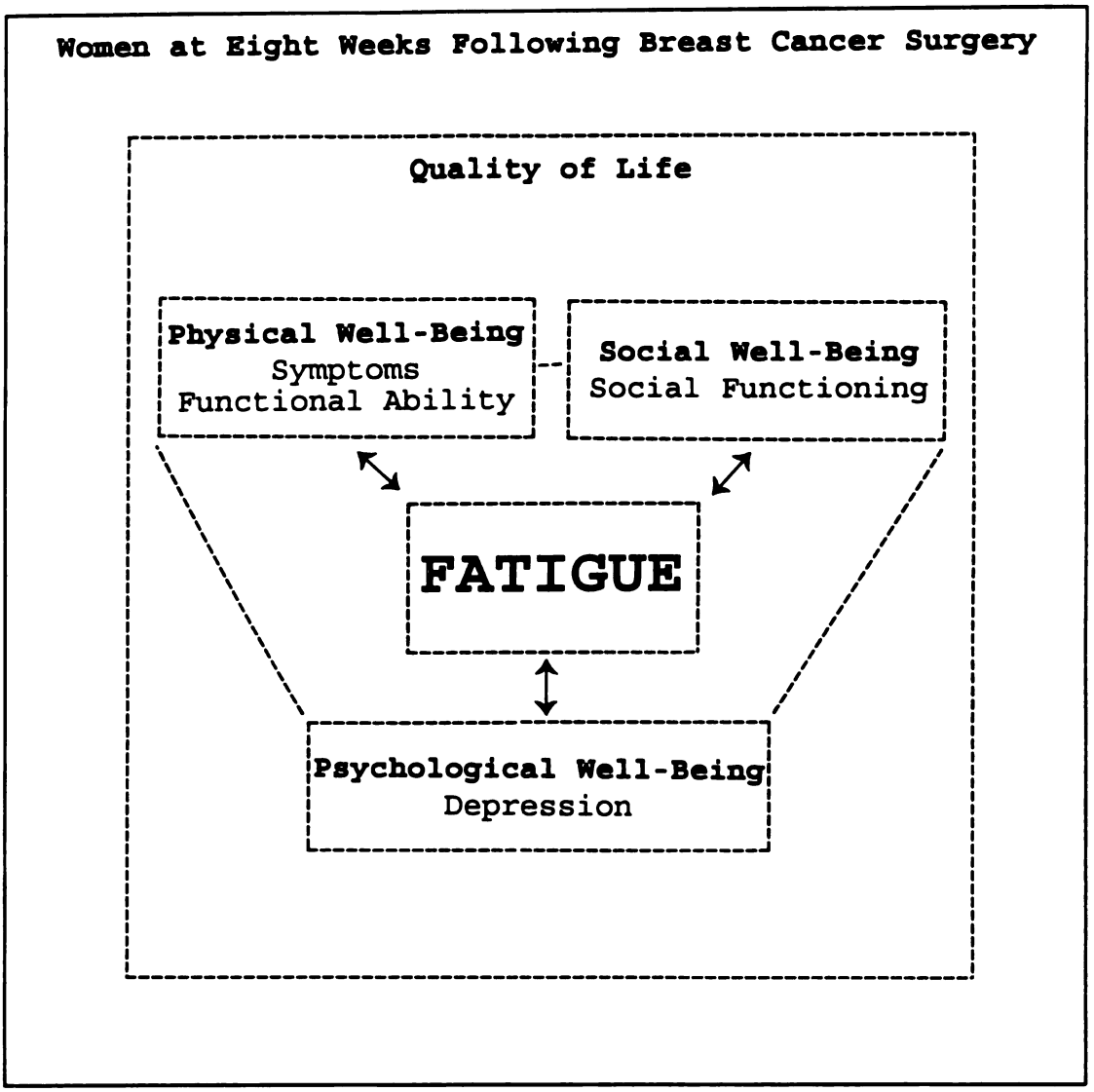


Figure 2. Adaptation of Fatigue Impacts Quality of Life in Women at Eight Weeks Following Breast Cancer Surgery Conceptual Model.

Each dimension is comprised of the characteristics used by patients to describe the state of their existence within each dimension. In the schematic representation of the model, each of the QOL dimensions and fatigue is bordered with dashed, open lines and connected to each other

with dashed lines or two way arrows, representing the permeation, interrelatedness, and complexity of the fatigue experience. The complete model represents the major impact fatigue can have on the quality of life for women after experiencing the surgical removal of breast cancer.

The importance of appropriate assessment and consideration of quality of life parameters when determining the outcome of different treatments for cancer, including breast cancer, has been documented by Fallowfield (1993) and Ferrell et al. (1991). As the treatment of cancer becomes more technologically advanced, it is crucial that quality of life is not overlooked when decisions about treatment to prolong the quantity of life are made. This adapted model, representing the far reaching effects fatigue can have on the quality of life for women after breast cancer surgery, can be a very helpful tool for the advanced practice nurse in guiding decisions made with the patient for their plan of treatment and care. However, a fully comprehensive model is needed to more accurately represent how extensively fatigue impacts women's perceptions of quality of life in the early weeks following breast cancer surgery.

## REVIEW OF THE LITERATURE

The literature search conducted for this study proved to be unsuccessful in finding research that has specifically correlated fatigue with quality of life in women after surgery for breast cancer. Some studies revealed in the

search did find fatigue to be one of the most highly reported and distressing symptoms of cancer diagnosis and cancer treatment, but did not explore the effect of fatigue on quality of life for women after surgery for breast cancer (Blesch et al., 1991; Kurtz, Given, Kurtz, & Given, 1994; Glaus, 1993; Dean et al., 1995; Cimprich, 1992). Recently, researchers have begun to explore and describe fatigue as a multidimensional experience impacting the quality of life in cancer patients (Ferrell et al., 1996). Several studies have also identified quality of life issues for breast cancer survivors (Graydon, 1994; Ferrans, 1994; Wyatt, Kurtz, & Liken, 1993; Ferrall et al., 1996).

The objective of this literature review is to provide an understanding of what is known in current literature regarding women's perceptions of fatigue and quality of life following breast cancer surgery. The literature review will cover the following categories: breast cancer and quality of life, fatigue in cancer patients, and impact of fatigue on quality of life.

Breast Cancer and Quality of Life

Graydon (1994) studied quality of life of 53 women after undergoing lumpectomy or other breast conserving surgery for breast cancer, followed by a course of radiation therapy. In this study, data were collected regarding the womens' functioning, emotional distress, and symptoms. Functioning was measured by the Sickness Impact Profile,

which assessed the woman's perception of what extent her performance of everyday activities had changed as a result of her illness. Emotional distress was measured using Profile of Mood States, and symptoms were measured using the Symptom Distress Scale developed by McCorkle and Young. Correlations indicated the more fatigue and anxiety the subjects experienced, the more symptoms they experienced, and the more changes they experienced in their usual functioning. The study also found fatigue was still present for some women four to twelve weeks after radiation therapy had concluded.

The studies of Ferrans (1994) and Wyatt, Kurtz, and Liken (1993) identified quality of life issues and needs of long term breast cancer survivors. Wyatt, Kurtz, and Liken (1993) studied 38 long term (≥five years) breast cancer survivors residing in Michigan. Using the Ferrell quality of life domains of the physical, psychological, social, and spiritual to guide the study, the researchers found that some issues crossed over into two or more domains. During the coding process, four themes were identified. Theme 1: Integration of the Disease Process into Current Life, included categories from the physical domain.

Two themes included categories from two quality of life domains. Theme 2: Change in Relationships with Others, and Theme 4: Unresolved Issues, included categories found in both the social and psychological domains. One theme

encompassed three domains. Theme 3: Restructuring of Life Perspective, included categories from the social, psychological, and spiritual domains.

The researchers concluded that the women had integrated their disease process into their current life and had been truly moved by the experience. The researchers also concluded that it may be implied that quality of life is a dynamic concept which diffuses greatly across domains.

Ferrans (1994) studied a convenience sample of 61 women who had survived breast cancer for at least five years. The mean length of time for the women since their diagnosis of breast cancer was 10.28 years (SD= 14.06, range 2-20 years). Ninety-seven percent of the women in the study had undergone surgical treatment for breast cancer. All patients diagnosed with breast cancer listed in the tumor registry of a major midwestern hospital were mailed questionnaires, followed with reminder postcards three days later. Nonrespondents were mailed a second questionnaire three weeks after the first mailing. The third questionnaire was mailed to nonrespondents three weeks after the second.

Ferrans' quality of life domains of health and functioning, psychological and spiritual, family, and social and economics were used to organize the findings of this study. Within the domain of health and functioning, both positive and negative aspects were reported. The positive

aspects respondents mentioned were return to good health, experiencing no pain whatsoever, and living healthier lifestyles than before they were diagnosed with breast cancer.

Negative aspects reported by respondents in the health and functioning domain made up the largest negative category of the four domains. Some of the negative aspects listed were poor health caused by chronic illness other than breast cancer, unrelieved chronic pain related to cancer therapy, side effects of cancer treatment, unmet health care needs, and dissatisfaction with their health care.

