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Correlates of Symptom Distress in Breast Cancer Patients Receiving Cyclophosphamide, Methotrexate, and Fluorouracil

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CORRELATES OF SYMPTOM DISTRESS IN
BREAST CANCER PATIENTS RECEIVING
CYCLOPHOSPHAMIDE, METHOTREXATE, AND FLUOROURACIL

By

Denise J. Bakker

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ABSTRACT

CORRELATES OF SYMPTOM DISTRESS IN
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The purpose of this study was to describe the relationship between symptom distress and health locus of control, perception of illness, perception of treatment efficacy, and social support in breast cancer patients receiving cyclophosphamide, methotrexate, and flourouracil as adjuvant chemotherapy in the outpatient setting. A prospective descriptive correlational design was used. A convenience sample of women ($N = 33$) with breast cancer was assessed using five measurement tools: the Symptom Distress Scale (McCorkle & Young, 1978), the Multidimensional Health Locus of Control scale (Wallston, Wallston, & DeVellis, 1978), the Norbeck Social Support Questionnaire (Norbeck, Lindsey, & Carrieri, 1981), and two 100-mm visual analog scales measuring perception of illness (Ehlke, 1988) and perception of treatment efficacy. Using the Pearson correlation coefficient no significant relationship was found between symptom distress and health locus of control, perception of illness, perception of treatment efficacy, and social support.

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CHAPTER 1

INTRODUCTION

Oncology patients encounter many challenges throughout their diagnosis and treatment. Nursing's role in assisting the individual to maintain health and well-being requires that nurses identify when the individual's coping resources are inadequate to meet the demands imposed by treatment. Side effects produced by chemotherapy agents administered as part of the disease treatment are a primary concern. The individual's response to treatment induced side effects can be identified by evaluating symptom distress.

McCorkle and Young (1978) define symptom distress as "the degree of discomfort from the specific symptom being experienced as perceived by the patient" (p. 374). Research has shown that incongruencies exist in the perception of symptom distress by care givers and the distress reported by patients (Holmes & Eburn, 1989 and Larson, P., Viele, C. Coleman, S., Dibble, S., & Cebulski, C., 1993). These incongruencies support the proposition that symptom distress is a subjective experience whose expression is dependent on the perception of the individual. It is important for nurses to gain an understanding of the reported symptom distress associated with cancer treatment in order to assist

patients to meet the demands of symptom management. Symptom assessment must include identification of the factors influencing the perception of the symptom and the interpretation of the meaning to the treatment (Giardino & Wolf, 1993).

This study was a partial replication of work by GraceAnn Ehlke (1988). The purpose of this study was to determine the factors influencing the symptom distress experienced by breast cancer patients receiving cyclophosphamide, methotrexate, and fluorouracil (CMF) as adjuvant chemotherapy in the outpatient setting. Knowledge of these relationships will assist in identification of patients at risk for significant symptom distress.

CHAPTER 2

LITERATURE AND THEORY

Conceptual Framework

Theoretical Framework

The framework used for this study is Lazarus's theory of psychological stress (Lazarus & Folkman, 1984). Lazarus defines psychological stress as "a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (p. 19). The concept of cognitive appraisal central to the theory is defined as "the evaluative process that determines why and to what extent a particular transaction or series of transactions between the person and the environment is stressful" (p. 19). The individual's appraisal of an event categorizes it as irrelevant, benign-positive, or stressful. "Stressful appraisals include harm/loss, threat, and challenge" (p. 32). Harm/loss and threat appraisals encompass actual or anticipated harm or loss from the encounter. Challenge appraisal focuses on the potential for gain or growth from the encounter.

Lazarus's theory has three primary assumptions:

(a) Each individual's perception of the situation is unique;
(b) the situation and the person's appraisal of and response to the situation interact in a dynamic relationship; and
(c) appraisal of the situation is influenced by "person" and situational factors. The "person" factors impacting appraisal refer to the beliefs and values held by the individual. The situational factors encompass the characteristics of the particular event.

The appraisal of an encounter influences the coping process. The coping process functions to manage the problem causing the distress and to regulate the emotional response to the problem. The way a person copes is influenced by the personal characteristics mentioned above as well as the person's material and social resources. (Lazarus & Folkman, 1984).

The diagnosis and treatment of neoplastic disease set the stage for activation of the coping process. For this study, chemotherapy treatment is identified as the situational factor which precipitates the coping process. The appraisal influences the individual's management of and emotional response to the stimulus. The individual's perception of illness, perception of treatment efficacy, beliefs about personal control, and perception of social support impact the appraisal of the treatment situation. The relationship between appraisal of the treatment situation and the individual's coping level is dynamic. With the implementation of coping strategies the evaluation

of the event is modified. When coping strategies are ineffective or inadequate, physiological and psychological stress may occur. The outcome variable of symptom distress is one indicator of coping level.

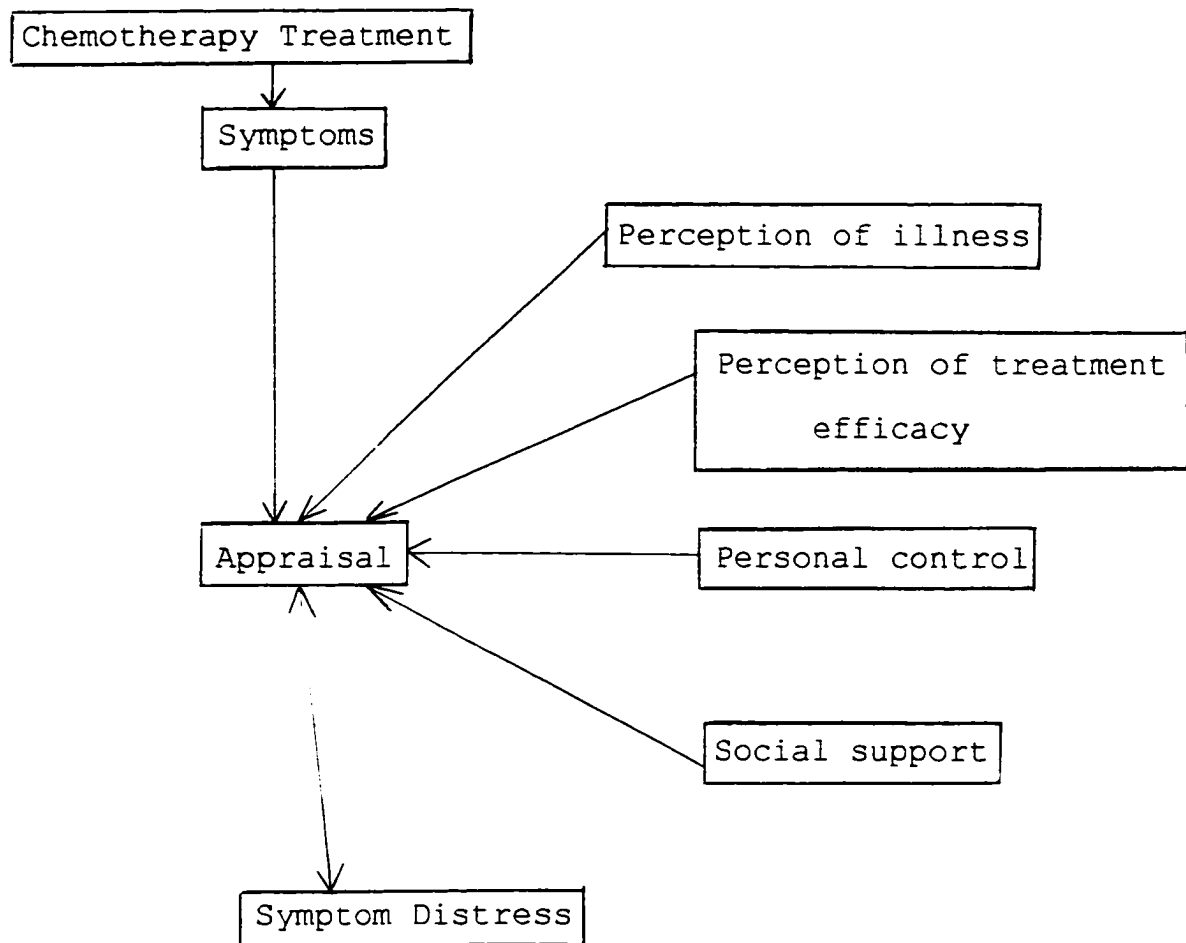
The multidimensional nature of symptom distress contributes to the difficulty formulating conclusions regarding the factors impacting symptom distress. A review of the research isolates three significant variables impacting the experience of symptom distress:

1. Personal control: Individuals undergoing treatment have reported that the ability to manage side effects mediates the distress associated with treatment.

2. Perception of illness: Research has also indicated that an outlook focused on maximizing potential, despite the limitations imposed by treatment, has a positive effect on emotional well being with a subsequent decrease in reports of symptom distress.

3. Social support: The role of social support in mediating symptom distress is supported by Tishelman, Taube, and Sachs (1991). Earlier findings by Elkhe (1988) had not supported this conclusion.

