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Barbarba Collier

Mississippi University for Women

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PERCEIVED NEEDS OF WOMEN WITH BREAST CANCER FROM DIAGNOSIS TO TREATMENT

by

BARBARA COLLIER

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Perceived Needs of Women with Breast Cancer from Diagnosis to Treatment

by

Barbara Collier

Lorraine Hamm
Instructor in Nursing
Director of Thesis

Bonnie Lockard
Professor of Nursing
Member of Committee

Linda Sullivan
Associate Professor of Nursing
Member of Committee

Director of the Graduate School

Abstract

Needs of women with breast cancer from the time they were given the diagnosis until treatment has received little attention by researchers. The purpose of this study was to identify the needs of women after they had been diagnosed with breast cancer and until treatment began. The theoretical framework underlying the study was based on Travelbee's human to human relationship model. A retrospective univariate descriptive study was done. The Collier Needs Assessment Survey identified needs experienced by the participants related to disease, family, and emotional/psychosocial. Data were collected from 25 women in rural North Mississippi who had been diagnosed with breast cancer within the past 2 years. Perceived needs of women from the time of diagnosis until treatment were described. The variables of age, length of time between diagnosis and treatment, and the length of time since treatment were correlated with needs regarding disease, family and emotional/psychosocial. Findings demonstrated that during the stage between breast cancer diagnosis and treatment, one of the major needs of women was to have their lives continue as normally as possible. The importance of a health care provider who demonstrated concern and respected the ability of the patient to participate in the decision regarding treatment emerged as the most important need. These findings underscore the need for health care providers to be cognizant of the needs experienced by women during the time between diagnosis and treatment for breast cancer. Also, findings from this study indicated that older women with breast cancer had different needs from younger women. Implications for nursing which emerged from this study include the need to be empathetic, concerned, and to allow the patient to participate in decision regarding treatment. Further research is recommended to determine if similar findings will occur with samples of younger women.

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In a devotional book given to me this year, Frederick Buechner writes about trust. He expresses righteousness as a "sense of being right with God." I thank God for the faith to trust "the deep down rightness" of the life He has created for me.

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Chapter I

The Research Problem

When a woman learns that she has breast cancer, she immediately begins to experience overwhelming psychological and physical challenges (Hilton, 1993). Shock, trauma, fear, anger, and sadness are only a few of the common emotions that eventually lead to acceptance and an ability to cope with the diagnosis (Loveys & Klaich, 1991). The most stressful time for a breast cancer patient, as well as her spouse, is the period between diagnosis and treatment (Derdiarian, 1989). This period varies with each patient and can range from a few days to a few months. Research conducted by Weisman and Wordern (1986) found that anxiety and psychosocial needs were at their highest at the time of the initial diagnosis of cancer. The time span may vary between the diagnosis and treatment, and so may the patient's need for information and psychological and spiritual support to help her cope with her illness. Little is known about the needs of women immediately after diagnosis, yet it is during this critical period of time that the woman must deal emotionally with the diagnosis and make decisions regarding her treatment.

Establishment of the Research Problem

Research conducted by Northouse, Jeffs, Cracchiolo-Caraway, Lampman, and Dorris (1995) explored the emotional distress of women and husbands prior to breast biopsy and identified influences which contribute to their levels of distress. The researchers concluded that women who had less support, lower marital satisfaction, poorer family functioning, and more concurrent stress did have more distress prior to biopsy. The husband's distress was lower than that of the wife, because husbands viewed the biopsy as a diagnostic procedure while the women anticipated the diagnosis of cancer. While the Northouse et al. (1995) study identified influences on the degree of distress experienced by women prior to biopsy, the needs of women before biopsy or from the time of a breast cancer diagnosis until treatment were not identified.

In a 1989 study, Derdiarian found that individuals in stressful situations seek information as a way to cope. The researcher specifically identified informational needs of patients recently diagnosed with cancer and suggested that lack of information can adversely affect their acceptance and ability to cope with the disease. The researchers found that one way the health care provider could assist patients to cope more effectively with a life-threatening disease was to provide each patient with formal, individualized information about his illness. The study identified four areas of information most needed by these patients: information about the disease itself, personal adaptations to it, effects on the family, and the social implications of having cancer (Derdiarian, 1989).

The Derdiarian (1989) research focused only on the informational needs of patients with cancer. It is not known whether the results would have been the same if the sample had been only women with breast cancer. However, the importance of identifying and meeting the informational needs as a way to assist cancer patients to cope with their disease was demonstrated. Still a dearth of empirical data remains regarding the kinds of needs women with breast cancer may have that are outside the realm of data and factual information.

Edgar, Rosberger, and Nowlis (1992) found that initially breast cancer patients have higher levels of stress than patients with other kinds of cancer. Those researchers believed that stress could be significantly lowered by supportive interactions, and quality of life improved if the intensity of the stress could be relieved early in the disease process.

In a study done in Finland by Suominen (1992), patients consistently reported that they did not receive sufficient information regarding economic support, different operation options, and internal prothesis. The patients did not feel that they had received adequate emotional support from health care providers. Perhaps that was because the providers were not sufficiently aware of the patients needs. Meeting the educational and psychological needs of women with breast cancer will continue to be within the scope of nursing. Nurse Practitioners in primary care settings are in a unique position to provide informational and psychological support, to reduce distress, and to enable effective decision making. For planning and intervention to be effective the perceived needs during that stressful time must be identified; therefore, the purpose of this study was to identify the needs of women from the time of diagnosis with breast cancer until initiation of treatment.

Significance to Nursing

No empirical studies were found that identified the needs of women with breast cancer from the time of diagnosis until initiation of treatment.

Knowing the needs of women who have been diagnosed with breast cancer is essential to nursing science in the realms of nursing practice, nursing education, nursing research and nursing theory. After a diagnosis of breast cancer has been made, the patient's concerns or problems are different in some respect from every other woman who has been diagnosed with breast cancer. Therefore, nurse clinicians should encourage the patient to verbalize or express her particular needs (Lovey, et al., 1991). A family nurse practitioner needs information about the needs of patients during during this particular time in the illness process. One can work in the primary care setting to understand the unique needs of women with breast cancer.

The identification of a patient's needs will enable the nurse practitioner to provide information and support in the areas most needed. A high degree of distress is common at the time of diagnosis and initial support is beneficial for reducing or alleviating this stress (Edgar, et al., 1992). Identification of the needs of patients, their peers, spouses, and medical personnel may well be an essential role for the nurse practitioner who may, in fact, be one of the first people to talk with a woman during or after the time that the devastating diagnosis is given.

A study conducted by Hilton (1993) stressed the responsibility of nurses and health care professionals to assess the impact that cancer has on patients and also their families. The period during diagnosis is especially difficult when information, counseling, and referrals must be assessed, and interventions planned. Perhaps the best place for nurses to begin to learn the skills necessary to determine the needs of women with breast cancer and to plan appropriate interventions is in nursing school. Therefore nurse educators at the baccalaureate and master's level should begin to better prepare students to provide appropriate needs assessments for women with recently diagnosed breast cancer.

The nurse practitioner's focus on family nursing is extremely important when dealing with breast cancer, because this disease affects not only the patient but the entire family. Nurses in advanced practice are in a position to utilize the information provided by women with breast cancer concerning needs and expectations to answer other women's questions about the breast cancer experience. This may best be achieved through empirical study and appropriate documentation of women's needs during the crucial time between breast cancer diagnosis and treatment. Therefore, the purpose of this descriptive study was to determine the perceived needs of patients with breast cancer from the time of diagnosis until initiation of treatment.

Theoretical Framework

This research was guided by Joyce Travelbee's (1971) "Human to Human Relationship" theory of nursing. This theory was chosen as the framework for this study because concepts of caring, nursing care, and needs identification are congruent with this researcher's philosophy. "The more knowledgeable and skillful a nurse was in the area of interpersonal relationships the more likely he or she would be able to meet the nursing needs of others" (Travelbee, 1971, p.1).

Travelbee's theory was based on her reading and her nursing experience. Travelbee believed that nursing needed "a humanistic revolution"(p.355). Nursing should be focused on the caring for and caring about ill persons. One of the theorist's assumptions was that illness included spiritual as well as emotional and physical components (Marriner-Tomey, 1994).