The psychological/spiritual domain held the most positive aspects of all the domains. Included positive aspects were help/strength provided by God, increased faith in God, and changing priorities in life. Negative aspects in the psychological/spiritual domain included depression, worry about the recurrence of cancer, and a sense of futility.

The family domain revealed the importance of support from the husband in the recovery of many of the study's respondents, as well as general support of the family. Respondents with young children were concerned about dealing with their children's fears of their mother dying.

Within the social and economic domain, respondents felt most positive about the support from friends, and help they could give to others coping with illness and

disabilities. However, a few respondents felt they had been forgotten by their friends. The most common economic aspect was not having enough money to pay for health care. Also, some respondents found it impossible to obtain health insurance having the diagnosis of cancer.

Ferrans' findings supported the conclusions of Wyatt, Kurtz, and Liken in that earlier experiences of cancer and treatment overlapped quality of life domains and continued to influence the women's lives in both positive and negative ways.

Quality of life in breast cancer survivors was also explored, and used to validate a breast cancer quality of life model in a study conducted by Ferrell et al. (1996). The domains in the QOL model validated in this study of 21 breast cancer survivors were physical well-being, psychological well-being, social well-being, and spiritual well-being. Fatigue was rated as the second worst of the physical aspects affecting the quality of life, scoring a mean of 6.48 on a scale of 0-10, with 0=worst outcome, 10=best outcome. Menstrual changes and fertility had the worst mean score of 4.12 in the physical well-being domain.

In the domain of psychological well-being, fear of spread of cancer, surgery distress, and fear of recurrent cancer, were the areas of biggest concern to patients. Family distress was the area of greatest disruption in the domain of social well-being. In the domain of spiritual

well-being, it was often found that the feeling of uncertainty inhibited the woman's optimum adjustment to her disease. Findings of Ferrell et al. (1996) again support previous findings of breast cancer survivors' multidimensional needs across each of the four domains of QOL.

These studies begin to demonstrate that quality of life issues and needs identified by breast cancer survivors can be categorized into variations of four basic quality of life dimensions: physical, psychological, social, and spiritual. The women's issues and needs of earlier experiences with cancer and treatment often overlapped with other quality of life dimensions, fitting in more than one dimension equally. The findings also suggest that the breast cancer process is a truly moving experience for women which strongly affects their lives. There is a need for further research which specifically explores the effects of fatigue on quality of life in breast cancer survivors.

Fatigue in Cancer Patients

Blesch et al. (1991) studied a convenience sample (n=77) of patients with lung (n=33) and breast (n=44) cancers. One aim of the study was to discern the behavioral, physiological, and biochemical factors linked to the cancer patient's subjective rating of fatigue. The researchers found that 99% of the subjects identified fatigue to be present to some degree, while 64% rated their

fatigue as moderate or severe. There was no significant difference in the responses of the lung cancer group and the breast cancer group.

In the same study Blesch and colleagues found biochemical factors including: hemoglobin, white blood count, narcotic use, antiemetic use, current antineoplastic therapy, and current radiation therapy, which did not significantly influence fatigue. Pain severity was the only physiological variable to show a significant correlation to fatigue. Psychological status subscale scores of tension-anxiety, depression-dejection, anger-hostility, confusion-bewilderment were measured with the shortened Profile of Mood States (POMS) and showed an inverse correlation with fatigue. A statistically significant positive correlation ($r$=.35, $p$=.02) was found between the duration of illness and fatigue in the breast cancer group. In the lung cancer group, the relationship between duration of illness and fatigue was found not to be significant. Blesch and colleagues concluded that fatigue is a more significant problem for breast cancer patients than it is for lung cancer patients. This significance is due to the fact that breast cancer patients live longer than lung cancer patients.

In a study of the interaction of age, symptoms, and survival status on the physical and mental health of cancer patients and their families, Kurtz, Given, Kurtz, and Given

(1994) found fatigue to be the most frequently reported symptom in all survivor groups participating in the study (n=208, 24% breast cancer). The researchers determined age did not have a significant effect on any of the patient variables in the study, but that symptoms played a major role in the level of patient functioning.

Glaus (1993) created and used the Visual-Analog Fatigue Scale (VAFS) to measure fatigue four times a day over a seven day period to explore the manifestations of symptoms in cancer patients, non-cancer patients, and healthy individuals in a hospital setting in St. Gallen Switzerland. The study population included three subsamples:

1. Twenty inpatients with known primary or secondary solid tumor cancers, including breast cancer.
2. Twelve inpatients with the diagnosis of chronic inflammatory gastrointestinal disease, hospitalized for an acute event.
3. Thirty healthy individuals mainly working as laboratory techs in the hospital.

There were no significant differences between the three subsamples in gender, employment, marital status, or familial environment. The mean age of the healthy individuals was 32.6 years, the mean age of the noncancer group was 50.2 years, and the mean age of the group with cancer was 54.4 years. Glaus found that fatigue was present

to some degree in all of the subgroups making fatigue appear to be a normal part of life. However, in the healthy individuals, fatigue seemed to serve as a protective factor in balancing energy expenditure, whereas, in the cancer patients, fatigue seemed to act as a refractory distress, and was unrelieved with rest. The healthy group felt the least amount of fatigue in the morning upon rising and felt a steady increase in fatigue throughout the day. The cancer patients felt fatigue was present all of the time.

Another finding of interest in Glaus' study was that the healthy group described their fatigue as being localized in the legs, head and eyes. The non-cancer group felt their fatigue mainly in their trunk, while the cancer group described a more generalized feeling of fatigue affecting their whole body or some in their trunk.

In a study of stable patients receiving interferon alpha for stage III/IV malignant melanoma (n=30), Dean et al. (1995) described patients' perceptions of fatigue causes and remedies. Using the Piper Fatigue Scale (PFS) to measure fatigue and The Symptom Distress Scale to test for concurrent validity of the PFS, the researchers identified 34 different descriptors used to explain the cause of fatigue and five categories in which remedies for fatigue could be grouped. The most frequently identified cause of fatigue in the study (n=11) was depression/worrying. Other symptoms, pain, nausea, and fever, were identified as the

second most frequent cause of fatigue (n=9). The researchers were surprised to find that few patients (n=7) identified their disease and its treatment as the major cause of their fatigue.

The majority of fatigue remedies (n=12) reported by Dean et al. were encompassed in the category of distraction, such as daydreaming, laughter, watching TV, reading, ignoring it, and praying. Conserving energy by such interventions as avoiding exertion, slowing down, and getting extra sleep and rest, was found to be beneficial to many patients (n=11). Fewer patients (n=5) found expending energy by exercising or doing something, to be helpful to them in relieving their fatigue. Remedies patients found to be less helpful were medical interventions (n=3), such as blood transfusions and pain control. Several patients felt eating food or drinking fluids helped their fatigue and one patient said nothing could relieve his fatigue. The researchers concluded that the results of their study support the belief of fatigue to be a subjective phenomenon that is more than just a bodily discomfort.

In a study focusing on the psychological components of fatigue and its impact on cognition, Cimprich (1992) studied 32 women who had undergone surgery for stage I or II breast cancer. Cimprich found these women to have a decreased capacity to direct attention toward a specific subject, task, or thought process during the initial period of

treatment for breast cancer, on the day before discharge from the hospital, following mastectomy or breast conservation surgery. Cimprich suggests this finding may be mainly due to the prolonged exertion of attentional effort required to comprehend the diagnosis and treatment options of breast cancer before even adding the physiological changes that occur with the intervention for cancer treatment.

The findings of these studies describe the complexity of the fatigue cancer patients experience. Beginning in the early time period during comprehension of disease diagnosis and treatment options, and continuing through later stages of the disease process, treatment side effects, worrying and depression, fatigue can progress beyond the point of being just a bodily discomfort. For patients living longer with their disease, such as breast cancer survivors, cancer can become a refractory distress which negatively affects the patient's physical and psychological functioning.

Impact of Fatigue on Quality of Life

Ferrell et al. (1996) conducted an exploratory secondary analysis of five data sources containing a total convenience sample of 910 men and women. The researchers focused on describing the impact fatigue has on the quality of life of cancer patients. Each participant included in the studies had experienced either breast cancer, ovarian cancer, or thyroid cancer. The guiding framework used in

this analysis to interpret the data was the Impact of Fatigue on the Dimension of Quality of Life Model (Ferrell et al., 1996) which is the same model this author has adapted for use in the present study. The researchers concluded from their analysis that "fatigue is a force that affects all dimensions of QOL rather than being just an isolated physical symptom" (1996, p.1546). The researchers suggest that fatigue should now be considered a priority topic for oncology nursing, just as pain has become recognized as a priority topic rather than just a symptom.

Research directly focused on describing the effect of fatigue on quality of life is scarce. The research of Ferrell et al. (1996) describing the gravity of the impact fatigue has on QOL warrants the need for further study on this topic.

Summary

Fatigue has been identified in the literature as a frequent and distressing symptom for cancer patients. Somestudies have shown fatigue to be a multidimensional experience, affecting patients' perception of their quality of life. Further research is needed to describe the relationships between fatigue and quality of life for women following breast cancer surgery.