Figure 1. Model of conceptual framework



The symptoms associated with the treatment event comprise the situational factors in the appraisal process. The perception of illness and treatment efficacy is the initial evaluation of the treatment situation as the individual interprets the meaning of the event in light of his/her life experience. The individual evaluates his/her ability to manage the event. The ability to exert control over the outcome influences the appraisal of the event as a challenge or threat. Finally, the social network functions as a resource to buffer the stress associated with the

event. This includes the individual's perception of the supportiveness of specific social relationships.

In this study, the outcome variable of symptom distress will be explored in relationship to the person factors of personal control, social support, and perception of illness and treatment efficacy given a defined treatment situation.

Study Question

Is there a relationship between symptom distress and health locus of control, perception of illness, perception of treatment efficacy, and social support?

Hypotheses

1. Individuals with higher internal health locus of control scores will have lower symptom distress scores.
2. Individuals with more positive perceptions of illness scores will have lower symptom distress scores.
3. Individuals with more positive perceptions of treatment efficacy will have lower symptom distress scores.
4. Individuals with higher social support scores will have lower symptom distress scores.

Definition of Terms

The key concepts identified for this study are the following:

1. Appraisal: "The evaluative process that determines why and to what extent a particular transaction or series of transactions between the person and the environment is stressful" (Lazarus & Folkman, 1984, p. 19). The process of

evaluation that identifies the meaning of events or situations.

2. Symptom Distress: "The degree of discomfort from the specific symptom being experienced as perceived by the patient" (McCorkle & Young, 1978, p. 374). The individual's report of discomfort from the side effects associated with chemotherapy.

3. Personal Control: The belief that one can shape or influence events and outcomes of importance.

4. Social Support: "The nature of the interactions occurring in social relationships, especially how these are evaluated by the person as to their supportiveness" (Lazarus & Folkman, 1984, p. 249). The personal network including family, friends, associates, acquaintances, health care personnel, and spiritual counsel identified by the individual and the meaning of that relationship to the individual.

5. Perception of Illness: The evaluation of the illness situation and its meaning.

6. Perception of Treatment Efficacy: The evaluation of the treatment situation and its ability to provide the desired result.

Literature Review

Chemotherapy is an important tool in the treatments available for neoplastic disease. It has produced significant response in many cancers. However, the hope for

response to treatment can be overshadowed by difficulties in coping with the treatment itself. Due to the systemic nature of chemotherapy treatments for malignant disease, a wide range of side effects affecting multiple systems can occur. Side effects are objective and subjective indicators related to illness or disease. Symptoms are side effects reported by the individual based on an awareness of sensations which depart from normal function, sensation, or appearance. The actual incidence of treatment related symptoms does not establish their significance. The significance of symptoms is established by the individual's evaluation of the physical sensation. The interpretation of the sensation determines the extent of discomfort associated with each particular symptom. Symptom occurrence is an essential antecedent to the perception of distress.

Research conducted describes the symptom distress experienced by individuals receiving chemotherapy. The literature reviewed investigates side effect incidence and the severity of distress associated with chemotherapy in populations with varied cancer diagnoses as well as populations with breast cancer diagnosis. The literature focuses on variables impacting symptom experience and mediating distress. Primary variables of interest include physiological variables (diagnosis, illness stage, treatment history, and symptom control measures), psychological variables (outlook, individual perception, and beliefs about

personal control), and psychosocial variables (social support).

Physiological and Pharmacological Variables

Nail, Jones, Greene, Schipper, and Jensen (1991) investigated the perceptions of side effect incidence and severity related to cancer diagnosis and chemotherapy treatment. In a heterogeneous sample ($N = 49$), a review of a self care diary 2 days after various courses of treatment revealed fatigue as the most frequent complaint followed by sleeping difficulty, nausea, and decreased appetite. The majority of side effects reported were rated as moderately severe. Hair loss, fatigue, and decreased appetite received the highest severity ratings. Self care activities, including obtaining extra sleep, using diversion, and taking anti-nausea medication, provided "some" to "moderate relief" from the side effects experienced.

Similar results were found by Love, Leventhal, Easterling, and Nerenz (1989) as they investigated distress parameters in a sample ($N = 238$) of patients with the diagnosis of breast cancer and malignant lymphoma. Subjects experienced a number of side effects while receiving varied chemotherapy treatment regimens. More than 80% reported experiencing hair loss, nausea, and tiredness at some time throughout six cycles of chemotherapy. Forty percent experienced vomiting, sleep disturbance, weight gain, mouth sores, and numbness/tingling. The outcome variables measuring distress were difficulty with chemotherapy,

emotional distress from chemotherapy, disruption in social life, and disruption in work life. Difficulty with chemotherapy, emotional distress, and disruption in work and social life from chemotherapy were experienced to some extent in a high percentage of the population studied, with higher levels of distress reported as treatment progressed. Nausea, vomiting, and anticipatory nausea predicted higher levels of the four outcome variables. Tiredness, weakness, and diarrhea showed a significant relationship to difficulty with chemotherapy. A significant positive correlation existed between the total number of side effects experienced and ratings on the outcome scales. While the side effect incidence and pattern were similar across drug regimens, the mean ratings for difficulty with treatment differed significantly. Cyclophosphamide, doxorubicin, and 5-fluorouracil (CAF) regimens were consistently associated with the highest levels of difficulty. In looking at factors which enhance distress, the researchers found that the ability to manage or cope with side effects has an inverse effect on the distress measures.

In a descriptive study exploring the onset, pattern, duration, intensity, and distress associated with fatigue in a sample ($N = 109$) heterogeneous for diagnosis and chemotherapy treatment, Richardson, Ream, and Wilson-Barnett (1998) found that 89% documented fatigue at some point in their cycle of chemotherapy. The visual analog scale and daily diary demonstrated that the pattern of fatigue

experienced by the study population was dependent on the chemotherapy regimen, timing of treatment and method of drug administration. The study revealed that the incidence of fatigue showed a comparable change in distress from fatigue and interference with daily activities.

Woo, Dibble, Piper, Keating, and Weiss (1998) further investigated the experience of fatigue in women receiving various cancer therapies (radiation, hormonal, chemotherapy, and their combinations) for breast cancer. The researchers found that the experience of fatigue varied by type of cancer therapy. Women who received combination therapy had the highest fatigue scores with those who received only radiation therapy had the lowest fatigue scores.

Tierney, Taylor, Closs, Chetty, and Rodger (1991) compared pretreatment knowledge and expectations with the side effects experienced by women with breast cancer ($N = 51$) receiving doxorubicin for locally advanced cancer and cyclophosphamide for adjuvant treatment of local disease. Interviews revealed that the women participating in the study expected more difficulty with hair loss and sickness than other side effects associated with treatment. Actual experience did not corroborate those expectations. Tiredness, the most frequently reported side effect, was also identified as the most difficult. Participants reported a high incidence of nausea, loss of appetite, mouth soreness, pain, sickness, and sore eyes.

Focusing on the experiences of women receiving chemotherapy for breast cancer, Green, Nail, Fieler, Dudgeon, and Jones (1994) compared the patient-reported side effects and disruption in usual activities resulting from treatment with CMF, CAF, or cyclophosphamide, mitoxantrone, and fluorouracil (CNF) regimens. The sample of 86 women, heterogeneous for disease stage, were asked to complete a self-care diary recording the incidence and severity of side effects as well as rating the disruption which occurred in their usual activities on day 2 and day 5 following the chemotherapy treatment. The time frames were established to assess acute side effects rather than later effects. The most frequently reported side effects for all three regimens, independent of time, were fatigue, nausea, anorexia, taste changes, and headache at mild to moderate severity. Controlling for stage of disease, the highest nausea severity rating was reported by participants receiving CAF. Some disruption in activities of daily living was reported by the women in all three treatment groups with higher scores reported by women receiving CAF. Despite this, ratings for overall disruption in usual activity did not vary significantly with respect to treatment regimen.

Research conducted by Longman, Braden, and Mishel (1996) with breast cancer patients ($N = 307$) in various stages of illness and undergoing various treatments reported common side effects including sore arm(s), pain, difficulty

sleeping, anxiety, nausea, swelling, depression, appetite change, hair loss, with fatigue being the most common and most problematic. The number of side effects and increase in side effects reported showed a moderately negative correlation with fatigue and depression. Extension of the investigation into impact on daily activities revealed a significant reduction in self-help (daily) activities as side effect burden increased. Negative correlations were found between self care (wellness promotion) behaviors and fatigue and depression. Forty-two percent of the possible correlations between side effect burden and quality of life showed a significant negative relationship. These reports suggest that side effect incidence does impact distress and normal daily activities. Longman, Braden, and Mishel (1997) further investigated side effect burden and its implication on self-help (daily) activities and self-care (wellness promotion) behaviors in women ($N = 53$) receiving various treatments for breast cancer. The study confirmed that fatigue was the most frequent and problematic side effect reported over time. Small to moderate negative relationships were revealed between difficulty concentrating, pain burden, and self-help over time. No significant relationship was identified between an increase in side effects and self-care behaviors.