Travelbee (1971) assigned three main functions to the nurse. The functions were to use specialized knowledge to assist others in preventing illness, to help others regain health, or to guide clients toward finding meaning in illness. For the nurse to be truly effective, Travelbee believed that the nurse must be caring and sympathetic. She defined sympathy as understanding the distress of another and having the desire to alleviate the distress. Understanding of distress was accomplished by determining the needs as perceived by the person in distress.

Determining the needs of women with breast cancer is a primary concern of the nurse practitioner. Meeting patients' needs is a way to assist these individuals to cope with illness and reduce the stress of illness. Because of the uniqueness of each patient, the nurse must never assume that she knows the needs or feelings of a patient without validating them with the patient. "The task of the nurse is clear; it is to break the bond of categorization in order to perceive the human being in the 'patient'" (Travelbee, 1971, p. 131). The first step in this process was to determine what the perceived needs are. Because the concepts of Travelbee's (1971) model was focused on sensitivity to needs, it is most appropriate that the research be based on her framework.

Research Question

One research question guided the study. The question was: What are the perceived needs of women with breast cancer from the time of diagnosis of breast cancer until initiation of treatment?

Defination of Terms

For the purpose of this research, the following terms were defined:

Needs: Self-reported needs of women recovering from breast cancer, reflecting on the time between diagnosis and until treatment had begun. Operationally, needs will be the responses of the research participants on the Collier Needs Assessment Survey (CNAS).

Women: Females ages 30 and older who were oriented to time, place, person, and situation, and who had a history of breast cancer which was diagnosed within the last 2 years.

Breast Cancer: Self-reported history of breast cancer within 2 years.

Diagnosis: A pathological determination based on structural lesions present.

Treatment: Surgery, chemotherapy, radiation or any medical regimen that has as its goal the treatment of breast cancer.

Time of Diagnosis: The moment the patient was informed of her diagnosis of breast cancer.

Assumptions:

The assumptions of this study were:

1. Women who are diagnosed with breast cancer have special needs.

2. Needs change over the life span.

3. Interpersonal relationships are essential for identification of needs, and the relationships are built between the nurse and patient by the communication process (Travelbee, 1971).

4. Perceived needs can be accurately measured.

Chapter II

Review of the Literature

A review of the literature was conducted to establish the status of current research relevant to the needs of women diagnosed with breast cancer. The review revealed that a diagnosis of breast cancer was stressful for the patient and her family, and this stress began during the diagnostic process. Research has been done to determine factors which influence one's ability to adapt or cope with the diagnosis of cancer (e.g., Hilton, 1993; Stanton & Snider, 1993; Edgar, 1992). Studies were conducted which identified needs of patients who were recently diagnosed but were limited to informational needs and included all types of cancer (e.g., Derdiarian, 1987, 1989). In this chapter, literature relevant to the needs of women with breast cancer from the time of diagnosis until treatment was reviewed.

Previous Research

Northouse, Jeffs, Cracchiolo-Caraway, Lampman, and Dorris (1995) researched the emotional distress of women and husbands prior to breast biopsy and identified factors related to their levels of distress. Two hypotheses guided the study: (1) women and their partners who had less support, lower marital satisfaction, poorer family functioning and more hopelessness, more concurrent stress, and more uncertainty would have more stress prior to biopsy. (2) distress levels of husbands would be positively related to distress levels of their wives. Six independent variables were identified: social support, marital satisfaction, family functioning, hopelessness, concurrent stress, and uncertainty. The researchers developed a model to predict women and their partners who were at high risk for distress.

Northouse et al.,(1995) utilized a non-experimental, prospective, longitudinal design. The sample was secured from several large surgical clinics. Women were informed about the study by the surgeon's office staff when the biopsy was scheduled. The sample included 300 women and 265 husbands. Women selected were either married or living with a male partner, had no previous history of cancer, and were scheduled for a biopsy. Wives and husbands were interviewed separately in their homes approximately 1 week prior to biopsy.

Six questionnaires were used: the Social Support Questionnaire (SSQ), Spancier Dyadic Adjustment Scale (SDAS), Family Apgar, Beck

Hopelessness Scale (HS), Michel Uncertainty in Illness Scale (MUIS), and Brief Symptoms Inventory (BSI). The SSQ provided an indication of personal support. The SDAS measured marital satisfaction. Family Apgar was used to measure family functioning, and HS measured hopelessness. The MUSI was modified to measure only those items that measured uncertainty before diagnosic procedures, and the BSI measured emotional distress (Northouse et al., 1995).

The researchers determined the levels of support, marital satisfaction, and family functioning as well as higher levels of hopelessness, concurrent stress, and uncertainty as related to the amount of stress experienced by the wives and their husbands. The overall distress level for women was .57 (SD = .43, range 0 to 2.13), which was significantly above the mean of .30 that was reported for a normal nonpatient population. Scores were two times higher on the BSI and three times higher on the anxiety scale; thus hypothesis number one was supported. The second hypothesis was not supported as the amounts of distress experienced by husbands and wives were not significantly related. An additional finding suggested that the more stressors that were present in both the wives' and husbands' lives the more vulnerable both partners were to stress associated with a biopsy.

A strong relationship was found among the variables of hopelessness, uncertainty, and family functioning. Because husbands did not usually discuss the biopsy with co-workers or friends, the family functioning test was a better indicator of their level of distress than was social support (Northouse et al., 1995).

The researchers concluded that breast biopsies were more stressful to women than to their husbands because the husbands viewed a biopsy as a diagnostic procedure while the wives anticipated the diagnosis of cancer. Although the study did not attempt to identify the needs of women with breast cancer it does provide support for this research by validating that breast biopsies are stressful and that women already anticipate the diagnosis of cancer. Knowing the factors that place women at risk for high levels of stress was important. However, identification of the needs of women immediately after diagnosis is an area that needs further research.

Another study that examined recently diagnosed cancer patients' ability to adjust and cope with their illness was conducted by Edgar, et al. (1992). The researchers' stated hypothesis was higher ego strengths would positively affect the patients' ability to adjust and cope with the diagnosis of cancer. Independent variables were the timing of the psychosocial interventions, ego strengths of patients, and the type and stage of the cancer. Dependent variables were depression, anxiety, intrusion, and personal control. There was no hypothesis regarding the time of the psychosocial intervention.

The design of the study was an experimental comparison. The sample consisted of 205 patients at least 18 years old who had been diagnosed with cancer. The patients were randomized in two groups. The early intervention (EI) group received psychosocial interventions at a mean of 10.8 weeks after diagnosis, and the late intervention (LI) group received the psychosocial intervention at a mean of 28.2 weeks after diagnosis.

Nurses were utilized to conduct interviews and have questionnaires completed at baseline, 4, 8, and 12 months for both groups. Edgar et al. (1992) developed a plan of intervention that incorporated strategies to increase knowledge, personal control, and coping. The intervention sessions were conducted by a nurse in a one to one encounter with the patient during five 1 hour meetings.

Several instruments were used to measure the dependent variables. Anxiety was evaluated using the Lewis, Dirsich, and Parsell Anxiety Scale. The Impact Scale-Intrusion Subscale measured the patient's perceived amount of stress related to the diagnosis. The Center for Epidemiologic Studies-Depression Scale (CES-D) evaluated depression. The Cronbach's alpha demonstrated internal validity and consistency. The researchers modified Cantril's Ladder to rate the patients' perception of personal control. The Ego Strength Scale, Physical Health Rating, and Demographic and Disease tools evaluated the independent variables and covariates. Chi-square statistics demonstrated no differences between EI (n = 103) and LI (n = 102) in demographics and illness variables. The scores from the dependent variables were analyzed with the multivariate analysis of variance (MANOVAs). A separate analysis of the four dependent variables at the four testing times resulted in data that at baseline suggested a high degree of correlation between anxiety and depression, physical health and mood, and an inverse relationship between ego strength and the four dependent variables (Edgar et al., 1992).

The results of the MANOVA at baseline, 4, 8, and 12 months demonstrated that the time of the intervention resulted in significant differences between the groups. Early intervention did not prove to have any effect on dependent variables; however, late intervention reduced distress in every area. The LI group realized lower distress levels earlier in the year than did the EI group. At baseline or at 4 months, there was no statistical difference in the four dependent variables ($p = 0.146$). At 8 months there was significant difference in the two groups. The LI group scores were lower on depression, anxiety, intrusion scales, and higher on control. The only difference in the groups at the 12 month test was the intrusion scale ($F[1,117] = 4.34$, $p< 0.039$). This suggested that LI participants' thoughts regarding the cancer had less interference on their lives at 12 months.