# METHODS

## Research Design

This study is a descriptive, non-experimental, correlational study to describe the relationship between perceived fatigue and quality of life among women who have had breast cancer surgery at eight weeks of hospital discharge, using secondary data analysis from a larger, longitudinal community cancer study. The larger study is following incident diagnosis of breast, prostate, lung, and colo-rectal cancer (Grant No.5RO1 NR/CA01915, "Family Home Care for Cancer--A Community-based Model," - Barbara A. Given, PhD, RN, FAAN, and Charles W. Given, PhD, Principal Investigators). This research project is a collaboration between Michigan State University (MSU) College of Nursing; College of Human Medicine, Departments of Family Practice, Medicine, and Surgery; the Cancer Center at MSU (CCMSU); and the MSU Cancer Treatment Consortium (MSUCTC).

## Sample Procedures

For this study, a convenience sample size of 145 women was identified. Data was collected from the women by questionnaire and individual phone interviews that were conducted by nurses and medical students trained to be data collectors during this study.

This study targets the population of women who had breast cancer surgical procedures. The inclusion criteria include the following:

1. Female
2. New diagnosis-an incident case of breast cancer with breast cancer surgery as initial form of treatment (including lumpectomy, radical mastectomy, and modified radical mastectomy; excluding needle localization biopsies)
3. English-speaking
4. Cognitively intact
5. Age 65 years or over
6. No hospitalizations in the previous 60 days for other problems
7. Assessment by eight weeks after surgery
8. No previous cancer treatment within the past two years

Data Collection Procedures

Patients who met the inclusion criteria were identified by nurse recruiters during hospitalization in one of the 27 community hospitals affiliated with the College of Human Medicine, College of Nursing, and Cancer Center at MSU in East Lansing, MI. No advertising was done to recruit study participants. The participants were not compensated, placed at increased physical risk, or responsible for any costs by participating in the study. After the patients were identified by the nurse recruiter, each patient was

presented with a brochure explaining the study, and her consent was obtained to review the medical record, obtain address and telephone number, and needed clinical information for the purpose of the study. The patient's physician was notified that the patient was participating in the study.

Patients in the study were informed that they were participating in a longitudinal study that would involve filling out an initial questionnaire, participation in four telephone interviews to be conducted within a 12 month time frame, and auditing of their medical records. They were told that participation was entirely voluntary, and that they could withdraw at any point during the study. The way in which patient confidentiality would be maintained was explained to the patients. If patients wished to participate in the study, they signed a consent form. The patients were enrolled for the study during their incident hospitalization, or prior to completing the first treatment cycle of chemotherapy or radiation therapy. After the consents were received by the university, the patients were assigned to interviewers for data collection. During wave I, by eight weeks of their hospital discharge, patients received an approximate 40 minute telephone interview conducted by their assigned interviewer.

In addition to the telephone interviews, self-administered questionnaires were mailed to the patient's

residence. Patients were instructed to complete and return the booklet/questionnaire in the self-addressed stamped envelope provided in the packet.

Training of Data Collectors

Health care students were recruited and rigorously trained to be data collectors. In an effort to decrease interviewer bias, these interviewers were extensively trained to follow the protocols set forth by the principal investigators for the study. The interviewers received training manuals and attended practice sessions which included taped practice interviews with each other, and practice interviews with the principal investigator(s) or designee.

In addition, the initial patient interview was audited by the principal investigator(s) or their designee, to provide further feedback to the interviewer. Monthly, ongoing quality assurance was accomplished by each interviewer submitting one taped interview for review each month, monthly protocol review sessions, and the auditing of ten percent of each of the interviewer's records for adherence to the study protocols.

Protection of Human Subjects

Subjects recruited for the larger community based, longitudinal study were patients diagnosed of an equal number of breast, colo-rectal, lung, and prostate cancer, over 65 years of age, and recently admitted to an acute care

setting. Patients who met the study criteria were approached by nurse recruiters who explained the study, and asked them to sign a consent form authorizing review of the medical record, obtain address and telephone number, and needed clinical information.

Patients were not placed at increased risk by participating in the study. There were no identified physical or legal risks. Patients did not participate in any physical activity. The patients were free to refuse to participate in the study, and were told they could withdraw from the study at any time. The patients were assured that refusal to participate in the study would in no way alter the care they received. There were no financial costs to the patient as a result of participating in the study.

The anonymity and confidentiality of the patients was protected by the use of subject identification numbers on all instruments, by the release of research data in aggregate form only, by omission of agency names and/or identification in all presentations and reports, and by not providing confidential interview data to the agency or participating physician. Nurses or other health care professionals collecting data from the patients were not involved in the patients' direct care.

Informed consent was obtained from each patient. Potential subjects who agreed to participate had the study described to them in detail, informed as to the nature of

their involvement in the study, and given an opportunity to ask questions. Patients who agreed to be in the study then signed a consent form. The participants were informed both verbally and in writing of their right to withdraw from the study at any point during the study period. If a participant had a cognitive deficit, consent was obtained from the guardian or designated family member. If this was not available, the patient was excluded from the Family Care Study. If consent was obtained from the guardian or designated family member, the patient was excluded from this study (See Appendix F, for UCRIHS letter of approval).

A subsample of elderly women with breast cancer in Wave I was taken from the larger Family Care Study for secondary data analysis in this study. As the data had already been collected, there were no additional risks to the patients. No additional time was requested from the patients. There were no patient identifiers given for the subsample of the secondary analysis. Before beginning any data analysis, approval for the subsample used in this study was granted by the University Committee on Research Involving Human Subjects at Michigan State University (See Appendix E, for UCRIHS letter of approval).

Instrumentation

A sociodemographic tool (See Appendix A) was used to collect sample characteristics for this study. The sociodemographic and other background characteristics of the

patient participants included: age, sex, education, comorbidities, ethnic background, marital status, household members, and living arrangements.

To measure women's perception of fatigue and quality of life following surgery for breast cancer, several instruments were used. Guided by the adaptation of the Fatigue Impact on Quality of Life Model (Ferrell et al., 1996) quality of life was defined as having three domains: physical well-being, psychological well-being, and social well-being. Although of extreme importance in defining quality of life, the domain of spiritual well-being was excluded as a result of the absence of clearly defined variables in the original study that could be used to justly represent spirituality in the secondary analysis.

To measure fatigue and the domain of physical well-being, the Symptom Experience Index (SEI) developed by Given et al. (1994) and the Medical Outcomes Study Form Health Questionnaire-SF 36 (McHorney, Ware, & Raczek, 1993), were used. The SEI includes 37 symptoms such as nausea, vomiting, pain, weakness, shortness of breath, fever, and insomnia that are rated by severity (See Appendix B). This instrument measured symptoms, and related the symptoms' effect on the patients' functional ability. The impact of the symptom fatigue was operationalized using a separate response scale.

For this study, only the ten most frequently reported

somatic symptoms addressed in the SEI were included. Given et al. (1993), developed the SEI to measure symptoms of coughing, bowel problems, pain, severity of pain, nausea, and severity of nausea, and found empirical evidence to support validity. The reliability coefficient for the revised tool was found to be 0.72 by Given et al. (1993).

In the SEI, patients were asked eight weeks after their hospital discharge, following breast cancer surgery, if a particular symptom had been experienced in the past two weeks (1=Yes, 2=No) and to rate the symptom's severity on a three-point scale (1=mild, 2=moderate, and 3=severe). If a symptom was not present, the severity was coded as "zero". The patient was then asked to rate the extent to which the symptom had disrupted or caused the patient to limit her regular daily activity (1=no extent, 2=small extent, 3=some extent, 4=great extent, and 5=very great extent).

The patients' physical functioning ability, also operationalized as a score in the domain of physical well-being in this study, was assessed eight weeks after their hospital discharge following breast cancer surgery, using nine of the items from the Medical Outcomes Study Form Health Questionnaire Survey Form 36 (MOS SF-36) (McHorney, Ware, & Raczek, 1993) which address physical functioning ability (See Appendix C). In a study of 150 cancer patients and caregivers, Kurtz et al. (1995) found good reliability for this scale (alpha=.84). The patient was asked about

activities she might do during a typical day, for instance, vigorous activities, such as running or lifting heavy objects; moderate activities, such as pushing a vacuum cleaner or playing golf; lifting or carrying groceries; climbing several flights of stairs, bathing and dressing herself; and so on.

The patient was asked to what extent her health limited her in each activity three months ago or before being diagnosed with cancer, and then currently (1=yes, limited a lot, 2=yes, limited a little, or 3=no, not limited at all). The individual item scores for physical functioning were then averaged to create a new variable to represent the level of physical functioning for the sample.

The MOS SF-36 was used in this study to represent the domain of social well-being by measuring social functioning. This scale was found by Kurtz et al. (1995) to have a reliability of alpha=.78. Social functioning was assessed during Wave I, eight weeks after their hospital discharge following breast cancer surgery using the MOS SF-36 social functioning section (See Appendix C). The patient was asked to what extent her physical health or emotional problems had interfered with her normal social activities with family, friends, neighbors, or groups during the previous four weeks (1=not at all, 2=slightly, 3=moderately, 4=quite a bit, 5=extremely) and a score was given.