Ketiku and Ajekigbe (1990) investigated the incidence of side effects and quality of life in breast cancer patients of Nigerian descent. The participants ($N = 57$)

receiving CMF for adjuvant therapy or treatment for metastatic disease reported slight nausea as the most common side effect. Malaise was reported as moderately severe in a small number of cases. Other side effects noted were vomiting, loss of appetite, and menstrual changes. The researchers reported no incidence of alopecia in the population studied. Ten percent of participants related that treatment interfered with their daily activities.

Pharmacological measures implemented to control nausea and vomiting need to be considered as having a significant effect on the experience of distress related to treatment. In a randomized, double-blind crossover study, Simmes, Rhodes, and Madsen (1993) compared the effectiveness of prochlorperazine and lorazepam in the management of post chemotherapy symptoms. Among the heterogeneous sample ($N = 24$) no difference in the amount of nausea and vomiting was identified between the two antiemetic regimens. Patients receiving lorazepam, however, did report less fatigue and pain.

Levitt et al. (1993) compared the antiemetic protocols of ondansetron and dexamethasone and metoclopramide in 164 patients receiving CMF for treatment of breast cancer. Results of the randomized trial revealed that patients receiving dexamethasone and metoclopramide had less nausea during the first 24 hours post chemotherapy. Aside from this variation, efficacy between antiemetic regimens did not differ significantly.

Gez, Strauss, Vitzheki, Cass, and Edelmann (1992) focused on the nausea experienced by breast cancer patients (N = 20) receiving CMF chemotherapy with methylprednisolone at two different frequencies: (a) A single dose of 125-mg methylprednisolone; and (b) two doses of 125-mg, one 2 hours prior to CMF treatment and the second immediately before the chemotherapy. They found two doses totaling 250-mg of methylprednisolone superior to 125-mg dosing without any increased incidence or severity of other side effects.

Psychological and Psychosocial Variables

Rhodes (1990) has indicated that social support has a positive effect on health status and can mediate the patient's experience of post-therapy nausea and vomiting. According to Rhodes, "social support lessens the effects of psychosocial and physical stress on an individual by increasing his or her coping ability" (p. 894). Studies concerning this association are limited. Picket (1991) examined the relationship of anticipatory nausea and vomiting with symptom distress, mood disturbance, stage of disease, sensitivity to conditioning cues, emetic potential of antineoplastic drugs, age, psychosocial stress, and ability to cope. In part Picket's research was based on Lazarus and Folkman's theory of stress, appraisal and coping. The heterogeneous sample of 60 adults receiving chemotherapy in the outpatient setting reported a 32% incidence of anticipatory nausea with a zero incidence of anticipatory vomiting. The study revealed that those who

developed anticipatory nausea received a drug regimen with higher emetogenic potential, were younger, and had an earlier stage of disease. A high degree of correlation was found between anticipatory nausea and emetogenic potential of drugs, symptom distress, psychosocial stress, ability to cope, and mood disturbance.

Research on the side effect of fatigue has been performed by Blesch et al. (1991). In a convenience sample of breast and lung cancer patients ($N = 77$) receiving chemotherapy and radiation, fatigue was reported by 99% of the participants. Two-thirds of the sample rated fatigue at moderate to severe levels. Biochemical (laboratory data, narcotic use, antiemetic use, and active treatment), physiological (illness stage, treatment history, height, weight, pain, and performance status), and behavioral (social support, marital status, employment, psychological status, and sleep changes) factors were evaluated to determine those impacting the fatigue experience. Biochemical factors showed no correlation with fatigue in the sample as a whole. Evaluation of physiological factors showed a highly significant correlation between fatigue intensity and severity of pain in the sample. The physiological factor of illness duration was correlated with fatigue in breast cancer patients and the biochemical factor of total narcotic use had a close to significant relationship with the fatigue reported by the lung cancer patients. Psychological status measured by the Profile of

Mood States revealed significant correlations between the scores for tension-anxiety, depression-dejection, and fatigue-inertia and fatigue reported in both diagnosis groups. Anger-hostility and confusion-bewilderment scores were positively correlated with fatigue in lung cancer patients while an inverse relationship was noted between fatigue in breast cancer patients and vigor-activity scores.

In a study of cancer patients and caregivers, Taylor, Baird, Malone, and McCorkle (1993) explored the relationship between anger and phase of the cancer trajectory along with the relationships to symptom distress, functional status, physical caregiver response, depression and demographic variables. Findings showed low, stable anger scores in both patients ($N = 52$) and caregivers ($N = 67$). Significant associations between anger and symptom distress, age, depression and church attendance were found. This information suggests that manifestations of anger may occur in different forms including increased distress from symptoms.

Other variables impacting the total symptom experience have been reviewed in the literature. Richardson (1991) suggested that self care measures taken by the patient to meet the demands associated with treatment impact the symptom experience. She identified knowledge, locus of control, self concept, socio-economic status, and social support as correlates of self care practices aimed at symptom control. Richardson further suggested that the

meaning associated with the symptoms influences the willingness to endure symptoms and the number and type of self care measures employed.

In looking at correlates of symptom distress in women with lung cancer, Sarna (1993) reported fatigue, frequent pain and insomnia as the most prevalent and distressing symptoms in the sample ($N = 69$). Other common distressing problems included poor outlook, dyspnea, and appetite disruptions. Higher symptom distress was evident in patients with recurrent disease, concurrent respiratory disease, previous chemotherapy, absence of previous surgical treatment, and low income. Those variables not associated with level of distress were (a) level of education, (b) age, (c) living alone, (d) religion, (e) type of metastasis, (f) time since diagnosis, (g) current radiation therapy, (h) current chemotherapy, (i) site of medical care, and (j) concurrent cardiovascular, or (k) musculoskeletal disease.

In an extensive study, Tishelman, Taube, and Sachs (1991) investigated correlates of symptom distress in a heterogeneous sample ($N = 46$) of cancer patients. The dependent variable of symptom distress was looked at as a total index as well as divided into sub-indexes: (a) Pain; (b) appetite and nausea; (c) functional aspects (bowels, breathing, cough, mobility, and fatigue); (d) psychological aspects (mood, outlook, insomnia); and (e) social aspects (appearance, concentration). Independent variables studied

included demographic, medical/clinical, individual/psychosocial, and views of care provided. Demographic data was collected on age, marital status, and gender. Researchers found significantly higher distress related to nausea and appetite reported by three groups of patients: (a) women patients; (b) unmarried individuals; and (c) younger individuals.

Medical or clinical data included (a) diagnosis group, (b) oncologic treatment with radiation or chemotherapy, (c) comorbidity, (d) number of weeks from notification of cancer diagnosis to cancer registry, (e) disease stage, and (f) death information. A significant positive relationship was found between oncologic treatment and the total symptom distress index as well as the sub-indexes of pain and psychological aspects. Higher levels in the sub-index of pain corresponded to increasing time after diagnosis. Women with breast and gynecological cancers reported less nausea and appetite-related distress. Individuals with the presence of chronic diseases other than cancer had increased distress related to the functional aspects of the illness experience. Disease stage was not shown to be statistically related to reported distress.

The psychosocial variables under study included sense of coherence, social relationships, source of support, and family function. The strongest and most consistent relationship to symptom distress reported in this study was the sense of coherence. Sense of coherence involves an

individual's confidence that (a) internal and external stimuli are structured, predictable, and explicable, (b) the resources are available to meet the demands imposed by these stimuli, and (c) these demands are challenges, worthy of investment and engagement. The measure of sense of coherence showed a significant negative relationship to the total symptom distress index as well as to the psychological and social aspects. Social relationships were evaluated based on the individual's perception of the source of support and the adequacy of that support to nurture and enhance the self worth and to aid in problem solving. Perceived strength in problem solving was related to less distress in functional aspects. Lower feelings of nurturance and support of self worth correlated with increased distress related to appetite and nausea. Higher satisfaction with family function was correlated with more distress concerning functional aspects and less distress attributed to social aspects.

The individual's view of the care provided by the health care system encompassed (a) how many doctors they have seen for treatment, (b) knowledge of which physician is responsible for the treatment of cancer, (c) satisfaction with the information received, (d) the health professional's assessment of individual needs, (e) the satisfaction with the manner in which they were treated by personnel, and (f) the perception that the health care personnel had shown a personal interest in them. A strong positive association

was evident between the lack of personal interest from health care providers and ratings on the pain sub-index. The subjects being seen by a more physicians reported higher total symptom distress.

In further analysis of the available data, Tishelman (1993) revealed few age related differences in symptoms distress in the study population. The study data did show that younger patients reported more distress in the sub-index of appetite and nausea and older patients reported increased distress related to mobility.

Coward (1991) explored the concept of self-transcendence and it's impact on emotional well-being and illness related distress in women with advanced breast disease (N = 107). Self transcendence was defined as an indicator of "becoming as much more as humanly possible within the limitations of a particular life situation" (Coward, 1991, p. 858). The study found that self-transcendence had a direct positive effect on emotional well-being and in this manner had an inverse effect on the illness distress perceived by the study participants.