The effect of diagnostic category or ego strength on the results was explored by dividing patients' breast cancer and all other sites. The results of this analysis demonstrated no difference in patients with diagnosis of breast cancer in early intervention or late intervention groups. Both experienced an initial decrease in distress and then leveled. The other cancer group scores indicated that late intervention was more effective at decreasing distress than early intervention. The only exception was that at 8 to 12 months, both disease categories in the late intervention group demonstrated a significantly greater reduction in intrusive thoughts than the early intervention. The group was analyzed in regard to high and low ego strength. The mean baseline score of the high ego strength and the early intervention group on the CES-D was 9.52 (SD = 6.71), and the mean low ego strength and the early intervention group score was 22.02 (SD = 10.30). At 12 months this group's scores were 8.72 (SD = 7.82) and 13.12 (SD = 9.44) which indicated a significant change for the low ego strength group. This indicated that patients with high ego strength experienced a lower level of depression after diagnosis than those patients with low ego strength. The patients with low ego strength experienced a greater level of distress and needed interventions more than high ego strength patients (Edgar et al., 1992).

The late intervention had a significant impact on overall distress during the year. The researchers found that the early intervention had little effect at 4 months. Edgar et al. (1992) theorized that the initial diagnosis was overwhelming, and it may prevent the patient from benefiting from a coping-skills training approach in the first few months. Patients with good ego strength would cope more effectively than those with poor ego strength. Based on the results of this study, the researchers concluded that patients whose physical health is poor should be evaluated for cognitive behavioral intervention. The time of the intervention with breast cancer patients was not a factor in reducing stress, and these patients improved on all variables over time. Edgar et al. (1992) concluded that patients who coped well may have received support that was not related to the intervention, which explains the decrease in distress. While the study implied that early interventions were not particularly effective, no assessment of the perceived needs of women with breast cancer immediately after diagnosis was done. The proposed study is an attempt to fill that gap in the empirical data by asking women to reflect on the needs they had during the time between breast cancer diagnosis and the initiation of treatment.

Roberts, Cox, Reintgen, Baile, and Gibertini (1994) conducted research for the purpose of determining if the physician's communication style and behavior, during the interview when a diagnosis of breast cancer was given, affected the patient's psychological adjustment to the diagnosis or influenced her ability to make decisions regarding treatment. The problem, as stated by Roberts et al. (1994) was:

> the patient must deal simultaneously with a potentially life-threatening diagnosis and the loss or altered appearance of a valued body part. In addition the physician must educate an emotionally overwhelmed patient about her disease and available treatments so she can participate in making decisions about her care. (p. 336)

The researchers hypothesized that patients whose physicians utilized techniques such as listening, expressing empathy, providing information, and reassurance would experience less psychological distress, and have a better adjustment to the diagnosis.

The sample consisted of 100 women between the ages of 29 and 82 years (mean age, 55.0) who had been newly diagnosed with breast cancer. Twenty-five were selected from each of two of the researchers' practices and 50 patients were selected from other physicians' practices. The time lapse after treatment averaged 5.7 months. Sixty-four percent had mastectomy and 36% had lumpectomy and radiation.

The researchers designed a questionnaire, the Cancer Diagnostic Interview Scale (CDIS), to assess the patient's perceptions of her surgeon's behavior during the interview when she was given the diagnosis of breast cancer and the treatment options available to her. The areas of physician behaviors of providing information about the cancer, using interpersonal skill such as empathy, listening, positive regard, and instilling hope were evaluated utilizing Likert items. Internal consistency was demonstrated by the Cronbach's alpha; the reliability coefficient for the CDIS was 0.92 (Roberts et al., 1994).

The SCL-90-R, a standardized instrument designed to assess the psychological symptomatic distress of medical patients, was administered. The instrument was designed to assess stress in nine dimensions and was comprised of a 90-item self report symptom inventory. Other variables that affected patient adjustment to the diagnosis of breast cancer were identified from previous research as premorbid psychologic adjustment, physical health status, and social support. These variables were measured, and multiple regression analysis was used to examine the effects and magnitude of those effects of the independent variables (cancer diagnostic interview, social support, health status, premorbid life stressors, and premorbid psychiatric history) on the dependent variable of psychologic adjustment.

Physician behavior during the cancer diagnostic interview was rated high with a mean of 76.8 with a possible score of 90. Statistical analysis using multiple regression demonstrated that the cancer diagnostic interview accounted for 20% (R2 = .210) of the variance in the dependent variable; psychological adjustment, and premorbid life stressors accounted for 25% (R2 = .249) of the variance in psychological adjustment. There was no demonstrated correlation between social support and psychological adjustment. The researchers concluded that health care providers should not assume that patients with supportive families will make a good adjustment nor that the absence of social support will indicate a poor adjustment. However, there was a correlation between psychiatric history, premorbid life stressors, and cancer diagnostic interview on psychological adjustment. The findings supported the hypothesis that physicians who use psychotherapeutic techniques can have a significantly positive influence on a patient's psychologic well being.

Roberts et al. (1994) recommended that surgeons or health care providers should: (a) have a prearranged appointment after the biopsy with the patient and suggest that a spouse or significant person accompany them for the interview; (b) allow sufficient time for the patient to absorb the news before giving medical information and explanations; (c) provide information about the cancer and treatment options; (d) the surgeon should listen to the patient to understand her concerns and fears and; (e) allow the patient to be involved in the treatment decisions.

The fact that findings in this study varied indicated that there are variations in patient preferences and reinforced the need for health care providers to listen and attend to patients as individuals. Some patients were angry with the physicians who attempted to rush their decision while others preferred the surgeon to make the decision for them (Roberts et al., 1994). The beneficial effect of using therapeutic communication skills when informing patients about their diagnosis was evident; however, there was no attempt in this study to identify the perceived needs of these patients.

In a study focused on needs of patients immediately after being diagnosed with cancer, Derdiarian (1989) researched the effect of structured information on spouses and patients. The hypothesis that guided the study was that patients and spouses who were given formalized individual information, referral, and follow-up would cope more effectively than the patients who did not receive the intervention. The independent variables identified were informal counseling and follow-up.

The theoretical framwork utilized by Derdiarian (1987) was based on Lazarus's theory that patients and spouses needed information to cope with the stress of illness. More specifically, information was needed in the following areas: "disease, personal, family, and social" (p. 286); information in these areas assisted the patients and spouses to realize the signficance and implication of the disease and increased their ability to cope.

Derdiarian's (1989) study utilized an experimental design. The sample was chosen from a cancer clinic in the United States and consisted of 60 male patients ages 25 to 55 and their spouses. All male participants had been diagnosed with cancer within seven to 10 days. Once the sample was chosen, randomization was used to determine a control or experimental group. Neither group was aware that there was a comparison group.

Two sets of instruments were used to assess needs in the four areas and measure outcomes. The first set was the Patient-Informational Needs Assessment and Spouse-Informational Needs Assessment. The second set was the Patient-Satisfaction and the Spouse-Satisfaction instruments.

Randomization was accomplished by numbering packets in consecutive order and as patients presented to the clinic they were given the next packet. The odd numbers were in the control group and the even numbers were in the experimental group. Research assistants were utilized to administer the DINA and Satisfaction instruments to both groups.

The control group was given informal, routine information. Referrals and additional information were given if requested. The experimental group received individualized formal information, counseling, and referral. A variety of literature pertinent to the participant's informational needs was provided. Names and telephone numbers of resource individuals were provided. The experimental group participants were encouraged to call if they had questions or needed additional information. In addition, the research assistants made one or two follow-up calls to determine the adequacy of the information. The second set of instruments was administered 5 to 10 days after the first contact. One-way analysis of variance (ANOVA) and Pearson chi-square statistical test were employed to analyze the data (Derdiarian, 1989).

The experimental group demonstrated a statistically significant decrease ($p = .001$) in the DINA scores the second time it was administered.

In the control group there was no difference in the scores on the DINA from time 1 to time 2 (p = 0.26). The conclusion drawn from the study was that formal individualized information provided a broader information base, increased satisfaction and perhaps coping in cancer patients. Another conclusion was that individuals in stressful situations seek information as a way to cope, and spouses have the same need for information as patients.