The MOS SF-36 is an instrument widely used for

measuring the health care concepts of physical functioning, role functioning, bodily pain, social functioning, mental health, and general health perceptions. McHorney et al. (1992) determined the validity and reliability of the MOS SF-36 to be statistically sound when compared to other similar instruments. In their study comparing the validity and relative precision of MOS short and long forms and the Dartmouth COOP Charts, McHorney and colleagues found the short-form scales generally achieved a high level of precision relative to the full-length scales they were designed to reproduce.

Representing the domain of social well-being in this study, only the concept of social functioning was measured. Therefore, the same validity and reliability documented for the entire instrument cannot be assumed to be accurate for this study.

The domain of the patient's psychological well-being was operationalized for each case as a composite score, averaged from the individual item scores from the Center for Epidemiologic Studies Depression Scale (CES-D) in this study. Four questions from the somatic subscale were removed and composite scores were taken from answers on the remaining somatic, depressive affect, well-being and interpersonal factor subscales. The somatic items removed include the following: had a poor appetite, felt everything was an effort, sleep was restless, and could not get going.

This strategy was used in order to reduce indicator overlap between the patient symptom and depression scales (Given et al., 1993 & Kurtz, Kurtz, Given, & Given, 1995). Given et al. (1993) found the modified scale to have a reliability coefficient of 0.86.

The patient was asked on the self-administered questionnaire, how she had been feeling during the past month, for instance, whether she had felt she couldn't shake off the blues, felt depressed, felt hopeful about the future, felt lonely (0=rarely or none of the time, 1=some of the time, 2=most of the time, 3=almost all of the time). A composite score was then computed as the average of the item scores for the modified scale (range 0-60) (See Appendix D). In order to make scale scores comparable with standard reporting conventions, a) all individual item scores were recoded from 0-3, b) the mean was computed for the sixteen items retained in the scale, and c) the mean score was multiplied by 20 so that the possible range of CES-D scores in this study is 0-60.

The measurement validity of the CES-D has been supported and documented in the screening of depression in older adults (Herzog, VanAlstine, & Usala, 1990). To avoid confounding depression indicators with physical symptom indicators present in the CES-D, Given et al. (1993) removed the somatic subscale from patients' CES-D score in their study of cancer patients' symptoms and functional states

influence on patients' depression and family caregivers' reaction and depression. These items included the following: was bothered by things that usually don't bother me, had a poor appetite, had trouble getting my mind on what I was doing, everything was an effort, sleep was restless, talked less than usual, and could not get going. This change produced a 0.54 correlation which was a reduction of 0.20 in the correlation from the original depression and symptom scales (Given et al., 1993). The empirical evidence supported the validity of the model.

Data Analysis

Descriptive statistics, such as numbers, percentages, means, and standard deviations were used to describe sociodemographic characteristics of the women at eight weeks following surgery for breast cancer. To quantify the strength of the relationship between fatigue and each of the variables, physical well-being, psychological well-being, social well-being, representing quality of life, Pearson product-moment correlation coefficients were computed using SPSS-PC statistical software. Correlations with a $p$ level of less than .05 were determined to be statistically significant in all analyses.

## RESULTS

The sociodemographic data for this sample are summarized in Table 1. The vast majority of the women was Caucasian (96.6% of n=145), married (55.2% of n=143,

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Table 1.

Frequency and Percent of Sociodemographic Characteristics of Sample (n=145)

| Characteristics | Frequency | Percent |
|---|---|---|
| **Patient Age** | | |
| 65-74 years | 100 | 69.0 |
| 75-84 years | 44 | 30.3 |
| 85+ years | 1 | 0.7 |
| **Education** | | |
| Less than high school | 26 | 17.9 |
| Completed high school | 64 | 44.1 |
| More than high school | 55 | 38.0 |
| **Marital Status** | | |
| Married | 80 | 55.2 |
| Not married | 63 | 43.4 |
| Missing | 2 | 1.4 |
| **Household Members** | | |
| Lives with spouse | 80 | 55.2 |
| Lives alone | 50 | 34.5 |
| Other | 15 | 10.3 |
| **Race** | | |
| Caucasian | 140 | 96.6 |
| African American | 5 | 3.4 |
| **Physical Comorbidities** | | |
| 0-2 | 79 | 54.5 |
| 3-4 | 51 | 35.2 |
| 5-6 | 14 | 9.7 |
| Missing | 1 | 0.7 |

missing=2), living with her spouse (55.2% of n=145), high school educated (44.1% of n=145), reporting up to two physical comorbidities (54.5% of n=144, missing=1) and age 65 to 74 years old (69%, n=100).

Research Question

To answer the research question "What is the relationship between women's perceptions of fatigue and quality of life following breast cancer surgery within eight weeks of hospital discharge", it was necessary to first describe the occurrence of fatigue, next create variables to represent the domains of quality of life depicted in this study, and lastly correlate fatigue with these quality of life variables.

Fatigue

The frequency of the occurrence of fatigue (Table 2) was first computed. Fatigue was reported as being present by 94 (64.8%) of the women in the sample (n=145). Fatigue was the most frequently reported of all symptoms in this sample.

Table 2.

Frequency and Percent of Presence of Fatigue in Sample (n=145)

| FATIGUE | Frequency | Percent |
|---|---|---|
| 0 no | 51 | 35.2 |
| 1 yes | 94 | 64.8 |
| **Total** | **145** | **100.0** |

Next, the average severity of fatigue was computed for those women reporting fatigue (Table 3). The severity of fatigue was scored from one to three, with the higher the score, the higher the severity. Of those reporting fatigue, 52 (35.9%) reported mild fatigue, 34 (23.4%) reported moderate fatigue, and 8 (5.5%) reported severe fatigue. The mean fatigue severity score was 0.993 (SD=.901).

Quality of Life Domain Physical Well-Being

The frequency of occurrence and average severity of the ten most frequently reported symptoms, excluding fatigue, were then computed (Table 3). As with fatigue severity, the severity of each symptom was scored from one to three. The higher the score, the higher the severity of the symptom. After fatigue, the highest reported mean symptom severity score was for pain ($\bar{x}$=0.628, SD=0.833). Among all patients sixty-one (42.1%) reported pain, thirty-four (23.4%) reported their pain to be mild, twenty-four (6.6%) reported moderate pain, and three (2.1%) reported severe pain.

Trouble sleeping was the third highest reported mean symptom severity score (0.586, SD=0.925) of women (33.8%, n=49) at eight weeks after surgery for breast cancer. Twenty-one (14.5%) women reported their trouble sleeping to be mild, twenty (13.8%) reported trouble sleeping to be moderate, and eight (5.5%) described their trouble sleeping to be severe. The fourth highest reported mean symptom

Table 3.

Symptom Severity of Top Ten Reported Symptoms and Fatigue of Sample (n=145, missing=0)

| | SEVERITY OF SYMPTOMS | | | | | | |
|---|---|---|---|---|---|---|---|
| SYMPTOMS | NONE=0 | MILD=1 | MOD=2 | SEVERE=3 | TOTAL SYMPTOMS PRESENT | AVERAGE SEVERITY REPORTED | STANDARD DEVIATION |
| Fatigue | 51 (35.2%) | 52 (35.9%) | 34 (23.4%) | 8 (5.5%) | 94 (64.8%) | .993 | .901 |
| Pain | 84 (57.9%) | 34 (23.4%) | 24 (16.6%) | 3 (2.1%) | 61(42.1%) | .628 | .833 |
| Trouble sleeping | 96 (66.2%) | 21 (14.5%) | 20 (13.8%) | 8 (5.5%) | 49 (33.8%) | .586 | .925 |
| Dry mouth | 93 (64.1%) | 32 (22.1%) | 16 (11.0%) | 4 (2.8%) | 52 (36.0%) | .524 | .800 |
| Poor appetite | 115 (79.3%) | 15 (10.3%) | 12 (8.3%) | 3 (2.1%) | 30 (20.6%) | .331 | .717 |
| Coughing | 109 (75.2%) | 28 (19.3%) | 5 ( 3.4%) | 3 (2.1%) | 36 (25.0%) | .324 | .644 |
| Constipation | 123 (84.8%) | 9 (6.2%) | 10 (6.9%) | 3 (2.1%) | 22 (15.0%) | .262 | .677 |
| Weight loss | 116 (80.0%) | 22 (15.2%) | 5 (3.4%) | 2 (1.4%) | 29 (20.0%) | .262 | .589 |
| Night sweats | 120 (82.8%) | 17 (11.7%) | 6 (4.1%) | 2 (1.4%) | 25 (17.2%) | .241 | .592 |
| Nausea | 123 (84.8%) | 17 (11.7%) | 4 (2.8%) | 1 (0.7%) | 22 (15.2%) | .193 | .504 |
| Difficulty breathing | 129 (89.0%) | 12 (8.3%) | 1 (0.7%) | 3 (2.1%) | 16 (11.0%) | .159 | .523 |

severity score was dry mouth (0.524, SD=0.800). In the sample (36.0%, n=52), thirty-two (22.1%) women reported mild severity, sixteen (11.0%) reported moderate severity, and four (2.8%) reported severe severity of the symptom dry mouth. The other mean symptom severity scores computed, such as poor appetite (0.331, SD=0.717), coughing (0.324, SD=0.644), constipation (0.262, SD=0.677), were lower than 0.5 (below mild) respectively, in severity. The mean

symptom severity score across the ten most frequently reported symptoms, controlling for fatigue, was 0.351 (SD=.35), with a range of 0-1.70.