To provide information about the breast cancer patient at risk of developing severe symptom distress, Ehlke (1988) studied the relationship of symptom distress to disease stage, chemotherapy protocol, health locus of control, social support and perception of illness. Using McCorkle and Young's 13 item symptom distress scale, Ehlke compared scores for 107 outpatients receiving chemotherapy. Data

collection instruments for the independent variables included the Multidimensional Health Locus of Control Scale, the Norbeck Social Support Questionnaire, and a visual analog scale identifying perception of illness. An overall analysis of subject experience revealed that fatigue, insomnia, nausea, and pain were the top four areas of symptom distress in the population studied.

Ehlke (1988) found three significant relationships to symptom distress: (a) Symptom distress scores decreased as the patient's perception of illness became more positive; (b) as chance health locus of control scores increased, symptom distress scores increased; and (c) as internal health locus of control scores increased, symptom distress scores decreased. The correlation between stage of disease and symptom distress approached significance with higher distress scores reported by patients as stage of disease increased. Those independent variables showing no significant correlation with symptom distress scores were aggressiveness of chemotherapy (measured by number, dosage, and incidence and severity of side effects of chemotherapy drugs), powerful others health locus of control, and social support scores.

Limitations identified by the researcher were the convenience sampling method of subject accrual and the lack of control for antiemetic use. In addition, the nebulous quantification of the aggressiveness of chemotherapy resulted in a lack of definitive categories which limited

the interpretation of this variable's relationship to symptom distress scores.

The previous studies have focused on symptom distress from two related viewpoints: (a) cumulative symptom distress scores; and (b) distress ratings for individual side effects associated with chemotherapy treatments. The research revealed that fatigue, nausea, and appetite changes are frequent complaints associated with chemotherapy treatments. Research also reported that patients experience distress and disruption in lifestyle during the treatment period. Based on the research cited, no definite conclusions can be made correlating diagnosis with the symptom distress experience. Information regarding the effect of disease stage on symptom distress showed inconsistent results ranging from no relationship to a positive relationship. Certain studies suggested that treatment regimen has some influence on symptom incidence and the reported distress. Reaching conclusions about symptom distress is complicated by the variety of definitions of distress used in the studies. Two levels of distress can be identified. In some studies, distress has been identified as the discomfort experienced from the symptoms associated with treatment. In this conceptualization, distress is directly related to the symptom experienced. In other studies, the concept of distress has been defined in broader terms encompassing quality of life and disruption in lifestyle. In these

conceptualizations, distress is associated with the changes in the individual's quality of life resulting from the symptoms experienced.

Continued research must be conducted to gain a clearer understanding of the dynamics of symptom distress in patients receiving chemotherapy. Controlling for stage of disease and chemotherapy treatment, this partial replication of the Ehlke (1988) study will explore the relationships between symptom distress and health locus of control, perception of illness, perception of treatment efficacy and social support.

CHAPTER 3

METHODS

Design

The purpose of this study was to describe the relationship between symptom distress and health locus of control, perception of illness, perception of treatment efficacy, and social support. A prospective descriptive correlational design was used. The prospective design involved the examination of the presumed mediating variables (health locus of control, perception of illness, perception of treatment efficacy, and social support) in relationship to the presumed effect or outcome (symptom distress). Knowledge of these relationships lends itself to clinical application and provides the groundwork for further research. Limitations inherent in the descriptive correlational design stem from the lack of control over the independent variables. There was no experimental manipulation of independent variables nor random assignment of subjects to different groups. Relationships can be explored; however, causal inferences can not be made.

Sample and Setting

Subjects for this study were selected from women with stage one breast cancer receiving weekly or day 1/day 8 CMF as adjuvant chemotherapy in the outpatient setting. A convenience sample of 36 women were invited to participate. Thirty-three women consented to participate in the study and completed the data collection. Subjects were completing the second month of treatment in the CMF protocol with no prior exposure to other chemotherapy protocols. In addition, the subjects were 18 years old or older, alert and oriented to person place and time, and able to read and write English.

Subjects were excluded from this study if their treatment history for the current diagnosis included radiation therapy or if they were receiving concomitant radiation therapy.

Instruments

The dependent variable of symptom distress was measured using the Symptom Distress Scale (SDS) developed by McCorkle and Young (1978) (Appendix A). The self-report scale contains 13 items to evaluate common symptoms of concern to patients. The symptoms include: nausea, outlook, appetite, insomnia, pain, fatigue, bowel pattern, concentration, appearance, breathing, and cough. Each symptom is rated on a 5-point Likert-type scale ranging from one (no distress) to five (extensive distress). Descriptive words at each point on the scale serve to operationalize the item and

enhance validity. The 13 items can be summed to provide the total symptom distress ranging from 13 to 65. Higher scores denote greater levels of symptom distress. The SDS has a reported reliability coefficient alpha of .82 in 53 patients receiving chemotherapy or radiation therapy. Internal consistency of the SDS in the current study was $\alpha = .89$.

The intervening variables of health locus of control, social support, perception of illness, and perception of treatment efficacy were measured as follows. Personal control was measured using the Multidimensional Health Locus of Control (MDHLC) scale developed by Wallston, Wallston, and DeVellis (1978) (Appendix B). The MDHLC scale is an 18 item instrument designed to measure beliefs about the source of reinforcement for health related behaviors. Three subscales of personal control beliefs are depicted in the tool: (a) internal (IHLC); (b) powerful others (PHLC); and (c) chance health locus of control (CHLC). The items are measured on a 6-point Likert scale ranging from one (strongly disagree) to six (strongly agree). Each subscale is scored by summing the responses to the items contained in that subscale. Possible scores on each subscale range from 6 to 36. Using two combined forms of the scale on a convenience sample of adults, alpha reliabilities for each subscale were reported: (a) IHLC = .859; (b) PHLC = .830; and (c) CHLC = .841. (Wallston, Wallston, and DeVellis, 1978). The alpha coefficients for this study were

IHLC = .744, PHLC = .565, and CHLC = .539. The low alpha coefficients obtained with this sample population may be explained by the small sample size.

Construct validity of each subscale has been established based on Pearson's R calculations. The IHLC and PHLC subscales are statistically independent ($r = .124$). The IHLC and CHLC are negatively correlated ($r = -.293$, $p < .05$). The external subscales, PHLC and CHLC, are positively correlated ($r = .204$, $p < .05$). These subscale relationships provide evidence that the MDHLC scale does distinguish internal and external control characteristics. Based on Levenson's (1973) internal (I), powerful others (P), and chance (C) locus of control scales, concurrent validity has been reported. Each subscale of the MDHLC scale correlates most highly with its theoretical counterpart of Levenson's scales. Correlations between health status and MCHLC scales help establish initial data on predictive validity. Health status was positively correlated with IHLC ($r = .403$, $p < .001$), and negatively correlated with CHLC ($r = -.275$, $p < .01$). Health status showed no correlation with PHLC ($r = -.055$). (Wallston, Wallston, and DeVellis, 1978)

Perception of social support was measured using the Norbeck Social Support Questionnaire (Norbeck, Lindsey, & Carrieri, 1981) (Appendix C). This instrument is a self report questionnaire measuring three components of social support: (a) total network; (b) total function; and

(c) total loss. The functional properties of social support include (a) affect, the expression of positive feelings of one person to another, (b) affirmation, endorsement of another's behaviors, perceptions, or expressed views, and (c) aid, the giving of symbolic or material aid to another. Respondents are asked to list persons who provide personal support and their relationship to the respondent. Functional aspects of each relationship are evaluated by the respondent using a 5-point Likert rating scale. Finally, information concerning recent losses of important relationships is collected.

Each functional subscale and network property subscale had a high degree of test-retest reliability. The test-retest correlations for these subscales ranged from .85 to .92. High levels of internal consistency have been established based on intercorrelations among all items. Alpha correlations for each subscale were reported: (a) affect = .97; (b) affirmation = .96; (c) aid = .89. (Schaefer, Coyne, & Lazarus, 1981). The alpha coefficients for this study were affect = .97, affirmation = .97, and aid = .96.

Moderate levels of concurrent validity have been established through intercorrelations with the social support questionnaire developed by Coyne and Lazarus (Schaefer, Coyne, & Lazarus, 1981). Initial construct validity was questionable when tested against the Profile of

Mood States and the Sarasen Life Experiences Survey.

(Norbeck, Lindsey, & Carrieri, 1981)

Further testing (Norbeck, Lindsey, & Carrieri, 1983) to establish concurrent validity revealed medium levels of association (range: $r = .35$ to $.41$) between the functional components of NSSQ and the Personal Resource Questionnaire (PRQ) (Brandt & Weinert, 1981). Association was also demonstrated between network properties of NSSQ and PRQ (range: $r = .24$ to $.32$). Construct validity was demonstrated by significant correlations between network property items and functional items of the NSSQ and the Fundamental Interpersonal Relations Orientation (FIRO-B) constructs of need for inclusion (range: $r = .17$ to $.26$) and need for affection (range: $r = .15$ to $.27$). Predictive validity data revealed that aid and duration of relationships have significant interaction effects on the outcome of negative mood and reflects a stress buffering role of social support. (Norbeck, Lindsey, & Carrieri, 1983).