Results of the Derdiarian study indicated the importance of providing individualized information to individuals and families experiencing the diagnosis of cancer. The study focused on verbal and written information needed by patients to cope and make appropriate decisions but did not explore the emotional/psychological needs of this group of patients. The study does support the current research in identification of patients percieved needs in the areas of disease, family, and emotional/psychosocial. In a study of breast cancer patients Suominen (1992) attempted to determine how patients felt about their ability to participate in their treatment, what support or guidance they received at the time of their care, and what expectations they had regarding support and guidance at the time of their care.

The study population was composed of 600 women who had had breast cancer in the previous 3 years. From this population 140 women were chosen by random sample. Of the 140 women, 78% responded to surgical treatment for breast cancer. Of the 140 women, 78% responded to the questionnaire. The ages ranged from 32 to 78 years. Twelve percent of the sample had had reoccurance of cancer.

The questionnaire was designed to explore the three major issues which were stated as the purpose of the study. The questionnaire was of a 5-point Likert Scale with open-ended questions and checklist responses. The data were analyzed using percentage distribution, correlations, cross-tabulations, and log-linear models. The p values of the models chosen were between 0.2 and 0.8.

Suominen (1992) reported that even though 72% of the patients were physically and mentally capable of participating in their care, only 30% were given the opportunity to be involved in their care. Seventy-eight percent felt that the nursing staff ignored their families and did not provide sufficient support. Patients believed that their mental attitude improved when they were asked for their permission to have different examinations.

Surprise and emotional shock were the initial feelings described by patients as their initial reaction to being given the diagnosis of breast cancer. The patients reported that they did not receive sufficient information regarding economic support, different operation options, and internal prosthesis. In response to the question of whether persons in the health care system provided support for patients before they had an operation their answer was "they do not" (p. 70). The patients responded that support was inadequate in the hospital, and most of the support received by the patients was from persons other than nurses and doctors.

Prior to treatment patients expected that they would receive information, a quick operation, and emotional support. They wanted to know more about the disease, the operation itself, and what to expect during and after hospitalization. They expected information about coping with disease, prosthesis, nutrition, and information provided by the Cancer Association; however, most of the expectations were directed to the doctor. After hospitalization women expected to receive mental rehabilitation, encouragement, and social support from health care workers, relatives, and friends (Suominen, 1992).

According to the findings of the study, shock was the most common reaction to the diagnosis. Patients received little information even though the need for information and support was high throughout treatment. The women were willing to participate in their care but were not allowed to do so in the health care system. In exceptional instances the patients were asked to give permission before treatments were done and in those cases the patients felt more comfortable with the treatments (Suominen, 1992). The goal of this current study was to obtain new information from breast cancer patients for the development of care from the view point of their need.

Dudgeon, Raubertas, Doerner, O'Connor, & Rosenthal (1995) conducted research that attempted to determine and compare the needs of cancer patients with first recurrence of disease and patients who had a second recurrence or progression of disease. The researchers attempted to identify both the physical and psychosocial needs of each group of patients.

Patients eligible for participation in the Dudgeon et al. (1995) study had both a proven cancer and laboratory, radiological, or physical signs of progression of the cancer. The first group had disease that reoccurred after receiving curative surgery or radiation therapy. The second group had disease progression or a second recurrence after noncurative treatment. Seventy-five patients were selected from each group. Each patient was given a questionnaire which consisted of 72-item self-assessment questionnaire that had been adapted from previous studies. The questionnaire was given after the appointment when they were told that they had a reoccurrence or progression of disease.

The age distribution of the two groups was compared using the Mann-Whitney. Fisher's exact test was used to compare sex, household composition, and previous treatment. The marital status, diagnosis, and biggest concern were compared using the exact text for 2 x C tables. The chi-square tests and t-tests were used to compare the self-assessment scores.

Seventy percent of the subjects were women, and forty percent of the patients had breast cancer. There were no statistical differences between the groups in age, gender, marital status or household composition. The progressive group had more patients with cancer of the breast, colon, and lymphoma and fewer with lung cancer than the first recurrence group.

Types of treatment for both groups were similar. The progressive group had more symptom-related problems than did the first recurrence group ($P < 0.05$). Pain and weakness were more common in the progressive group ($p = 0.032$ and $p = 0.042$), although pain and weakness were frequent complaints of both groups. In patients' self-assessment of psychological state, no evidence of difference between groups ($p > 0.10$) was noted in levels of depression, personality change, fearfulness, and nervousness. Patients in the progression group complained more often that there was "no one to talk to" ($p = 0.02$), "no one who understood" ($p = 0.001$), and that " they were treated differently" ($p = 0.04$). Patients in this group expressed more spiritual and marital concerns ($p = 0.055$) than patients in the first recurrent group. Another finding was that patients who were told of first recurrence experienced more shock ($p = 0.029$) and less loneliness (p = 0.013) than patients told of progression of their disease. Their major concerns in both groups were essentially the same. They identified "being a burden" and "family" as the two biggest concerns. "Pain," "suffering," and "dying" were listed less frequently.

Dudgeon et al. (1995) utilized the results of their research to examine whether the results of this survey supported the new paradigm of palliative treatment. Previously palliative care referred to the last 3 to 6 months of life when the patient was considered terminal and efforts were not aimed at curing the disease process but relieving symptoms. The shift of treatment paradigms has been in the direction of considering palliative treatment throughout the course of the illness and not merely during terminal phase. The researchers assumed that patients who were experiencing a progression of disease would have more needs and greater distress than those with first recurrence, and also hypothesized that the progressive group would have more distress because of the terminal stage of disease and death.

The Dudgeon, et al. (1995) research did demonstrate that the progressive group experienced greater physical needs than the recurrent group. The most prominent physical symptoms were pain, inability to sleep, and weakness. However, there were no differences in the expressed psychological problems in each group. Anxiety and psychosocial problems were highest among newly diagnosed and terminal patients and less in the intervening period.

The researchers concluded that if only physical symptoms and functional status were considered, then the previous paradigm would be correct. However, if palliative care encompassed both psychosocial and spiritual elements then palliative care should be included throughout the course of the disease.

The Dudgeon et al. (1995) study compared and identified needs of cancer patients at the time of first recurrence and after the disease had progressed, and included patients with all types of cancer. However, 40% of the patients had breast cancer which was the single largest cancer diagnosis. This study supported the need to identify the perceived needs of breast cancer patients from the time of diagnosis until treatment.

Conclusion

The review of the literature confirms that stress is higher initially in women who are diagnosed with breast cancer (Dudgeon et al., 1995). Women experience stress prior to breast biopsy because they anticipate the outcome (Northouse et al., 1995). Immediately after diagnosis, information is needed to assist patients to cope and to make decisions regarding their care (Roberts et al., 1994). Other needs that patients have are emotional and psychological. None of the studies attempted to identify both informational needs and emotional needs immediately after a diagnosis of breast cancer and until treatment has begun. Therefore, the need for the proposed study, the identification of needs of women from time of diagnosis to initiation of treatment, is substantiated. There is a dearth of literature in the nursing and social sciences regarding a comprehensive determination of women's needs during that critical time frame.

Chapter III

The Method

The purpose of this study was to determine the percieved needs of women from the time they are given the diagnosis of breast cancer until treatment. This chapter will include the research design and procedures which were utilized for the collection of data.

Design of the Study

A descriptive research design was chosen to describe the needs. A retrospective approach was utilized because it allowed participants to reflect on what their needs were at the particular time between diagnosis of breast cancer and treatment. Patient reports were considered to be valid because clinical observations revealed that most patients could recall exactly when, where, and how they were told they had cancer (Roberts, et al., 1994). The descriptive design allows the researcher to describe the variables without implying relationships or causal effects (Polit & Hungler 1995).

Setting, Population, and Sample

The setting of the study was North Mississippi a rural area approximately 65 miles south of Memphis, Tennessee. There was a 150 bed

Medical Center located in the town where the population received treatment. Located 50 miles away was the largest hospital in the state and the largest rural hospital in the country. All needed treatment could be performed at the local hospital with the exception of radiation following lumpectomy. The women had to travel to either Memphis, Tennnessee or to Tupelo, Mississippi for the course of radiation. For some elderly patients this was a barrier in their choice of treatment.