Physical functioning, another component within the QOL physical well-being is represented in Table 4. Limitations were greatest in the category of vigorous activities such as running. A majority of women (78%, n=113) reported some limitations with a mean limitation score of 1.79 (SD=.77), where a score of three is equal to no limitation and a score of one is equal to limited a lot. Of those reporting limitation in this category, 61 (42.1%) were limited a lot, and 52 (35.9%) were limited a little.

Walking more than one mile was the physical function reported by women (56.9%, n=82) in this sample to be the second most limited function, with an average limitation score of 2.08 (SD=.88). For this function, 50 (34.5%) women reported they were limited a lot to walk more than one mile, and 32 (22.1%) reported they were limited a little.

Not surprisingly, in the physical functions requiring more physical stamina and strength patients were significantly limited at eight weeks after surgery for breast cancer. Activities requiring upper body strength frequently encountered during the course of a normal day such as bending, stooping (43.4%, n=63), and carrying groceries, lifting (47.2%, n=68), were reported to be limited by nearly half of the women in the sample.

Table 4.

Physical Functioning Limitations at Eight Weeks of Breast Cancer Surgery (n=145)

| | LIMITATIONS | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Functioning | Limited a lot=1 | Limited a little=2 | At Least Somewhat Limited (1&2) | No Limits =3 | Mean Limit. Score | Standard Deviation | Missing Data | n |
| Moderate activities such as moving a table, vacuuming, or bowling | 37(25.5%) | 36(24.8%) | 73(50.3%) | 72(49.7%) | 2.24 | .84 | 0 | 145 |
| Vigorous activities such as running, lift heavy objects, or strenuous sports | 61(42.1%) | 52(35.9%) | 113(78.0%) | 31(22%) | 1.79 | .77 | 1 | 144 |
| Lifting or carrying groceries | 26(17.9%) | 42(29.0%) | 68(47.2%) | 76(52.4%) | 2.35 | .77 | 1 | 144 |
| Climbing several flights of stairs | 29(20.0%) | 35(24.1%) | 64(44.8%) | 79(54.5%) | 2.35 | .80 | 2 | 143 |
| Climbing one flight of stairs | 12(8.3%) | 22(15.2%) | 34(23.4%) | 111(76.6%) | 2.68 | .62 | 0 | 145 |

## LIMITATIONS

| Functioning | Limited a lot=1 | Limited a little=2 | At Least Somewhat Limited (1&2) | No Limits =3 | Mean Limit. Score | Standard Deviation | Missing Data | n |
|---|---|---|---|---|---|---|---|---|
| Bending, kneeling, or stooping | 23(15.9%) | 40(27.6%) | 63(43.4%) | 82(56.6%) | 2.41 | .75 | 0 | 145 |
| Walking more than one mile | 50(34.5%) | 32(22.1%) | 82(56.9%) | 62(42.8) | 2.08 | .88 | 1 | 144 |
| Walking several blocks | 25(17.2%) | 35(24.1%) | 60(41.4%) | 85(58.6%) | 2.41 | .77 | 0 | 145 |
| Walking one block | 16(11.0%) | 16(11.0%) | 32(22.1%) | 113(77.9%) | 2.67 | .67 | 0 | 145 |

The mean physical functioning score across the nine physical functioning variables was computed to be 2.33 (SD=.51) with a minimum score equal to one, maximum score equal to three, and range of 0-3. Cronbach's alpha was computed for the nine physical function variables. The reliability among the variables was found to be very good (alpha=.84).

Quality of Life Domain Psychological Well-Being

To represent the domain of psychological well-being in this study, a modified version of the CES-D was used (Table 5). In order to control for symptoms already accounted for in the domain of physical well-being, four questions pertaining to somatic symptoms were removed from the CES-D for this study. The somatic items removed included 1) had a poor appetite, 2) felt everything was an effort, 3) sleep was restless, and 4) could not get going. The remaining sixteen items give alpha reliability of .8957.

In this sample, the CES-D question 12, "Were you happy?", had the highest mean score ($\bar{x}$=1.021). The second highest mean score ($\bar{x}$=.8681) was computed for CES-D question 16, "Have you enjoyed life?". CES-D questions 8, "Have you felt hopeful about the future?" had the third highest mean score ($\bar{x}$=.8621). For these three questions, because of reverse coding, a high score indicates a more negative response.

Table 5.

CES-D Minimum, Maximum, Mean and Standard Deviation Scores Reported at Eight Weeks After Breast Cancer Surgery (n=145)

**DEPRESSION**

| | N | Minimum | Maximum | Mean | SD |
|---|---|---|---|---|---|
| **PCESD1** **Bothered by things** | 143 | .00 | 2.00 | .5105 | .5798 |
| **PCESD3** **Couldn't shake blues** | 144 | .00 | 3.00 | .3357 | .5559 |
| **PCESD5** **Trouble keeping mind on** | 145 | .00 | 3.00 | .6759 | .7060 |
| **PCESD6** **Felt depressed** | 142 | .00 | 3.00 | .5352 | .6702 |
| **PCESD9** **Thought life a failure** | 145 | .00 | 3.00 | .1724 | .4908 |
| **PCESD10** **Felt fearful** | 144 | .00 | 2.00 | .5139 | .5911 |
| **PCESD13** **Talked less than usual** | 143 | .00 | 3.00 | .4755 | .6261 |
| **PCESD14** **Felt lonely** | 145 | .00 | 3.00 | .4483 | .6448 |
| **PCESD15** **People were unfriendly** | 145 | .00 | 3.00 | .1241 | .4546 |
| **PCESD17** **Had crying spells** | 143 | .00 | 3.00 | .3357 | .5559 |
| **PCESD18** **Felt sad** | 142 | .00 | 3.00 | .5634 | .6127 |
| **PCESD19** **Felt people disliked me** | 145 | .00 | 3.00 | .1379 | .4187 |
| **Reverse Coded** | **N** | **Minimum** | **Maximum** | **Mean** | **SD** |
| **RPCESD4** **Felt good as other people** | 143 | .00 | 3.00 | .5105 | .7303 |
| **RPCESD8** **Felt hopeful future** | 145 | .00 | 3.00 | .8621 | .8710 |
| **RPCESD12** **Was happy** | 145 | .00 | 3.00 | 1.0207 | .8618 |
| **RPCESD16** **Enjoyed life** | 144 | .00 | 3.00 | .8681 | .9479 |

The CES-D questions with the lowest means were 15- "Were people unfriendly?" ($\bar{x}$=.1241), 19-"Have you felt that people disliked you?" ($\bar{x}$=.1379), and 9-"Have you thought your life has been a failure?" ($\bar{x}$=.1724).

Although CES-D questions 16 and 9 seem to embrace a concept spanning over the lifetime rather than a current feeling, deletion of those questions did not improve the alpha value (alpha with 16 deleted =.89, alpha with 9 deleted =.89) so the questions were not removed from the scale in this study.

The mean depression score for this sample was 10.27 (SD=8.18) with a minimum score reported of 0 (n=13) and the maximum score reported of 40 (n=1). In this sample, 26.2% (n=38) had depression scores of 16 or more, indicating they are at a high risk for clinical depression.

Quality of Life Domain Social Well-Being

The level of social functioning is represented in Table 6. Health problems were reported not to interfere at all with normal social functioning by 76 (52.8%) of the women in the sample (n=144, missing=1). Six (4.2%) of the women reported their health problems had extremely interfered with their normal social functioning.

Table 6.

Frequency and Percent of the Extent Health Problems Interfered With Normal Social Functioning (n=144)

| Interfered with Social Functioning | Frequency | Percentage |
|---|---|---|
| extremely | 6 | 4.2 |
| quite a bit | 10 | 6.9 |
| moderately | 21 | 14.6 |
| slightly | 31 | 21.5 |
| not at all | 76 | 52.8 |
| **Total** | **144** | **100.0** |

## Fatigue and Quality of Life

Pearson Pairwise Correlation Coefficients were computed to measure the strength of relationships between fatigue and the variables representing quality of life in this study (Table 7). All relationships were found to be highly statistically significant with moderate to weak correlations.

Symptom severity ($r$=.361, $p$=.000) and depression ($r$=.176, $p$=.034) were positively correlated with fatigue. Physical functioning ($r$=-.357, $p$=.000) and social functioning ($r$=-.299, $p$=.000) were negatively correlated with fatigue, i.e. when fatigue was present, physical functioning and social functioning decreased. The strongest correlations were found to be between physical functioning and symptom severity ($r$=-.441, $p$=.000) and social functioning and symptom severity ($r$=-.407, $p$=.000). When

Table 7.