The subject's perception of the illness was measured with a 100 millimeter visual analog scale designed by Ehlke (1988) (Appendix D). Subjects were asked to respond to the question "How stressful has this illness been to you?" by placing an "x" on the scale where it best represents how they feel. Anchors were (a) this is the best thing that has happened to me, and (b) this is the worst thing that has happened to me.

The subject's perception of treatment efficacy was measured using a 100 millimeter visual analog scale (Appendix E). Subjects were asked to respond to the question "How effective are your chemotherapy treatments in fighting your cancer?" by placing an "x" on the scale where it best represents how they feel. Anchors were (a) not effective and (b) extremely effective.

A demographic data form was utilized to obtain descriptive information about the subjects (Appendix F). A chart review form was utilized to obtain information relevant to the chemotherapy protocol the patient is receiving (Appendix G). To assist in tool identification, data collection tools will be color coded to distinguish each form being used.

Procedure

Application was made to the Grand Valley State University Human Research Review Committee for approval. Approval was also obtained from the Research Committee of Holland Community Hospital as well as physicians in the office where subject recruitment occurred. Once approval from the above agencies had been obtained, subject recruitment and data collection proceeded.

Recruitment of subjects occurred in the identified office based outpatient oncology clinic. Identification of subjects who met basic eligibility criteria occurred through chart review by the nursing staff at the identified office.

The researcher then reviewed the patient's chart to confirm that the patient met the subject criteria.

Once eligible subjects had been identified, the researcher made personal contact with each subject on week 7 of treatment to briefly explain the nature of the research and the process for data collection. The subject was given the opportunity to read the consent form (Appendix H) privately, after which the researcher returned to answer any questions. Once consent was obtained, one copy of the signed form was placed in the subject's chart, one copy given to the subject, and the final copy retained by the researcher. The subject was advised to plan 30 minutes in addition to their appointment for week 8 of chemotherapy to complete the Multidimensional Health Locus of Control Scale, the Norbeck Social Support Questionnaire, and the patient perception visual analog scales.

On week 8, the researcher completed the chart review form. The researcher interviewed the subject using the demographic data form. The subject completed the Multidimensional Health Locus of Control Scale, the Norbeck Social Support Questionnaire, and the patient perception visual analog scales. The researcher was available if questions arose related to completion of the tools. The Symptom Distress Scale (SDS) was given to the subject. Based on data collected by Greene, Nail, Fieler, Dudgeon, and Jones (1994) reporting increased side effects 2 days post treatment, subjects were requested to complete the SDS

in the privacy of their home 2 days after week 8 of treatment. An estimated ten minutes was required to complete the SDS. To enhance confidentiality, data collection forms were coded by number and subjects were instructed not to identify themselves on any of the questionnaires completed during the study. An index of subjects with the associated code number was kept in a locked file. Subjects were requested to mail the SDS back to the researcher in a stamped, addressed envelope that was provided. If the SDS was not received by the researcher within 10 days of being given to the subject, a follow-up phone call to the subject was made. Upon receipt of the completed form, the information associating the subject with the code number was destroyed. If requested at the time of informed consent, results of the study were mailed to the subject at the completion of the study.

Table 1

Time Line of Interaction with Subjects

| Time | Activity |
|------------------------------|--|
| Week 7 | Identify subject Obtain consent |
| Week 8 | Complete: Chart review form Demographic data form Health Locus of Control Scale Norbeck Social Support Questionnaire Visual analog scales Provide SDS for completion at home |
| 2 days after week 8 appt | Subject completes SDS and mails back to the researcher |
| 10 days after week 8 appt | Follow-up call if SDS not received by researcher. |

The researcher recognized the potential risk of subject fatigue when completing the questionnaires. To prepare the patient, the time line allowed for the subject to be notified at the time of informed consent of the additional time required for week 8 of treatment. The study design allowed for completion of the SDS in the subject's home which allowed the subject to rest as needed.

CHAPTER 4

DATA ANALYSIS

The intervening variables of personal control, perception of illness, perception of treatment efficacy, and social support are measured at the interval level producing a total score for the components of each variable. The dependent variable of symptom distress is measured at the interval level for the total score. The Pearson correlation coefficient is used to determine the relationship between symptom distress and health locus of control, perception of illness, perception of treatment efficacy, and social support. Relationships were considered to be significant at the 0.05 level. The strategy used to handle missing data was the substitution of the mean value on the variable for those cases with missing values (Polit & Hungler, 1994). All data were analyzed using the SPSS/PC package.

Characteristics of Subjects

Identification of potential subjects for the study was made over a one and one-half year period. The initial criteria for inclusion in the study was weekly CMF only. Due to difficulties with subject accrual, the criteria was extended to include those women receiving day 1/day 8 CMF.

The sample of 33 women ranged in age from 36 to 78 years of age. The mean age was 50.54, with a standard deviation of 10.71. Subjects were predominantly caucasian (97% caucasian, 3% asian) and well-educated. The distribution of the sample by education is shown in Table 2.

Table 2

Distribution of Sample by Education

| Characteristic | Group | |
|---------------------------|-----------|------------|
| | Frequency | Percentage |
| Less than High School | 2 | 6.1 |
| High School | 8 | 24.2 |
| Partial College | 13 | 39.4 |
| College | 3 | 9.1 |
| Beyond 4 years of College | 7 | 21.2 |
| Total | 33 | 100.0 |

A relatively high percentage of subjects reported identification with the Dutch culture. The breakdown of subjects according to cultural identification is shown in Table 3.

Table 3

Distribution of Sample by Ethnicity

| Characteristic | Group | |
|----------------|-----------|------------|
| | Frequency | Percentage |
| Dutch | 13 | 39.4 |
| Southern | 1 | 3.0 |
| Hispanic | 1 | 3.0 |
| Italian | 1 | 3.0 |
| French | 1 | 3.0 |
| Japanese | 1 | 3.0 |
| German | 1 | 3.0 |
| Polish | 1 | 3.0 |
| Irish | 1 | 3.0 |
| None | 12 | 36.4 |
| Total | 33 | 100.0 |

The types of occupations of the women in the sample included professional (21.2%), technical (3.0%), clerical (27.3%), industrial (9.1%), entrepreneur (9.1%), and missionary (3.0%) with 27.1% of the sample reporting no occupation. The range of hours worked per week was zero (42.4%) to forty (24.2%). The mean number of hours worked per week was 18.75, with a standard deviation of 17.90.

A review of past and present significant health problems revealed that 30.3% could identify no health

problems they viewed as significant, 66.7% identified at least one significant health problem, and 6.1% identified three significant health problems. Comorbid conditions identified in the sample included arthritis, congestive heart failure, diabetes, emphysema, hepatitis, migraines, hypertension, graves disease, hypothyroidism, gallbladder disease, and sleep apnea. At least one comorbidity was identified in 48.5% of the sample with a small percentage (6.1%) with three comorbid conditions.

Essentially all of the sample population received surgical intervention prior to chemotherapy treatments. Distribution of sample by surgical intervention is reported in Table 4.

Table 4

Distribution of Sample by Surgical Intervention

| Characteristic | Group | |
|--------------------------------|-----------|------------|
| | Frequency | Percentage |
| Lumpectomy | 16 | 48.5 |
| Modified Mastectomy | 10 | 30.3 |
| Mastectomy with Reconstruction | 7 | 21.2 |
| Total | 33 | 100.0 |

Cumulative drug doses were calculated and reported as follows: (a) cyclophosphamide, range = 3450-mg to 7650-mg, mean = 5096.97-mg, SD = 950.98; (b) methotrexate,

range = 75-mg to 340-mg, mean = 198.15-mg, SD = 63.37;
(c) fluorouracil, range = 2100-mg to 5350-mg,
mean = 4083.63-mg, SD = 657.47. Twenty-three subjects, or
69.7% of the sample, received their treatments on a weekly
basis, while the remaining 10 subjects, or 30.3% received
their treatments on a day 1/day 8 schedule. Antiemetics
were available to 100% of the study population with 87.9%
reporting antiemetic usage at some point in their
chemotherapy treatments. Pain medications were available to
60.6% of the sample with one third reporting usage.

Out of a possible symptom distress score ranging from
13 to 65, the study subjects revealed a mean symptom
distress score of 22.86 with a standard deviation of 7.15.
With higher scores indicating greater symptom distress,
analysis of SDS scores in the sample revealed low to medium
distress associated with the CMF protocol for adjuvant
treatment of breast cancer.

The subjects were administered the Multidimensional
Health Locus of Control Scale (MDHLC) which encompasses
three personal control beliefs: (a) internal (IHLC);
(b) powerful others (PHLC); and (c) chance (CHLC) health
locus of control. The items pertaining to each of the three
subscales of personal control beliefs when summed have a
potential to range from 6 to 36 with higher scores
reflecting a stronger belief in the control of that
particular source of reinforcement for health related
behaviors. The mean scores and the standard deviations for

the MDHLC subscales are shown in Table 5. The sample population showed an overall higher belief that the individual can control or shape the outcome of events and less belief in this control resting in others.