The population was women who had been diagnosed with breast cancer. A non-random sample of 28 women who received a screening or diagnostic mammogram at an Obstetrical and Gynecological Clinic in Oxford, MS, was utilized. The women were given their diagnosis of breast cancer at the physician's office following either a sterotactic large core needle biopsy or an open biopsy. The open biopsies were performed by a surgeron after being referred by the Gynecologists for either a lump or abnormal mammogram. Twenty-eight participants were included in the study. This sample size was chosen assuming a large effect size in the population r = .50, alpha = .05, two-tailed test, and power = .80 (Cohen, 1988). Three participant's surveys were excluded because of excessive missing data leaving n = 25. The criteria for participant selection was women older than 30 years of age, who had been diagnosed with breast cancer within the past

2 years and were experiencing their first diagnosis of cancer.

Method of Data Collection

Procedures. The method of data collection for this cross-sectional descriptive study was self administered questionnaires with three questions that were designed to elicit other needs not identified. Approval was obtained from the MUW committee on Use of Human Subjects in Experimentation (see Appendix A) and the Obstetrical and Gynecological Clinic (see Appendix B). Prospective participants were contacted by the researcher by phone. The nature and purpose of the research was explained. The participants were assured of confidentiality and that their care would not be affected by their decision. Verbal permission was obtained to mail each participant a cover letter (see Appendix C), a questionnaire (see Appendix D), a participant agreement (see Appendix E), and a demographic data sheet (see Appendix F). A self-addressed stamped envelope was included for return of the questionnaire. The return envelopes were coded to permit follow-up of nonrespondents. After 2 weeks those participants who had not returned their questionnaires and signed informed concents were contacted once by the researcher, by means of a reminder telephone call.

Instrumentation. The Collier Needs Assessment Survey (CNAS) (see Appendix D) was utilized as the primary research instrument. The instrument was a researcher developed tool based on information in popular literature about needs identified by women who have had breast cancer.

It was submitted to a panel of experts for recommendations and revisions. Internal consistency measurements for the needs assessment scales was calculated using Cronbachs alpha coefficient. Alpha for the Disease Related Needs scale was .8592. Alpha for the Family Related Needs scale was .4354. Alpha for the Emotional/Psychological Related Needs scale was .6537. Alpha for all three scales combined was .8575.

Validity was addressed by correlating measurements from the DINA needs assessment scales with measurements from the needs assessment scales used in this study. The disease related measurements correlated, $r = .2297$, $p = .269$. The family related needs measurements correlated, $r = .3029$, $p = .141$.

Test re-test reliability measurements were planned to be collected as part of this study. However, because the questionnaire was psychologically stressful for the participants to complete, retest measurements were not collected in order to protect the participants from further stress.

Methods of Data Analysis

The purpose of the study was to identify the needs of women with a diagnosis of breast cancer from the time they were given the diagnosis until treatment. Descriptive statistics were utilized to examine the demographic characteristics of the sample. Those were measures of central tendency, frequency distribution, and variability. Quantitative analysis was guided by the research question for the study. Additional data were obtained by correlating the three subscales of the three categories of the CNAS which were Disease Related Needs, Family Related Needs, and Emotional/Psychological Needs with the variables of age at time of diagnosis, length of time between diagnosis and beginning of treatment, and length of time between diagnosis and time of completing questionnaire utilizing Pearson R (alpha = .05), two tailed test.

The questions related to other needs not previously identified or how the health care provider could have been more sensitive to their needs were analyzed and like statements or comments grouped into similar categories. They were then qualitatively analyzed and results were presented in written form.

Chapter IV

The Findings

The purpose of this study was to identify the perceived needs of women with breast cancer from the time of diagnosis until treatment. A retrospective descriptive study was conducted among women in rural north Mississippi who had been given the diagnosis of breast cancer within the past two years. The research sample was composed of 25 women. Data from the study were obtained by completion of The Collier Needs Assessment Survey (CNAS) which included four parts: (a) the demographic data sheet; (b) questions regarding needs relating to disease, family, and emotional/psychological issues; (c) three opened ended questions designed for identification of further needs; and (d) scale to rate the importance of information related to breast cancer and the importance of the health care provider discussing the impact of disease on the family.

The data collected and analyzed for this study are presented in this chapter. Characteristics of the participants are described first, followed by identification of perceived needs, and additional findings.

Characteristics of the Participants

The sample for this study was comprised of 25 women who had been diagnosed with breast cancer within the past two years. The participants ranged in age from 30 to 81 years old. Additional demographic characteristics of the participants are presented in Table 1.

The type of treatment received by the participants in this study varied. Nine participants had a simple mastectomy, ten participants had a modified radical mastectomy, and six participants underwent a lumpectomy followed by radiation therapy.

Results of Data Analysis

The purpose of this research study was to determine the perceived needs of women with breast cancer from the time of diagnosis until treatment. The Collier Needs Assessment Survey and solicition of other needs not identified on the survey served to elucidate the needs of breast cancer patients from the time of diagnosis until treatment. The responses to the survey in the areas dealing with Disease Related Needs, Family Needs, and Emotional/Psychological Needs are presented in this chapter as positively stated needs. Each item on the CNAS are listed in Tables 2, 3, and 4. The items from all the needs listed on the CNAS which received the the highest average rating by all participants were: (a) I needed my life

Table 1

Participants Demographic Information

Variable	M	SD
Age	59.28	14.30
Children	2.24	1.88
Education Level	13.92	3.26
Number of Days Between Diagnosis and treatment	20.38	16.84
Number of Months since Treatment	13.48	9.68

Table 2

Responses to Items on the Collier Needs Assessment Survey-Disease Related Need

Need	Responses	
	F	%
More information about test results	14	56
Health care provider to answer questions	20	80
Health care provider to be available for questions	19	76
Information regarding treatment choices	21	84
Health care provider to tell me what treatment to have	18	72
Control over the decision regarding treatment	20	80
Time for second opinion	11	44
Encouragement to have a second or third opinion	14	56
Follow-up appointment to discuss information given at time of diagnosis	12	48
More information than was given about the disease	12	48
More information about the prognosis	13	52
Detailed information about what to expect during treatment	15	60
Written information about the disease	16	64
Information on breast reconstruction	12	48

(table continues)

Need	Responses	
	F	%
More information on breast reconstruction than was given	11	44
Time to talk with additional health professionals regarding treatment options	10	40
Health professionals to respect my concerns	21	84
Health care provider to respect my ability to make my own decision	22	88
Health care provider to respect my intelligence	23	92

Table 3

Responses to Items on the Collier Needs Assessment Survey-Family Related Needs

Need	Responses N	%
Help in telling my spouse or partner that I had cancer	7	28
Help in telling my children about my diagnosis of cancer	7	28
Help in telling my parents about my diagnosis of breast cancer	12	48
Health Care provider to tell my family that I had breast cancer	8	32
Openly discuss my diagnosis with my family	18	72
Spouse/partner to talk with me about treatment choices	17	68
To be able to express my fears to my spouse/ partner	16	64
Reassurance from spouse/partner regarding changed body image	13	52
Make my decision regarding treatment without help from my family	11	44

Table 4

Responses to Items on the Collier Needs Assessment Survey-Emotional/ Psychological Related Needs

Needs	Responses F	%
Reassurance from someone who had a similar experience with breast cancer	21	84
Close friend to talk with to express my fears and reservations	19	76
Talk with friends	8	32
Talk with someone who had coped successfully with breast cancer	19	76
Someone with me when I was given the results of the biopsy	14	56
Time by myself after being given the diagnosis	15	60
Friends to treat me the same	20	80
Talk with my pastor/priest/ or religious leader	8	32
Someone to encourage me to express my feelings about my breast	16	64
Express anger	9	36
Others to realize the significance of my disease	14	56
Time for developing a personal coping strategy for dealing with altered or loss of breast	15	60

(table continues)

Needs	Responses	
	F	%
Time for psychological adjustment to recommended treatment	16	64
My life to continue as normally as possible up to the time of treatment	24	96
Health care provider to seem concerned	23	92

to continue as normally as possible up to the time of treatment, (b) I needed my health care provider to seem concerned, and (c) I needed my health care provider to respect my intelligence.

The CNAS contained three questions that allowed for additional needs or comments. The first question was, "From the time of diagnosis until treatment, what other needs did you have which were not identified in the survey?"