Pairwise Correlations Among Fatigue and Quality of Life Variables

| Fatigue | Symptom Severity | Physical Functioning | Depression | Social Functioning |
|---|---|---|---|---|
| Symptom Severity | .361<br>*p*= .000 | | | |
| Physical Functioning | -.357<br>*p*=.000 | -.441<br>*p*=.000 | | |
| Depression | .176<br>*p*=.034 | .363<br>*p*=.000 | -.175<br>*p*=.035 | |
| Social Functioning | -.299<br>*p*=.000 | -.407<br>*p*=.000 | .364<br>*p*=.000 | -.378<br>*p*=.000 |

symptom severity increased, not surprisingly physical functioning and social functioning decreased.

At eight weeks after surgery for breast cancer, women who report experiencing fatigue, perceive more symptom severity, less physical functioning, less social functioning, and an increase of depression.

## DISCUSSION

### Research Question

In answer to the research question explored in this study, "What is the relationship between women's perceptions of fatigue and quality of life following breast cancer surgery within eight weeks of hospital discharge", pairwise correlations demonstrated women in this sample perceived

that when fatigue was present, they also perceived decreased quality of life. Not surprisingly, when women were fatigued, they experienced an increase in the severity of other symptoms such as pain and trouble sleeping, a decrease in physical functioning needed to accomplish moderate and vigorous activities, an increase in depression scores, and a decreased level of social functioning.

It is understandable, given these correlations between fatigue and quality of life, how fatigue has the ability to impact many important aspects of the daily lifestyles of these women. Not only are the women coping with the emotional impact of the diagnosis of breast cancer followed by the physical impact of surgery and anesthesia to remove the cancer, they may not be able to return to the comfort of their normal activities due to the impact of fatigue.

While the basis of this study was focused on how fatigue effects quality of life in women after breast cancer surgery, it is plausible to interpret the observed correlations three possible ways. For instance, decreased quality of life, manifested by depression for example, may be experienced by cancer patients and lead to fatigue as an outcome. Another possible interpretation of the observed relationship that needs to be mentioned is the correlations between cancer and the variables of quality of life and fatigue. However, the scope of this study was to explore only one of the possible interpretations, how fatigue

impacts the quality of life in women following breast cancer surgery.

The findings of the correlations in this study support the findings of Graydon (1994); Wyatt, Kurtz, and Liken (1993); Ferrans (1990); Ferrell et al. (1996); Blesch et al. (1991); Kurtz, Given, Kurtz, & Given (1994); Dean et al. (1995); and Cimprich (1992) in that the more fatigue patients experience, the more symptoms they experience and the more changes they experience in their usual functioning. The correlation between fatigue and depression in this study supports the research of Ferrans (1990) and Dean et al. (1995). The decreased levels of social functioning found when fatigue is present in this study is supportive of the findings of Ferrell et al. (1996), who reported family distress and the disruption of relationship patterns. In summary, findings in this study support earlier research done on breast cancer patients' fatigue and quality of life.

The guiding framework of this study depicts fatigue, not only as a symptom, but as a concept that influences three of the four central dimensions of quality of life as defined by Ferrell et al. (1996). Fatigue was indeed found to radiate through each of the women's layers of physical well-being, psychological well-being, and social well-being after breast cancer surgery. As depicted in the model, each quality of life dimension effected the other.

Limitations

Several features of this study make it difficult to generalize the findings beyond this sample. First, the non-experimental study utilized a convenience sample of a highly homogeneous group consisting largely of white elderly women. While this sample is not ethnically diverse, more that 85% of all Americans over the age of 65 are white. However, a sample including women from other ethnicity in greater numbers would increase the ability to generalize the findings of the study to the population. Also, the non-experimental design of this study does not allow the prediction of causal effect between the variables.

Secondly, due to utilizing secondary data, the variables were removed from larger measurement tools to get the closest representation for the variable representing the concepts in this study. Although the reliabilities for the scales extracted from the tools were very good, it is possible that more accurate results may have been captured, using measurement tools specifically designed to measure fatigue and quality of life.

Thirdly, no relationships between the demographic data and the variables of fatigue and quality of life were described. The symptom experience, functional limitations, social limitations, and depression can only be thoroughly understood in relationship to characteristics such as comorbidities, educational level, age, living arrangements,

and the stage and treatment of the disease. Married women who experience stage I and II breast cancer, with no other comorbid conditions, are more likely to experience less impact on their quality of life from fatigue than other sicker women who are widowed and have later stage breast cancer. Further research is needed to explore fatigue as its correlations between demographic and background characteristics to help identify women at risk for developing fatigue.

Some limitations were evident in regards to the conceptual framework used to guide this study. In the guiding framework, Ferrell et al. (1996) identified components within the QOL dimension physical well-being to include strength, energy, functional ability, pain, sleep and energy. In this study, physical symptoms and physical functioning were measured. Due to the limitations of secondary analysis, strength and energy were unmeasurable in this study.

In the QOL dimension of psychological well-being, only one component, depression, was represented in this study. Other components in the psychological well-being dimension in the Ferrell et al. framework include the following: anxiety, frustration/feeling useless, fear of the meaning of fatigue, coping and acceptance, loss of independence, and cognition/attention. Data describing these components were not available for analysis in this study.

The QOL dimension of social well-being in this study was also represented by only one component, social functioning, included in the Ferrell et al. (1996), social functioning. Other components Ferrell et al. include within this dimension, and not measured in this study are: caregiver burden, impact on work/financial impact, leisure activities, family roles and relationships, and affection/sexual function.

Spiritual well-being was excluded completely from this study. Changes in spirituality, alter priorities to balance diminished energy, hopelessness, and meaning of fatigue, were components Ferrell et al. identified within the QOL dimension of spiritual well-being. These components were unmeasurable in the original data set from which this study was conceived. As a result, the limitations and changes people experienced within the four QOL dimensions and their components, as identified in the Ferrell et al. framework, were not fully explored due to limitations incurred from secondary data analysis.

Finally, the QOL dimensions in the Ferrell et al. (1996) framework were not mutually exclusive of one another. This overlapping of dimensions make it difficult to measure and identify components within the QOL dimensions. As a result, clear definitions, measurements, and interventions for each component within the QOL dimensions is very difficult. However, the conceptualization of fatigue as a

multidimensional experience effecting all dimensions of QOL in the Ferrell et al. (1996) fatigue/QOL model represents how far reaching the depths of fatigue can be for breast cancer patients.

Implications for Advanced Practice Nurses

As 65% of the women in this study reported fatigue at eight weeks after surgery for breast cancer, great opportunities abound for the APN to make a positive impact as educator, collaborator, case manager, clinician, advocate, and researcher. As an educator, the APN in primary care is in a position to spend time with women facing surgery for breast cancer. During the preoperative time period, it is vital for the APN to begin teaching patients that many women, as a matter of course, have reported fatigue to be a significant factor they experience in the weeks following breast cancer surgery.

Planning for fatigue can lead to less loss of control during this vulnerable and crucial recovery period. The APN can collaborate with the woman preoperatively to set realistic and attainable goals and to plan strategies to cope with fatigue, i.e. recognizing the body's signals of getting tired so they can rest before becoming fatigued, pace activities throughout the day, create shortcuts when doing household activities, plan short rest breaks when possible, accept help from others, and do not expect too much out of yourself-live day to day. This education can

help patients to reprioritize their precious time and reserve their energy for focusing on important aspect of their life, often family and relationships.

As case managers, APNs in primary care serve an important role for their patient. The age of this sample alone indicates the patients will have the need for more help with physical activities. The APN can assess and individualize plans for appropriate services for the patient, and discuss with the patient the art of delegating certain tasks to other family members or friends during the recovery period. The patient's reallocation of usual roles during the recovery period can be a very energy conserving intervention.

Dean et al. (1995) reported the major cause of fatigue to be other symptoms, such as pain, nausea and fever, in his sample of cancer patients receiving systemic cancer therapy. In this study, symptom severity was highly significant, as well. The expected patient outcome of symptom control to help decrease fatigue, could be accomplished by careful management and follow up by the APN serving in the role of care manager. In most cases, the APN in primary care has an established relationship with her patient and has the opportunity for in depth assessment of the health history.

Many times, the patient is able to identify her own past patterns of fatigue and previous interventions she has successfully used to arrest the fatigue at the acute stage.

Mapping out a plan to recognize these patterns of fatigue during the recovery period and activating selected strategies to relieve fatigue can be very reassuring and effective for the patient.

The APN is able to coordinate the care of the patient, following up on lab reports, consultative reports, marking important milestones, and evaluating care plans and treatments throughout the patient's cancer experience. As a care manager, the APN falls naturally into the role of advocate for the patient. Interpretation of data into understandable information the patient can use on her course of healing, along with adjustments to the regimen,can be crucial for the patient's recovery from cancer.