Table 5

Mean Scores of the MDHLC Subscales

| Scale/Subscales | Score | |
|-----------------|----------|-----------|
| | <u>M</u> | <u>SD</u> |
| IHLC | 24.43 | 5.28 |
| CHLC | 16.46 | 4.28 |
| PHLC | 18.00 | 5.01 |

The Norbeck Social Support Questionnaire (NSSQ) includes the subscales of emotional support with a possible range of scores of 0 to 384, and tangible support with a possible range of 0 to 192. Sample responses for tangible support ranged from 34 to 156 with a median score of 64. Sample responses for emotional support ranged from 77 to 358 with a median of 189. The mean scores and standard deviations for the NSSQ and selected subscales are shown in Table 6.

Table 6

Mean Scores of the NSSQ and Subscales

| Scale/Subscales | Score | |
|-------------------|--------|--------|
| | M | SD |
| NSSQ Total | 278.46 | 116.60 |
| Tangible Support | 80.00 | 36.99 |
| Emotional Support | 200.82 | 81.85 |

The sample results concerning perception of illness revealed a mean of 62.09 with a SD of 23.03. Responses ranged from 12 to 100 with a median of 59. Using the median split of the sample to evaluate perception, individuals with scores below the median indicate a more positive view of their illness and those with scores above the median a more negative view of their illness. Perception of treatment efficacy scores reported a mean of 76.57 with a standard deviation of 18.04. The perception of treatment efficacy scores ranged from 35 to 100 with a median of 77.5. Higher perceptions of treatment efficacy are associated with scores above the median with lower perceptions of treatment efficacy revealed in scores below the median.

Study Question

Pearson coefficients were used to answer the study question: Is there a relationship between symptom distress and health locus of control, perception of illness,

perception of treatment efficacy, and social support? The reported coefficients are shown in Table 7. The lack of significant correlations indicates that there is no identifiable relationship between symptom distress and personal control, perception of illness, perception of treatment efficacy, and social support. With no relationship between the variables established, a multiple regression analysis would not add value to the discussion and was therefore deferred.

Table 7

Correlations with Symptom Distress

| Independent Variable | Coefficient | Significance |
|----------------------------------|-------------|--------------|
| IHLC | -.24 | .20 |
| CHLC | .33 | .08 |
| PHLC | .10 | .61 |
| Aid | -.01 | .94 |
| Emotional Support | .08 | .66 |
| Total Support | .12 | .56 |
| Perception of Illness | .21 | .27 |
| Perception of Treatment Efficacy | -.34 | .09 |

Hypotheses

Using T-tests for equality of means to test the study hypotheses confirmed the absence of relationship between the independent variables and symptom distress.

Hypothesis 1: Individuals with higher internal health locus of control scores will have lower symptom distress scores was not supported ($t = .93$; $df = 26$; $p = .36$).

Hypothesis 2: Individuals with more positive perceptions of illness scores will have lower symptom distress scores was not supported ($t = -.88$; $df = 27$; $p = .39$).

Hypothesis 3: Individuals with more positive perceptions of treatment efficacy will have lower symptom distress scores was not supported ($t = 1.98$; $df = 27$; $p = .06$). Although these results approached significance the relationship does not prove to be strong enough to lend predictive value to the hypothesis.

Hypothesis 4: Individuals with higher social support scores will have lower symptom distress scores was not supported ($t = .00$; $df = 21$; $p = .99$).

CHAPTER 5

DISCUSSION AND IMPLICATIONS

Discussion

This study was designed to examine the relationship between symptom distress and health locus of control, perception of illness, perception of treatment efficacy, and social support in breast cancer patients receiving cyclophosphamide, methotrexate, and fluorouracil as adjuvant chemotherapy in the outpatient setting. McCorkle and Young (1978) recognized symptom distress as a subjective experience whose expression is dependent on the individual's perception. In a heterogeneous sample in relationship to chemotherapy regimen and disease stage, Ehlke (1988) was able to document significant relationships between symptom distress and perception of illness, chance health locus of control, and internal health locus of control. Controlling for disease stage and chemotherapy regimen this study attempted to replicate these findings. The findings of this study revealed no statistically significant relationships between symptom distress and health locus of control, perception of illness, perception of treatment efficacy, and social support in the study population.

Although no effort was made to identify the role of cultural tendencies in the response to illness, the cultural influences identified by the study population showed a predominance of dutch associations. This is thought to be reflective of the geographic location from which the sample was collected. While 72.9% of the sample reported an occupational history, few subjects (24.2%) reported maintaining a 40 hour work week during their treatment period with some reporting to the researcher that they were not working at that time due to their illness and treatment. This indicates the need to focus on self care and recovery during the treatment period.

Although direct correlations between symptom distress and comorbid conditions were not the attempt of this study, reported comorbidity was included to provide information about the sample population. Given the report of no comorbid conditions in the majority (51.5%) of the study population, the researcher believes that comorbidity does not confound the symptom distress scores reported by the study participants.

The availability and usage of antiemetics and pain medication allow for the individual to take personal control of the symptoms that can occur with treatment and could impact the amount of distress associated with treatment. It is important to note that usage of antiemetics by 87.9% of the sample during the chemotherapy treatments provides evidence to support the researchers conclusion that the

sample has an overall higher belief that the individual can control or shape the outcome of events.

The study participants reported low to medium distress after treatment with CMF. This may indicate that the CMF protocol is associated with a mild side effect profile. The low distress scores may also be due to a selection bias inherent in the voluntary nature of subject accrual. Two to three eligible subjects declined to participate in the study due to a stated inability to cope with an additional stressor. Results may have been impacted by exclusion of those experiencing more distress.

Reports of illness perception and perception of treatment efficacy may be influenced by a number of factors. Individual's experiences and encounters with other individuals receiving chemotherapy regardless of diagnosis may impact the participants evaluation of their treatment experience. Ratings concerning perception of treatment efficacy could be based on specific information shared by the health care team, the participants recall and belief in the information presented, or a generalized hopefulness inherent in the individual. On a societal level information has been widely disseminated related to cancer, its treatment, potential side effects, and the increasing frequency of positive outcomes.

The findings of this study did not identify a correlation between symptom distress and health locus of control, perception of illness, perception of treatment

efficacy, and social support. The low to medium reports of symptom distress may have made it difficult to make correlations with potential mediating factors.

Limitations of the Study

Although the study is designed to control for threats to validity, there remain three major threats to the generalizability of the study. The performance of the subjects may have been affected by the subject's perception of the researcher's expectations. Recognizing the researcher's interest in the study, subjects may have answered the questions in the manner they thought the researcher expected them to be answered. To reduce this threat the introductory statement by the researcher was brief and simple, avoiding any reference to expected relationships. The small sample size was a limitation to the study. Finally, the generalizability of the study results to a larger target population may also be limited due to the use of a convenience sample from this particular geographical location. Using the CMF protocol as an inclusion criteria way be considered a limitation of the study. As discussed above the mild side effect profile associated with the CMF protocol may have made correlations between variable difficult to establish.

Implications for Nursing Practice

Because the hypotheses of relationships between the independent variables and symptom distress were not supported in the study assumptions can not be made related

to individual experiences. Important information to note is the identification of low to medium symptom distress reported by the subjects receiving CMF regardless of the independent variables identified_in the study. Nursing practitioners can use the mild side effect profile reported as a guide in preparing individuals for the chemotherapy experience. Information and encouragement can be given related to the expected experience with deviations from the expected response addressed on a case by case basis.

Recommendations for Future Research

Although no statistically significant relationship was identified between symptom distress and health locus of control, perception of illness, perception of treatment efficacy, and social support, this does not preclude further investigation of the possible correlation between these variables in other populations. Application of the study design to a larger study population as well as populations receiving different chemotherapy protocols for different cancer diagnoses may prove advantageous. As investigation into the variables influencing symptom distress continues consideration of spirituality as it relates to distress is suggested.

APPENDICES

APPENDIX A

Symptom Distress Scale

ID# _____ DATE _____

(SDS) Each of the following sections lists 5 different statements. Think about what each statement says, then place a circle around the one statement that most closely indicates how you feel 2 days after treatment. Please circle one statement for each section.