Only three participants described needs not previously covered. The needs were: (a) a 70 year old wrote that she needed assistance in planning care for her husband while she was hospitalized, (b) a 42 year old stated that she should have had additional diagnostic test, such as a CAT Scan and Bone Scan to determine if there was metastasis prior to treatment, and (c) another stated that she needed an immediate support system. The other comments reemphasized needs that were listed in the survey. One participant stated that there were other needs but the Reach to Recovery Volunteers had assisted her and she could continue with her life and be a productive person. Four participants expressed needs related to post-operative care. The interval between diagnosis and treatment was so short for one participant that she did not have time to experience any of these emotions. A 73 year old stated that she was in denial for three weeks, and found it difficult to believe that she had cancer because she was experiencing no symptoms. Another need that one participant verbalized was that she and her family needed as much verbal and written information as was available to assist her to make a decision regarding treatment. A 53 year old woman stated that she felt rushed by her surgeon. She needed to get additional information but the surgeon wanted her to have surgery the next day. Raw data responses to the open ended question 1 may be found in the appendix (see Appendix G).

The second open ended question was, "How could your health care provider have been more sensitive to your needs?" Nineteen of the participants responded positively regarding the care and concern they experienced from their health care providers. The participants described their health care providers with the following adjectives: great, kind, understanding, best, caring, wonderful, excellent, sensitive, helpful, concerned, and pleased. Three of the participants responded with negative comments. They responded that their health care provider (a) was insensitive about the need for time to decide about treatment, (b) should have done additional diagnostic tests prior to treatment, and (c) should not have given her the diagnosis on the phone. Raw data for all the responses to question 2 may be found in the appendix (see Appendix H).

The third open ended item requested that the participants include other comments regarding their breast cancer experience. Fifteen participants responded with a comment. Some of the most pertinent comments are as follows: "Lucky it was detected early," "Thankful that the only treatment was surgery," "Blessed," "Leading a normal life and taking a pill daily as chemotherapy," and "Experience not bad because I had a caring doctor and loving husband."

There were other comments that indicated needs which were not mentioned in responses to Question 1. One woman stated that, "lack of some members of my family acceptance of my disease made it more difficult." Another stated "This diagnosis changes your life completely and the future is uncertain... I will never be the same again." Additionally she stated, "A part of me is dead and gone... it is easier to die with cancer than to live with cancer."

Two other participants stated that their religion and belief in God gave them peace and reassurance. Fear of follow-up treatment was expressed by one individual. One participant, who now serves as the co-coordinator of Reach to Recovery, said that she prayed that her volunteer work can give someone else the hope and positive outlook that she received from a Reach to Recovery volunteer.

A lack of knowledge about current treatment and cure of breast cancer was expressed by one participant. She states "my biggest fear was death... I have a 15 year old daughter...only thing I knew was that people died with cancer." Raw data for the opened ended question 3 can be found in the appendix (see Appendix I).

Additional Findings

Each participant was asked to rate the importance of their need for information from their health care provider in areas of diagnosis, children, treatment, and prognosis. The number of participants that indicated that information was extremely important with a score of 90 or above is illustrated in Table 5.

Table 5

Importance of Participants Need for Information from Health Care Provider

Disease Concern:	F	%
1. Diagnosis	19	90
2. Children	6	43
3. Treatment	19	90
4. Prognosis	19	90

The participants also were asked to indicate the importance of having their health care provider discuss with them the impact of their illness on their family. The number of participants who indicated that this was an extremely important need with a score of 90 or above is in Table 6.

Table 6

Importance of Need for Health Care Provider to Discuss Impact of Disease on Family

Family Concerns:	F	%
1. Spouse	11	65
2. Children	6	35
3. Siblings	8	47
4. Parents	6	46

When responses were evaluated according to age groups, the most highly rated needs assessment items changed. For women age 30 to 45 years old, the items that received the highest average ratings were: (a) I needed to have some control over the decision regarding treatment, (b) I needed my health care provider to respect my concerns, (c) I needed my health care provider to respect my ability to make my decisions, and (b) I needed my health care provider to answer my questions. For women age 46 to 60 years the most important needs were (a) the reassurance from someone who had a similar experience with breast cancer, (b) I needed my life to continue as normally as possible up to the time of treatment, (c) I needed my health care provider to be available for questions, and (d) I needed information regarding treatment choices. For women age 60 to 81 years, the items that received the highest average ratings were: (a) I needed my life to continue as normally as possible up to the time of treatment, (b) I needed my health care provider to seem concerned, (c) I needed my health care provider to respect my intelligence.

Person Product Moment was used to test for relationships between age and each of the three needs related scales a significant negative correlation emerged between age and Disease Related Needs, $\underline{r} = -.56$, $\underline{p} = .003$. The older a participant was, the lower were her disease related needs. Another marginally significant correlation was between age and Emotional/ Psychological Related Needs, $\underline{r} = 0.39$, $\underline{p} = .056$. This pattern demonstrated that with increased age, Emotional/Psychological Needs decrease.

An analysis correlating length of time between diagnosis and treatment with the three needs related scales revealed a significant negative correlation with Emotional/Psychological Related Needs, $\underline{r} = .-55$, $p =.01$. A correlational analysis correlating length of time since treatment with the three needs related scales demonstrated that the longer it had been since treatment, the less the participants had disease related needs, r = .-47, p = .031.

An analysis of variance (ANOVA) was conducted to compare the three treatment groups (simple mastectomy, modified radical mastectomy, and lumpectomy with radiation) on the three needs related scales. However, no significant differences between the treatment groups were found.

Summary

The results of data analysis have been described. The characteristics of the population were given, and a description of patient's needs was presented. Correlational statistics were used to determine if there was a relationship between the patient's age, length of time between diagnosis and treatment, and length of time since treatment and needs related to disease, family, and emotional/psychological.

In Chapter V, a summary and discussion of the findings are presented. The implications for nursing and recommendations are addressed.

Chapter V

The Outcomes

Women from young adulthood to frail elders are developing breast cancer. The National Cancer institute estimated that there would be 183,000 new cases of breast cancer in 1995 (Richards, 1995). The needs of women who are diagnosed with breast cancer are varied and to some extend unique; however, the results of this study revealed that women in different age groups shared similar concerns. Breast cancer victims not only have concerns regarding their health and prognosis but are concerned about how the diagnosis will impact their families.

This chapter includes an interpretation of the findings of the study. The conclusions, implications, and recommendations that emerged from the findings also are presented.

Summary of the Findings

The purpose of this study was to determine the perceived needs of women with breast cancer from the time of diagnosis until treatment. Joyce Travelbee's Human to Human Relationship theory of nursing was used to guide this retrospective descriptive study.

The sample consisted of 25 women who had been diagnosed with breast cancer. The participants ranged in age from 30 to 81 years with a mean age of 59.28. The average number of days between diagnosis and treatment was 20.38, and the average number of months since treatment was 13.48. The treatments experienced by the women were as follows: (a) nine had a simple mastectomy, (b) ten had modified radical mastectomy, and (c) six had a lumpectomy followed by radiation.

The Collier Needs Assessment Survey was a self administered questionnaire used to collect the data. The three highest ranking needs identified by the participants were: (a) I needed my life to continue as normally as possible up to the time of treatment, (b) I needed my health care provider to seem concerned, and (c) I need my health care provider to respect my intelligence. Only the overall top ranking need and the top ranking needs by age groups will be discussed.

Discussion

Data from this study revealed the highest ranked need among participants was for their lives to continue as normally as possible until breast cancer treatment was begun. However, when needs were correlated with age groups it was ascertained that the highest ranked needs for all participants were the same as for the age group of 60 to 81. This is explained by the fact that the mean age of the participants = 58.28. The review of the literature concerning needs of women who have been diagnosed with breast cancer from the time of diagnosis until treatment revealed no research to identify or describe the needs of older women with breast cancer. This researcher asserts that a possible reason for women wanting their lives to continue as normally as possible could be denial. A 73 year old participant stated, " I went through a period of denial. It was so hard to believe I had reached the age of 73-had no symptoms... It took me about three weeks to accept it." Kumasaka et al. (1993) found that denial is used by some patients as a means of coping. However, based on responses from this study this researcher believed that the majority of participants received the information regarding diagnosis and treatment options and made decisions regarding treatment based on the information given during that initial interview or shortly thereafter. Kumaska et al. (1993) reported that the impact of a breast cancer diagnosis was such that it caused "a degree of disintegration of mind, body and spirit." Therefore, once the decision was made as to the treatment, continuing with normal activities and routines was a mechanism that assisted them to cope with the disease. This speculation was further supported by Travelbee's (1971) theory of nursing which addresses needs identification for the purpose of assisting individuals to cope with illness and find meaning in the experience.