Continuing in the role of care manager, the APN needs to follow the patient's progress toward returning to normal levels of physical functioning. At eight weeks post breast cancer surgery, the findings of this study show that over half of the women are still significantly limited in their ability to perform moderate activities involving upper body strength. Since many of the normal daily activities, such as bathing, dressing, and house cleaning,require upper body strength, an inability not to perform these activities would be very concerning to the patient. The APN needs to assess the level of physical functioning limitations,and develop a plan to address the limitations identified in order to achieve the expected outcome of returning to normal physical

functioning. Interventions designed to conserve and restore energy, such as pacing oneself and sandwiching periods of activity with periods of rest,may prove to be helpful in abating fatigue.

The APN needs to assess the patient postoperatively for the presence of depression. Ferrans (1990) and Dean et al. (1995) reported depression correlated with fatigue. The researchers suggest depression may even be related to the initial cause of fatigue. In this study, the presence of fatigue had a highly significant correlation with depression. As counselor, the APN has an excellent opportunity to assess for signs of depression and develop a plan to decrease the symptoms of depression her patient experiences, as well as making appropriate referrals to other appropriate health care providers.

The patient's level of social functioning is negatively correlated with fatigue. This finding affords the APN the opportunity to discuss with the patient her priorities for energy expenditures. For instance, this would allow the patient to limit activities to meaningful, pleasurable activities with friends and loved ones while accepting help with household chores, etc.

As clinicians, APNs need to incorporate assessment of fatigue into routine assessments of women with breast cancer, beginning in the initial phases of diagnosis, and throughout the disease and treatment trajectory. This

assessment can help establish the timing, onset, and duration of fatigue.

The results of this study show that the relationship between fatigue and quality of life is highly significant. Since fatigue is subjective, the patient's self report is the number one most important aspect of the assessment. The APN should assess for manifestations of fatigue in the patient's physical, psychological, social, and spiritual well-being. While the physical symptoms of fatigue can be more overt, Ferrell and colleagues have found fatigue to affect all dimensions of quality of life (Ferrell et al., 1996). Care should be taken by the APN to not overlook signs and symptoms of fatigue in the psychological, social, and spiritual domains.

As researcher, the APN can strive to increase the knowledge base for clinical innovations in fatigue. More scientific, experimental research is needed to understand and quantify the meaning and the depth of fatigue for people with cancer. With scientific research focused on pinpointing the timing, onset, and duration of fatigue, as well as effective interventions, more accurate description of the fatigue experience, treatment and cure in the general population is possible. This valuable information will help practitioners elicit better patient outcomes by: 1) ultimately taking measures to prevent the development of fatigue altogether, or 2)developing fatigue education and

interventions to help cancer patients take more control over fatigue, and 3) identifying crucial points in the disease and treatment trajectory, at which aggressive use of interventions can be used to prevent fatigue from becoming an overwhelming condition.

Any future research describing strategies to control symptoms, timely return to optimal level of physical functioning, decrease depression, and increase social functioning experienced by women after breast cancer is called for by the findings of this study. Research using ethnically diverse sample populations would be helpful in understanding how fatigue affects women of culturally diverse backgrounds.

The use of an instrument specifically designed to measure fatigue in all dimensions of quality of life, would provide data more accurately representing fatigue. This instrument would include the spiritual dimension of quality of life.

Future research describing the relationship between fatigue and demographical data, including disease staging and adjuvant therapies, is necessary to recognize patterns in the population and individualize strategies for the control of fatigue.

Also, future research describing measures to *prevent* fatigue is crucial. This research may include the relationship between fatigue and the immune system as it is

influenced by nutritional status, optimism, and other important factors. This inestimable information could restore some balance to the quality of the lives of people with cancer suffering from fatigue.

Summary

There is a highly significant relationship between fatigue and quality of life at eight weeks after breast cancer surgery reported by women in this study. Fatigue was significantly related to symptom severity and depression, indicating that women who reported fatigue had a higher level of symptom severity and a higher depression score. A significant negative relationship was found between fatigue and physical functioning and social functioning, indicating that women reporting fatigue reported lower levels of physical and social functioning. The significance of the findings of this study challenge APNs to consider fatigue and it's management a serious problem that can negatively impact the quality of life for women after breast cancer surgery.

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# LIST OF REFERENCES

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# APPENDICES

# APPENDIX A

# DEMOGRAPHIC INSTRUMENT

Circle if: **SHORTENED**

cs:W1PTNOCG.INT
4/2/96

**WAVE I**

**PATIENT WITHOUT CAREGIVER TELEPHONE INTERVIEW**

**"Family Home Care for Cancer – A Community-Based Model"**

**Grant #2 RO1 NR/CA01915**
**Funded by the National Institute of Nursing Research and the National Cancer Institute**
**Barbara A. Given, PhD, RN, FAAN, and Charles W. Given, PhD, Co-Principal Investigators**

NINR/NCI SCREENING

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

**SCREENING CANCER PATIENT**
**NAME AND ADDRESS from Pre-Enrollment Form**

1. **Name of Patient:** _____
2. **Address of Patient:** _____
   _____
   _____
3. **Telephone:** (_____)_____
4. **Name and phone number of contact person if unable to reach patient:**
   **Name:** _____
   **Relation to patient:** _____
   **Telephone:** (_____)_____
   **Location:** _____
   _____

**Attempts to contact patient (date and time).**

_____ _____ _____

_____ _____ _____

NINR/NCI SCREENING

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

Introduction:

"Hello, my name is _____. I am a project staff member for the Family Care Study at Michigan State University. Recently we sent you information about the study and you signed a consent form and sent it back to us."

"The questions I would like to ask you will take approximately 45 minutes to an hour. Is now a good time for you to answer these questions or would you like to schedule another time, or perhaps, I could ask some of the questions now and schedule another time to finish? Whatever is most convenient for you. Would you like to try some now?"

Interviewer: Set up appointment for interview:

_____ Day _____ Time

Interviewer: Some of the participants need to be reminded of the amount of time and involvement that this study will require of them.

1. Only telephone conversations, although there may be home visits for special circumstances.
2. Can withdraw from study at any time.
3. Can always contact us for information, at (517) 353-3843 ext 433 (Keely Englesby), or 1-800-654-8219.
4. Interviewer will contact participant by telephone to set up appointment at participant's convenience. Self-administered questionnaire will then be mailed to allow at least one week for patient to fill out.

Interviewer: If patient DOES want to participate:

"We appreciate your willingness to participate. I would like to remind you that all information will be held in the strictest confidence and will not be linked to you as an individual in any way. This information is necessary to describe the situations of individuals with cancer as a group to try to identify needed resources."

Interviewer: If patient DOES NOT want to participate:

"Would you be willing to let us know what your reasons are for not participating in the study at this time?"

Reasons for not participating: _____

_____

"At this time, we will not plan to contact you again. If for any reason you change your mind and decide that you would like to participate, feel free to call us. Do you have our number?"

"Thank you for your time."

NINR/NCI WAVE I PATIENT W/O CAREGIVER TELEPHONE

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

Prior to interview– Enter date (month, day and year) and interviewer number on each page, if indicated.

## SOCIODEMOGRAPHIC INFORMATION FOR CANCER PATIENT

1. Sex of patient: (check one) ____ Male (1) ____ Female (2)

2. What is your birthdate? (write in)

__ __/__ __/__ __
Month/ Day /Year

3. What is your highest level of education completed? (check one)

_____ No formal education (1)
_____ Completed grade school (2)
_____ Completed some high school (3)
_____ Completed high school (4)
_____ Completed some college or technical training (5)
_____ Completed college (6)
_____ Completed graduate/professional degree (post baccalaureate degree) (7)
_____ NA/Refused (9)

4. What is your race or ethnic background? (check one)

_____ Caucasian/White (1)
_____ African American/Black (2)
_____ Mexican American/Hispanic/Chicano (3)
_____ Native American/Alaskan (4)
_____ Oriental/Asian/Pacific Islander (5)
_____ Other (6) (specify _____)
_____ NA/Refused (9)

5. What is your marital status? (check one)

_____ Never married (1)
_____ Married (2)
_____ Divorced/Separated (3)
_____ Widowed (4)
_____ NA/Refused (9)

(GO TO NEXT PAGE)

NINR/NCI WAVE I PATIENT W/O CAREGIVER TELEPHONE

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

6. In which county do you live?

_____
(write in county)

_____ NA/Refused

7. When was the month and year you moved to this county? (write in)

_____/_____
Month/Year

Now we are going to ask you questions about who lives with you, and about persons who might help you.

8. Who lives in your household with you? (check all that apply)

___ No one - lives alone (1)
___ Spouse (2)
___ Other (3)
___ NA/Refused (9)

9. Do any children live with you?

___ Yes (Go to 9a)
___ No (Go to 10)
___ NA/Refused

9a. If Yes was checked, then:

(a9A) How many children under 13 years of age?

_____(write in number)

(b9A) How many 13 to 17 years of age?

_____ (write in number)

(c9A) How many 18 years or older?

_____ (write in number)

9b. ___ Any other children under 18 years of age (4)

(a9B) How many children under 13 years of age?