1. Appetite

- 1 I have my normal appetite
- 2 My appetite is usually, but not always, pretty good
- 3 I don't really enjoy my food like I used to
- 4 I have to force myself to eat my food
- 5 I cannot stand the thought of food

2. Insomnia

- 1 I sleep as well as I always have
- 2 I have occasional spells of sleeplessness
- 3 I frequently have trouble getting to sleep and staying asleep
- 4 I have difficulty sleeping almost every night
- 5 It is almost impossible for me to get a decent night's sleep

3. Pain (a)

- 1 I almost never have pain
- 2 I have pain once in a while
- 3 I frequently have pain - several times a week
- 4 I am usually in some degree of pain
- 5 I am in some degree of pain almost constantly

4. Pain (b)

- 1 When I do have pain, it is very mild
- 2 When I so have pain, it is mildly distressing
- 3 The pain I do have is usually fairly intense
- 4 The pain I have is usually very intense
- 5 The pain I have is almost unbearable

Please go to next page

5. Fatigue

- 1 I am usually not tired at all
- 2 I am occasionally rather tired
- 3 There are frequently periods when I am quite tired
- 4 I am usually very tired
- 5 Most of the time, I feel exhausted

6. Bowel

- 1 I have my normal bowel pattern
- 2 My bowel pattern occasionally causes me some discomfort
- 3 I frequently have discomfort from my present bowel pattern
- 4 I am usually in discomfort because of my present bowel pattern
- 5 My present bowel pattern has changed drastically from what was normal for me

7. Concentration

- 1 I have my normal ability to concentrate
- 2 I occasionally have trouble concentrating
- 3 I often have trouble concentrating
- 4 I usually have at least some difficulty concentrating
- 5 I just can't seem to concentrate at all

8. Appearance

- 1 My appearance has basically not changed
- 2 My appearance has gotten a little worse
- 3 My appearance is definitely worse than it used to be, but I am not greatly concerned about it
- 4 My appearance is definitely worse than it used to be, and I am concerned about it
- 5 My appearance has changed drastically from what it was

Please go to next page

9. Breathing

- 1 I usually breathe normally
- 2 I occasionally have trouble breathing
- 3 I often have trouble breathing
- 4 I can hardly ever breathe as easily as I want
- 5 I almost always have severe trouble with my breathing

10. Outlook

- 1 I am not fearful or worried
- 2 I am a little worried about things
- 3 I am quite worried, but unafraid
- 4 I am worried and a little frightened about things
- 5 I often have persistent and severe coughing spells

11. Cough

- 1 I seldom cough
- 2 I have an occasional cough
- 3 I often cough
- 4 I often cough, and occasionally have severe coughing spells
- 5 I often have persistent and severe coughing spells

12. Nausea a

- 1 I seldom feel any nausea at all
- 2 I am nauseous once in a while
- 3 I am often nauseous
- 4 I am usually nauseous
- 5 I suffer from nausea almost continually

13. Nausea b

- 1 When I do have nausea, it is very mild
- 2 When I do have nausea, it is mildly distressing
- 3 When I have nausea, I feel pretty sick
- 4 When I have nausea, I feel very sick
- 5 When I have nausea, I am as sick as I could possibly be

APPENDIX B

Multidimensional Health Locus of Control Scale

MHLC Form A

This is a questionnaire designed to determine the way in which different people view certain important health-related issues. Each item is a belief statement with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6). For each item we would like you to circle the number that represents the extent to which you disagree or agree with the statement. The more strongly you agree with a statement then the higher will be the number you circle. The more strongly you disagree with a statement then the lower will be the number you circle. Please make sure that you answer every item and that you circle only one number per item. This is a measure of your personal beliefs; obviously, there are no right or wrong answers.

Please answer these items carefully, but do not spend too much time on any one item. As much as you can, try to respond to each item independently. When making your choice, do not be influenced by your previous choices. It is important that you respond according to your actual beliefs and not according to how you feel you should believe or how you think we want you to believe.

SD = Strongly Disagree
MD = Moderately Disagree
D = Slightly Disagree
A = Slightly Agree
MA = Moderately Agree
SA = Strongly Agree

1. If I get sick, it is my own behavior which determines how soon I get well again.

| <u>SD</u> | <u>MD</u> | <u>D</u> | <u>A</u> | <u>MA</u> | <u>SA</u> |
|-----------|-----------|----------|----------|-----------|-----------|
| 1 | 2 | 3 | 4 | 5 | 6 |

2. No matter what I do, if I am going to get sick, I will get sick.

| <u>SD</u> | <u>MD</u> | <u>D</u> | <u>A</u> | <u>MA</u> | <u>SA</u> |
|-----------|-----------|----------|----------|-----------|-----------|
| 1 | 2 | 3 | 4 | 5 | 6 |

53

3. Having regular contact with my physician is the best way for me to avoid illness.

SD MD D A MA SA

1 2 3 4 5 6

4. Most things that affect my health happen to me by accident.

SD MD D A MA SA

1 2 3 4 5 6

5. Whenever I don't feel well, I should consult a medically trained professional.

SD MD D A MA SA

1 2 3 4 5 6

6. I am in control of my health.

SD MD D A MA SA

1 2 3 4 5 6

7. My family has a lot to do with my becoming sick or staying healthy.

SD MD D A MA SA

1 2 3 4 5 6

8. When I get sick, I am to blame.

SD MD D A MA SA

1 2 3 4 5 6

9. Luck plays a big part in determining how soon I will recover from an illness.

SD MD D A MA SA

1 2 3 4 5 6

10. Health professionals control my health.

SD MD D A MA SA

1 2 3 4 5 6

11. My good health is largely a matter of good fortune.

SD MD D A MA SA

1 2 3 4 5 6

12. The main thing which affects my health is what I myself do.

SD MD D A MA SA

1 2 3 4 5 6

13. If I take care of myself, I can avoid illness.

SD MD D A MA SA

1 2 3 4 5 6

14. When I recover from an illness, it's usually because other people (for example, doctors, Nurses, Family, friends) have been taking good care of me.

SD MD D A MA SA

1 2 3 4 5 6

15. No matter what I do, I'm likely to get sick.

SD MD D A MA SA

1 2 3 4 5 6

16. If it's meant to be, I will stay healthy.

SD MD D A MA SA

1 2 3 4 5 6

17. If I take the right action, I can stay healthy.

SD MD D A MA SA

1 2 3 4 5 6

18. Regarding my health, I can only do what my doctor tells me to do.

SD MD D A MA SA

1 2 3 4 5 6

APPENDIX C

Norbeck Social Support Questionnaire

SOCIAL SUPPORT QUESTIONNAIRE

PLEASE READ ALL DIRECTIONS
ON THIS PAGE BEFORE STARTING.

Please list each significant person in your life on the right. consider all the persons who provide personal support for you or who are important to you.

Use only first names or initials, and then indicate the relationship, as in the following example:

Example:

| | First name or Initials | Relationship |
|----|------------------------|-----------------|
| 1. | <u>Mary T.</u> | <u>Friend</u> |
| 2. | <u>Bob</u> | <u>Brother</u> |
| 3. | <u>M.T.</u> | <u>Mother</u> |
| 4. | <u>Sam</u> | <u>Friend</u> |
| 5. | <u>Mrs. R.</u> | <u>Neighbor</u> |
| | etc. | |

Use the following list to help you think of the people important to you, and list as many people as apply in your case.

- spouse or partner
- family members or relatives
- friends
- work or school associates
- neighbors
- health care providers
- counselor or therapist
- minister/priest/rabbi
- other

You do not have to use all 24 spaces. use as many spaces as you have important persons in your life.

1980 by Jane S. Norbeck, D.N.Sc.
University of California, San Francisco
Revised 1982

PERSONAL NETWORK

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
15. _____
16. _____
17. _____
18. _____
19. _____
20. _____
21. _____
22. _____
23. _____
24. _____

1. _____
2. _____
3. _____
4. _____
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6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
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17. _____
18. _____
19. _____
20. _____
21. _____
22. _____
23. _____
24. _____

WHEN YOU HAVE FINISHED YOUR LIST, PLEASE TURN TO PAGE 2.

For each person you listed, please answer the following questions by writing in the number that applies.

- 1 = not at all
- 2 = a little
- 3 = moderately
- 4 = quite a bit
- 5 = a great deal

Question 1:

Question 2:

How much does this person make you feel liked or loved?

How much does this person make you feel respected or admired?

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
15. _____
16. _____
17. _____
18. _____
19. _____
20. _____
21. _____
22. _____
23. _____
24. _____

1. _____
2. _____
3. _____
4. _____
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8. _____
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11. _____
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15. _____
16. _____
17. _____
18. _____
19. _____
20. _____
21. _____
22. _____
23. _____
24. _____

GO ON TO NEXT PAGE

- 1 = not at all
- 2 = a little
- 3 = moderately
- 4 = quite a bit
- 5 = a great deal

Question 3:

How much can you confide
in this person?

- 1. _____
- 2. _____
- 3. _____
- 4. _____
- 5. _____
- 6. _____
- 7. _____
- 8. _____
- 9. _____
- 10. _____
- 11. _____
- 12. _____
- 13. _____
- 14. _____
- 15. _____
- 16. _____
- 17. _____
- 18. _____
- 19. _____
- 20. _____
- 21. _____
- 22. _____
- 23. _____
- 24. _____

Question 4:

How much does this person
agree with or support your
actions or thoughts?