The second highest rated need the participants identified was for the health care provider to seem concerned. The caring attitude of the physician was perceived by women as more important than any information which was provided. Surprisingly the need for a physician who was concerned was a more highly rated need than the need for information regarding disease, or treatment. Again this finding also was more strongly reflected among the needs of women ages 60 to 81. This finding was consistent with a study by Roberts et al. (1994) which concluded that support from spouse, family, and friends may be less influential than perceived support from physicians during the early stages of diagnosis and treatment. The importance of a caring physician was expressed by a 72 year participant. She said, "my doctor was great-patient-kind (sic), and understanding. My surgery was not bad at all. I had a caring doctor and a loving husband."

The need which ranked third highest among the respondents was the need for the health care provider to respect their intelligence. Having a physician who respected the ability of a woman with a breast cancer diagnosis to receive and process information regarding disease, and to participate in the decision regarding which type of treatment was best for her was vitally important. Eighty-eight percent of the respondents wanted their health care provider to respect their ability to make their own personal decision about treatment. Such decision making allowed the woman who had breast cancer to have some control over her situation, thus improving the ability to cope with the disease. Findings by Hilton (1993) supported the need to be informed and to actively participate in the decision regarding treatment. Roberts' et al. (1993) results not only demonstrated the need for physicians to allow patients to participate in the decision making process but concluded that the physician's interaction influences psychological symptoms of depression and anxiety.

When the needs of women in the 30 to 45 year old group, who comprised 20% of the sample population, were extrapolated; the four highest ranked needs were disease related. Two of the needs concerned making the decision regarding treatment options. First and foremost the women needed some control over what treatment they would have, and secondly they needed the health care provider to respect their ability to make the decision regarding treatment. This researcher suggests one reason for these issues being more important for the 30 to 45 age group is that the participants in this study were most often married and had children. Because younger womens' families are dependent upon them not only for mothering, but often as a provider of income also, the main focus of these women was on surviving. One 32 year old expressed her feeling this way: "My biggest fear was that I would die! I had a 15 year old daughter and the only thing I knew about cancer was that a lot of people would die with it."

Women who are faced with the diagnosis of cancer often feel that they have very little control over the disease. They expected information about the disease, prognosis and treatment options such as mastectomy or lumpectomy and then needed their health care provider to allow them to make decisions based on the information given. The finding supported the Deridieran (1989) study in which adults 35-55 years of age needed more information about disease, family, and social concerns than did individuals in the 56-70 year age group.

Another important need, ranking 4th, among women in the 30-45 age group, was to have a health care provider who would answer questions and respect their concerns. Women who want to have control over decisions and who seek information by asking questions are attempting to cope with the disease. Having health care providers who are empathetic would be helpful in assisting patients to cope with the illness.

Seeking information was a primary mechanism through which individuals coped with new and stressful situations (Derdiarian, 1989). Roberts et al. (1993) emphasized the need for physicians to understand the concerns and fears of patients with breast cancer. Suominen's (1992) study supports the findings of this research concerning expectations of patients to receive information and support early in the disease process.

The highest ranked needs among the middle group of participants ages 46-60 were needs in common with both the younger (30 to 45) and older (60 to 81) groups. Like the participants in the 30 to 45 age group, this middle-aged group also needed their health care provider to be available to answer their questions and provide information regarding treatment options. The results of good physician/patient communication was best illustrated by a comment made by a 56 year old participant who stated:

> When he told me my problem, I accepted it as a matter of fact. When he explained my options, I asked him if it was his wife, what would he recommend. He told me and explained why... the only time I shed a tear was when Dr.[name omitted]... patted me on the hand and said, "be strong." It was his tenderness and thoughtfulness that made me cry.

The middle agers also had the same need as the participants ages 60 to 81 for their lives to continue as normally as possible up to the time of treatment.

The unique need expressed by the middle age group was their need for reassurance from someone who had a similar experience with breast cancer. This researcher believed one possible explanation for this finding was the need to have concerns and feelings understood. Often that kind of understanding is impossible for anyone who has not had the same experience. One participant stated, "I feel that through my Reach to RecoveryVolunteer, ... I was made to feel that I could continue with my life and be a productive person." Dudgeon (1995), in a needs assessment involving patients with recurrent disease, found that patients with progressive disease also had a need for someone to talk to and someone who understood. Communicating with someone who has survived the same disease provided encouragement to begin treatment and to realize that others do survive (Kumasaka et al., 1993).

The findings of this study support the researcher's assumption that needs will vary depending on the stage of life an individual is in when faced with the diagnosis of breast cancer. The findings further indicated that the older an individual was at the time of diagnosis of breast cancer the less were her needs related to disease and emotional/psychological support. Most previous research concerning the needs of women with breast cancer (Suominen, 1991) did not investigate needs in relation to age. However, Derdiarian (1987) found that adults 36-55 years of age had more informational needs than the older adults.

Data analysis correlating the length of time between diagnosis and treatment with the three needs related categories (Disease, Family, and Emotional/Psychological) demonstrated that longer waiting periods between diagnosis and treatment are associated with decreased emotional/ psychological related needs. Caution must be exercised when interpreting this finding because the decrease in emotional/psycholoigcal needs may not be related to the length of time between diagnosis and treatment, but may have resulted because of the time that has elapsed since treatment (Edgar et al., 1992).

The length of time since treatment was correlated with the perceived needs related to disease, family, and emotional/psychological. The results illustrated that the longer the time since treatment the less the perceived needs were related to diagnosis. This is congruent with the past research of Derdiarian, (1989) and Edgar (1992) who found that emotional distress and informational needs related to disease lessen with time. This researcher surmised that the reason for this finding in the current study was the impact of the diagnosis of breast cancer was greatest immediately after the diagnosis and was lessened by time.

This researcher expected to find that the more radical the treatment needed or chosen the greater the participant's need would be in the three needs categories. However, analysis of variance (ANOVA) demonstrated no significant differences between the treatment group. This finding was congruent with research published by Edgar et al. (1992), who found that "less invasive or disfiguring treatments, such as lumpectomy, do not necessarily lessen the level of distress experienced by patients" (p. 817). One possible reason for the finding is that the initial choice of treatment was not always based on knowledge of the extent of the disease or prognosis but was based on ease of treatment and follow-up. One of the participants stated that her surgeon advised a lumpectomy and radiation but that traveling for radiation would be a hardship for her family; therefore, she chose to have a mastectomy.

Participants in this study were asked to rate the importance of the need for information regarding diagnosis, prognosis, treatment, and children. Results indicated that information related to disease, prognosis, and treatment was extremely important, and information related to the family of less importance. This can be explained because the disease, prognosis, and treatment are more closely related early in the diagnosis with survival (Derdiarian, 1987). This researchers discovered that on all items concerning disease the participants perceived their needs to be greater than those needs concerning the family. None of the items on the Family Related Need category was rated as being more important than disease. The highest ranked items concerned diagnosis and treatment and included the need to discuss with the family the diagnosis, treatment choices, and fears.

Findings regarding the need for the health care provider to discuss the impact of the disease on the family revealed the majority of the participants regarded the impact on spouse to be most important. This may be explained by the fact that the participant realizes that the well-being of the spouse has a more immediate impact upon the well-being of the participant (Derdiarian, 1987).

The needs of women with breast cancer from the time of diagnosis until treatment are many. The need for a concerned and caring health care provider immediately after diagnosis was apparent from the data generated by the CNAS. Even though that was an extremely stressful time, the women wanted to be given information regarding diagnosis, treatment, and prognosis and allowed to assimilate the information and participate in the decision regarding treatment.

Conclusions

Based on the results of this study, this researcher derived the following conclusions:

1. The greatest needs of women from the time of diagnosis of breast cancer until iniation of treatment were for their lives to continue as normally as possible and for their health care provider to be concerned and to respect their intelligence.

2. The greatest informational needs of the total sample were in the areas of diagnosis and prognosis of the disease.

3. There was a significant negative correlation between age and Disease Related Needs. The older a participant was, the lower were her needs related to the diagnosis, treatment, and prognosis of the disease.