_____(write in number)

(b9B) How many 13 to 17 years of age?

-----(write in number)

(GO TO NEXT PAGE)

9c. ___ Adult relatives other than your children (18 years or older) (5)

(a9C) How many adult relatives?

_____(write in number)

9d. ___ Other unrelated adults (18 years or older) (6)

(a9D) How many unrelated adults?

_____(write in number)

9e. ___ NA/Refused (9)

(Interviewer: Step-daughter, -son; check as daughter, son.)

10. Is there someone who helps you with care of any type, including bathing, dressing, medications, or even transportation? (check one)

___ Yes (1)
___ No (2) (If NO, go to question 11)
___ NA/Refused (9)

10a. If YES, who helps you? (Indicate relationship to patient, including step-children, e.g., if a daughter is helping her mother, check daughter) (check as many as apply)

___ Wife (1)
___ Husband (2)
___ Daughter (3)
___ Son (4)
___ Daughter-in-law (5)
___ Son-in-law (6)
___ Sister/sister-in-law (7)
___ Brother/brother-in-law (8)
___ Mother (9)
___ Father (10)
___ Aunt (11)
___ Uncle (12)
___ Niece (13)
___ Nephew (14)
___ Granddaughter (15)
___ Grandson (16)
___ Other (please specify _____) (17)
___ NA/Refused (99)

10b. From among all the persons you have indicated that may help you, which one person helps the most or is most willing to help should the need arise? (write in)

Name of person and relationship: _____

NINR/NCI WAVE I PATIENT W/O CAREGIVER TELEPHONE

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

Note: We will refer to this person as your PRIMARY CAREGIVER.

10c. Does your primary caregiver live with you? (check one)

___ Yes (Go to question 11) (1)
___ No (Go to question 10d) (2)
___ NA/Refused (9)

10d.

Interviewer: If not spouse, then get mailing address and telephone number of primary caregiver:

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Telephone: (_____)_____

Is this person paid by you, or is anyone paid to assist you?

_____ Yes _____ No

If yes, what is the weekly/monthly wage? $_____

11. Because of the need for assistance with cancer, did ... (check one)

_____ You move to caregiver's home (Go to question 11a) (1)
_____ Caregiver move into your home (Go to 11a) (2)
_____ You move closer to caregiver (Go to 11a) (3)
_____ Caregiver move closer to you (Go to 11a) (4)
_____ You move to a facility that provides care (Go to 11a) (5)

Please describe facility: _____

_____

_____ No one move (Go to question 12) (6)
_____ NA/Refused (9)

11a. If movement occurred, what was the month and year of movement? (write in)

_____/_____ _____ NA/Refused (9)
Month/Year

(GO TO NEXT PAGE)

# APPENDIX B

# SYMPTOM EXPERIENCE INDEX

NINR/NCI WAVE I PATIENT W/O CAREGIVER TELEPHONE

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

**PATIENT SYMPTOM EXPERIENCE**

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

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

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

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

NINR/NCI WAVE I PATIENT W/O CAREGIVER TELEPHONE

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

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

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

NINR/NCI WAVE I PATIENT W/O CAREGIVER TELEPHONE

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

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

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

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

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# APPENDIX C

## MEDICAL OUTCOMES STUDY FORM HEALTH QUESTIONNAIRE-SF 36

## INSTRUMENTAL ACTIVITIES OF DAILY LIVING FOR THE PATIENT

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

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

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

The next few questions will ask only about your current condition.

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

(GO TO NEXT PAGE)

NINR/NCI WAVE I PATIENT W/O CAREGIVER TELEPHONE

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

4. During the past four weeks, have you had any of the following problems with your work or other regular activities as a result of your physical health? (please check YES or NO)

| | YES (1) | NO (2) |
|---|---|---|
| 4a. Cut down on the amount of time you spent on work or other activities? | | |
| 4b. Accomplished less than you would like? | | |
| 4c. Were limited in the kind of work or other activities? | | |
| 4d. Had difficulty performing the work or other activities; for example, it took extra effort? | | |

5. During the past four weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems, such as feeling depressed or anxious? (please check YES or NO)

| | YES (1) | NO (2) |
|---|---|---|
| 5a. Cut down on the amount of time you spent on work or other activities? | | |
| 5b. Accomplished less than you would like? | | |
| 5c. Didn't do work or other activities as carefully as usual? | | |

6. During the past four weeks, to what extent have your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups? (circle one)

| Not at All (1) | Slightly (2) | Moderately (3) | Quite a Bit (4) | Extremely (5) |
|---|---|---|---|---|

7. Please choose the answer that best describes how true or false each of the following statements is for you. (check one per statement)

| | Definitely True (1) | Mostly True (2) | Not Sure (3) | Mostly False (4) | Definitely False (5) |
|---|---|---|---|---|---|
| 7a. I seem to get sick a little easier than other people. | | | | | |
| 7b. I am as healthy as anybody I know. | | | | | |
| 7c. I expect my health to get worse. | | | | | |
| 7d. My health is excellent. | | | | | |

# APPENDIX D

## CENTER FOR EPIDEMIOLOGIC STUDIES DEPRESSION SCALE

ID # _____
INT # _____

cs:ptsab.wv1
5/15/95

**WAVE I**

**PATIENT SELF ADMINISTERED BOOKLET**

The answers you give to these questions are very important in helping us to better understand the experiences of dealing with cancer. You should try to mark the response which is most like your own feelings and experiences. Your answers will be of great help to us and we want to remind you that the answers you give are strictly confidential.

If you have questions, please call Keely Englesby or Charles W. Given at (517) 353-3843 ext. 433 or toll free at 1-800-654-8219.

We appreciate the time that you spend answering these questions and we value the answers you give. Your help is the most important factor in our efforts to learn more about patients dealing with cancer.

Please complete and return this booklet in the self-addressed stamped envelope by _____. Thank you.

Family Home Care for Cancer - A Community-Based Model

Grant #2 R01 NR/CA01915
Funded jointly by the National Institute of Nursing Research
and the National Cancer Institute.

NINR/NCI WAVE I PT SAB
PAGE 2

## CURRENT FEELINGS

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

| | DURING THE PAST MONTH, HOW MUCH OF THE TIME... | ALMOST ALL OF THE TIME | MOST OF THE TIME | SOME OF THE TIME | RARELY OR NONE OF THE TIME |
|---|---|---|---|---|---|
| 1. | Were you bothered by things that usually don't bother you? | | | | |
| 2. | Have you not felt like eating; had a poor appetite? | | | | |
| 3. | Have you felt that you could not shake off the blues, even with the help of family or friends? | | | | |
| 4. | Have you felt that you were just as good as other people? | | | | |
| 5. | Have you had trouble keeping your mind on what you were doing? | | | | |
| 6. | Have you felt depressed? | | | | |
| 7. | Have you felt that everything you did was an effort? | | | | |
| 8. | Have you felt hopeful about the future? | | | | |
| 9. | Have you thought your life has been a failure? | | | | |
| 10. | Have you felt fearful? | | | | |
| 11. | Has your sleep been restless? | | | | |
| 12. | Were you happy? | | | | |
| 13. | Have you talked less than usual? | | | | |
| 14. | Have you felt lonely? | | | | |
| 15. | Were people unfriendly? | | | | |
| 16. | Have you enjoyed life? | | | | |
| 17. | Have you had crying spells? | | | | |
| 18. | Have you felt sad? | | | | |
| 19. | Have you felt that people disliked you? | | | | |
| 20. | Could you not get "going?" | | | | |

# APPENDIX E

# UCRIHS APROVAL LETTER

MICHIGAN STATE
UNIVERSITY

June 27, 1997

TO: Barbara A. Given
A230 Life Sciences

RE: IRB#: 97-393
TITLE: FEMALE BREAST CANCER PATIENTS' PERCEPTIONS OF FATIGUE AND QUALITY OF LIFE FOLLOWING BREAST CANCER SURGERY
REVISION REQUESTED: N/A
CATEGORY: 2-H
APPROVAL DATE: 06/27/97

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

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

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

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

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

Sincerely,

David E. Wright

David E. Wright, Ph.D.
UCRIHS Chair

DEW:bed

cc: Linda Abent

OFFICE OF
**RESEARCH AND GRADUATE STUDIES**

**University Committee on Research Involving Human Subjects (UCRIHS)**

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

517/355-2180
FAX 517/432-1171

# APPENDIX F

## UCRIHS APPROVAL LETTER FOR FAMILY CARE STUDY

MICHIGAN STATE
UNIVERSITY

May 7, 1996

TO: Barbara A. Given
A230 Life Sciences

RE: IRB#: 92-280
TITLE: FAMILY HOME CARE FOR CANCER--A COMMUNITY-BASED MODEL
REVISION REQUESTED: 04/22/96
CATEGORY: FULL REVIEW
APPROVAL DATE: 05/06/96

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

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

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

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

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

Sincerely,

David E. Wright, Ph.D.
UCRIHS Chair

DEW:bed

cc: Charles Given

OFFICE OF
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STUDIES

University Committee on
Research Involving
Human Subjects
(UCRIHS)

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