- 1. _____
- 2. _____
- 3. _____
- 4. _____
- 5. _____
- 6. _____
- 7. _____
- 8. _____
- 9. _____
- 10. _____
- 11. _____
- 12. _____
- 13. _____
- 14. _____
- 15. _____
- 16. _____
- 17. _____
- 18. _____
- 19. _____
- 20. _____
- 21. _____
- 22. _____
- 23. _____
- 24. _____

GO ON TO NEXT PAGE

- 1 = not at all
- 2 = a little
- 3 = moderately
- 4 = quite a bit
- 5 = a great deal

Question 5:

If you needed to borrow \$10, a ride to the doctor, or some other immediate help, how much could this person usually help?

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
15. _____
16. _____
17. _____
18. _____
19. _____
20. _____
21. _____
22. _____
23. _____
24. _____

Question 6:

If you were confined to bed for several weeks, how much could this person help you?

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
15. _____
16. _____
17. _____
18. _____
19. _____
20. _____
21. _____
22. _____
23. _____
24. _____

GO ON TO NEXT PAGE

Question 7:

How long have you known this person?

- 1 = less than 6 months
- 2 = 6 to 12 months
- 3 = 1 to 2 years
- 4 = 2 to 5 years
- 5 = more that 5 years

- 1. _____
- 2. _____
- 3. _____
- 4. _____
- 5. _____
- 6. _____
- 7. _____
- 8. _____
- 9. _____
- 10. _____
- 11. _____
- 12. _____
- 13. _____
- 14. _____
- 15. _____
- 16. _____
- 17. _____
- 18. _____
- 19. _____
- 20. _____
- 21. _____
- 22. _____
- 23. _____
- 24. _____

Question 8:

How frequently do you usually have contact with this person? (Phone calls, visits, or letters)

- 5 = daily
- 4 = weekly
- 3 = monthly
- 2 = a few times a year
- 1 = once a year or less

- 1. _____
- 2. _____
- 3. _____
- 4. _____
- 5. _____
- 6. _____
- 7. _____
- 8. _____
- 9. _____
- 10. _____
- 11. _____
- 12. _____
- 13. _____
- 14. _____
- 15. _____
- 16. _____
- 17. _____
- 18. _____
- 19. _____
- 20. _____
- 21. _____
- 22. _____
- 23. _____
- 24. _____

PLEASE BE SURE YOU HAVE RATED EACH PERSON
ON EVERY QUESTION. GO ON TO THE LAST PAGE.

9. During the past year, have you lost any important relationships due to moving, a job change, divorce or separation, death, or some other reason?

_____ 0. No
_____ 1. Yes

IF YES:

- 9a. Please indicate the number of persons from each category who are no longer available to you.

_____ spouse or partner
_____ family members or relatives
_____ friends
_____ work or school associates
_____ neighbors
_____ health care providers
_____ counselor or therapist
_____ minister/priest/rabbi
_____ other (specify) _____

- 9b. Overall, how much of your support was provided by these people who are no longer available to you?

_____ 0. none at all
_____ 1. a little
_____ 2. a moderate amount
_____ 3. quite a bit
_____ 4. a great deal

APPENDIX D

Perception of Illness

How stressful has this illness been to you?
(Put an X somewhere on the line below).

This is
the best
thing
that has
happened
to me.

This is
the
worst
thing
that has
happened
to me.

APPENDIX E

Perception of Treatment Efficacy

How effective are your chemotherapy treatments
in fighting your cancer?
(Put an X somewhere on the line below).

Not Effective _____ Extremely Effective

APPENDIX F

Demographic Data

1. Age: _____ years (to the nearest year)
2. Race:
 - 1 _____ Caucasian
 - 2 _____ Black
 - 3 _____ Hispanic
 - 4 _____ Asian
 - 5 _____ Native American
 - 6 _____ Other (please identify) _____
4. Highest level of education completed:
 - 1 _____ Less than high school
 - 2 _____ High school
 - 3 _____ Partial college education (3 years or less)
 - 4 _____ College education (4 years)
 - 5 _____ Beyond 4 years of college
5. Which ethnic group do you identify with?

6. Occupation: _____
7. Hours of work outside the home: _____ hrs/week
8. What health problems, past or present, have you experienced that you consider significant?

APPENDIX G

Chart Review Form

1. Chemotherapy Treatment--starting with initial doses as indicated and titrated weekly to achieve white blood count between 2.5 - 3.0 and platelet count above 100.

| Drug | Dosage | |
|------------------------|---------|------------|
| | Initial | Cumulative |
| Cyclophosphamide | _____ | _____ |
| po, (100mg continuous) | | |
| Methotrexate | _____ | _____ |
| IV, (20 - 25mg) | | |
| Fluorouracil | _____ | _____ |
| IV, (500mg) | | |

(Attach copy of dosing schedule with weekly counts)

2. Surgical intervention prior to chemotherapy

- 1____lumpectomy
- 2____simple mastectomy
- 3____modified mastectomy
- 4____radical mastectomy
- 5____unknown

3. Antiemetics for home use (chart review with patient confirmation)

What is the highest number of doses used to control
nausea in one day? _____

During what week of treatment did this occur? _____

4. Pain medications for home use (chart review with patient
confirmation)

What is the highest number of doses used to control
pain in one day? _____

During what week of treatment did this occur? _____

5. Comorbidity

- | | |
|--------------------------------------|-----------------------------------|
| 1____anemia | 2____arthritis |
| 3____alcohol/drug abuse | 4____asthma |
| 5____bronchitis | 6____cancer |
| 7____CHF | 8____COPD |
| 9____cirrhosis of liver | 10____chronic fatigue syndrome |
| 11____diabetes | 12____emphysema |
| 13____fibromyalgia | 14____GI bleeding |
| 15____heart disease | 16____hepatitis |
| 17____infectious disease | 18____kidney disease |
| 19____MI | 20____migraines |
| 21____psychiatric disorder | |
| 22____peripheral vascular disease | 23____seizures |
| 24____stroke | 25____ulcer |
| ____other _____ | |

APPENDIX H

Consent to Participate in Study

I am aware that this is a study of how people view certain important issues related to their health. I also understand that this study will examine how I feel just after I receive my chemotherapy treatment. I understand that the knowledge gained is expected to help nurses and physicians provide health care in a manner which will be responsive to the needs of patients receiving chemotherapy.

I also understand that:

1. participation in this study will involve a brief interview that will be conducted at my eight week appointment for chemotherapy. Participation will also include five paper and pencil questionnaires to be completed. The first and second forms will deal with my feelings about my illness and treatment. The third questionnaire will deal with the support systems which are available to me. The forth questionnaire will deal with how I view certain issues related to my health. The fifth questionnaire will deal with general information about how I feel after my chemotherapy. Four questionnaires will be given to me for completion at the time of my appointment. One questionnaire will be given to me so that I can complete it in my home.
2. there are no anticipated physical or emotional risks as a result of participation in this study.
3. completion of the questionnaires may increase feelings such as anxiety or depression
4. the information I provide will be kept strictly confidential and the data will be coded so that identification of individual participants will not be possible.
5. a summary of the results will be made available to me upon my request.

I acknowledge that:

In giving my consent, I understand that my participation in this study is voluntary and that I may withdraw at any time without affecting the care I receive from my physicians or the staff.

I understand I will receive no payment for my participation.

The investigator, Denise Bakker, has my permission to review my chart regarding my chemotherapy drugs and dosage.

I authorize the investigator to release the information obtained in this study to scientific literature. I understand that I will not be identified by name.

I have been given an opportunity to ask questions regarding this research study, and that these questions have been answered to my satisfaction.

I acknowledge that I have read and understand the above information and that I agree to participate in this study.

Denise Bakker
Principle Investigator
(616) 394-3371

Dr. Howard Stein
Chairman, Human Subjects
Review Committee
Grand Valley State
University
(616) 895-2476

Witness

(Participant Signature)

Date

(Date)

_____ I am interested in receiving a summary of the study results.

Consent to Participate in Study

I am aware that this is a study of how people view certain important issues related to their health. I also understand that this study will examine how I feel just after I receive my chemotherapy treatment. I understand that the knowledge gained is expected to help nurses and physicians provide health care in a manner which will be responsive to the needs of patients receiving chemotherapy.

I also understand that:

1. participation in this study will involve a brief interview that will be conducted on day eight of my second course of chemotherapy. Participation will also include five paper and pencil questionnaires to be completed. The first and second forms will deal with my feelings about my illness and treatment. The third questionnaire will deal with the support systems which are available to me. The forth questionnaire will deal with how I view certain issues related to my health. The fifth questionnaire will deal with general information about how I feel after my chemotherapy. Four questionnaires will be given to me for completion at the time of my appointment. One questionnaire will be given to me so that I can complete it in my home.
2. there are no anticipated physical or emotional risks as a result of participation in this study.
3. completion of the questionnaires may increase feelings such as anxiety or depression
4. the information I provide will be kept strictly confidential and the data will be coded so that identification of individual participants will not be possible.
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Denise Bakker
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(616) 394-3371

Dr. Howard Stein
Chairman, Human Subjects
Review Committee
Grand Valley State
University
(616) 895-2476

Witness

(Participant Signature)

Date

(Date)

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