4. Women in the 30 to 45 age group needs centered around decisions regarding treatment. They needed control, respect, and questions about the disease, treatment, and prognosis answered.

Limitations

Most of the limitations of this research involved instrumentation. The instrument was researcher designed and in its first use.

The research instrument contained positively and negatively worded statements. At least two of the participants found this format confusing. A straight forward statement of need followed by positive or negative response might have been clearer.

Even though internal consistency was calculated, test retest reliability was not calculated. The researcher had planned to collect retest measures, but because completing the questionnaire was psychologically stressful to the participants, a retest was not done. Therefore the reliability of this instrument over time is unknown.

Another limitation of this study was the entire sample was chosen from one clinic. The sample may not represent the population in general.

Implications for Nursing

A number of implications for nursing science were derived from this study. Implications emerged for nursing research, theory, education, and practice.

Research. Many studies have been done to identify stress related to the diagnosis of breast cancer and to ascertain how certain women cope with this stress. Other studies have examined the informational needs of people with cancer, but were not limited to breast cancer. However, no research was found concerning needs related to Disease, Family, and Emotional/Psychological from the time they were diagnosed with breast cancer until treatment was begun. Findings from this study lend strong support to the conduction of future research with a sample of women ages 30 to 45.

Theory. Theory is tested through research. This researcher utilized Travelbee's Human to Human Relationship theory as it applied to identifying and describing the needs of women with breast cancer. The findings of this research supported the Human to Human Relationship theory by identifying the importance of establishing relatedness/rapport and responding to the humanness of others. Two of the needs that were identified most frequently by all ages related to relationships between health care provider and participant. The Human to Human Relationship theory should be tested with larger and younger population in other areas of Mississippi and the United States.

<u>Education</u>. The number of women with breast cancer is increasing; therefore, it is essential that nurses be prepared to respond to patients who are experiencing the diagnosis of breast cancer. This study emphasizes the necessity for nursing curricula to include physical, spiritual, and emotional components in care of persons who are ill.

Curricula should also be included to allow students to explore their own values and beliefs because they determine the quality of nursing care provided. Nursing education should include the importance of the provider/recipient relationship in management of care.

<u>Practice</u>. Providing primary care for women will involve patients who are diagnosed with breast cancer. Providing information about the disease process, treatment options, and prognosis will be an important aspect of the nurse practitioner's care of patients with breast cancer. Communicating with patients is one of the greatest skills possessed by nurse practitioners. Listening to and understanding what is being communicated is invaluable in

assisting patients with breast cancer cope with the disease. Patient education by the nurse practitioner is centered on recognition of the need of patients to be informed and to be an active partner in the decision making process. This study emphasizes the importance of a caring concerned attitude when dealing with patients during this stressful time.

Recommendations for Further Study

Based on the findings from this study recommendations for future work in the area of needs of women with breast cancer are as follows:

Recommendations for Research

1. Replication of this study utilizing a sample largely comprised of younger women.

2. Modification and testing of the CNAS on similar populations to establish reliability of the instrument.

3. Replication of this study with less passage of time between treatment of breast cancer and completing needs assessment.

Recommendations for Nursing

1. Encouraging newly diagnosed breast cancer patients to verbalize their needs and concerns.

2. Providing information that is individualized to the patient's expressed or identified needs.

3. Demonstrating caring for women with breast cancer by being empathetic and listening with respect to the concerns of the patient and family.

4. Allowing the woman with breast cancer to be an active participant in decisions regarding treatment options.

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Appendix A

Approval of Mississippi University for Women Committee on Use of Human Subjects in Experimentation

MISSISSIPPI
UNIVERSITY
FOR WOMEN
Columbus, MS 39701

Office of the Vice President for Academic Affairs
Eudora Welty Hall
P.O. Box W-1603
(601) 329-7142

March 5, 1996

Ms. Barbara L. Collier
c/o Graduate Program in Nursing
Campus

Dear Ms. Collier:

I am pleased to inform you that the members of the Committee on Human Subjects in Experimentation have approved your proposed research provided the following standards are met:

a) There must be a written facility agreement.

b) The consent form must include the statement that the standard of care will not be affected in the event a person chooses not to participate.

c) The consent form needs to be modified to properly explain that no names will be used on the survey or the results.

I wish you much success in your research.

Sincerely,

Susan Kupisch
Vice President
for Academic Affairs

SK:wr

cc: Mr. Jim Davidson
Dr. Mary Pat Curtis
Dr. Rent

Where Excellence is a Tradition

Appendix B

Permission to Conduct Study

Oxford Clinic for Women

John P. McLaurin, Jr., M.D.
William H. Henderson, M.D.
Ira Lamar Couey, M.D.
R. Blake Smith, M.D.
OBSTETRICS AND GYNECOLOGY

December 4, 1995

Dear Ms. Collier:

We have discussed your request to obtain your participants for your research study from the patients at the Oxford Clinic for Women. We agree that learning the perceived needs of patients following the diagnosis of breast cancer would be useful in meeting the needs of future patients with this diagnosis.

You may obtain the names of patients who have been diagnosed with breast cancer in the last two years, and telephone them to ask if they would voluntarily participate in your study. We understand that confidentially will be maintained.

Sincerely,

I. L. Couey, M.D.

(601) 234-1731 1-800-649-5633

2200 South Lamar Boulevard, Suite C, Oxford, Mississippi 38655

Appendix C

Cover Letter

Cover Letter

Dear Mrs.

Thank you for agreeing to participate in the study. As I told you on the phone, I am a graduate student at Mississippi University for Women, and for my thesis I am conducting a study to determine the needs experienced by women who have been diagnosed with breast cancer.

I am interested in the needs that you experienced from the time you were told you had breast cancer until you had treatment. I would like for you to reflect back to that period and identify all need whether met or unmet.

Please complete the enclosed questionnaire. Listed are some needs that have been identified by other breast cancer survivors, and there is space for you to write any additional physical, informational, or emotional needs that you may have experienced. Your opinions and experiences are very important to this study and are needed to identify needs of women with breast cancer.

A postage-paid return envelope has been provided for your convenience. Please return the participant agreement and questionnaire. To allow time to analyze the information, please return the questionnaire by April 13, 1996.

Thank you for your cooperation and assistance.

Sincerely,

Barbara Collier, R.N.
234-7131

Appendix D

Collier Needs Assessment Survey

COLLIER NEEDS ASSESSMENT SURVEY

Please read each statement, and place a check in the column that best describes the degree to which you agree/disagree with each statement. Answer these questions based upon your recollection of your needs during the time period between diagnosis and beginning of treatment.

Code:
1-Strongly disagree
2-Moderately disagree
3-Slightly disagree
4-Slightly agree
5-Moderately agree
6-Strongly agree

	1	2	3	4	5	6
Disease Related Needs						
1. I needed more information about my test results.						
2 I needed my health care provider to answer my questions.						
3. I did **not** need the health care provider to be available for questions.						
4. I did **not** need information regarding treatment choices.						
5. I needed my health care provider to tell me what treatment to have.						
6. I needed to have some control over the decision regarding treatment.						
7 I did **not** need time for a second opinion.						
8. I needed to be encouraged to have a second or third opinion.						
9. I did **not** need a follow-up appointment to discuss information given at the time of diagnosis.						
10. I did **not** need more information than was given about the disease.						
11. I needed to have had more information about the prognosis.						
12. I needed detailed information about what to expect during treatment.						
13. I did **not** need written information to read about the disease.						
14. I did **not** need information on breast reconstruction.						
15. I needed more information on breast reconstruction than was given.						
16. I needed time to talk with additional health professional regarding treatment options.						
17. I needed by health care provider to respect my concerns.						
18. I needed by health care provider to respect my ability to make my own decisions.						
19. I needed by health care provider to respect by intelligence.						
Family Related needs						
1. I did **not** need help in telling my spouse or partner that I had cancer.						
2. I needed help in telling my children about my diagnosis of cancer.						
3. I did **not** need help in telling my parents about my diagnosis of breast cancer.						
4. I needed my health care provider to tell my family that I had breast cancer.						
5. I needed to openly discuss my diagnois with my family.						
6. I needed my spouse/partner to talk with me about treatment choices.						
7. I did **not** need to be able to express my fears to my spouse/partner						

SURVEY

Please read each statement, and place a check in the column that best describes the degree to which you agree/disagree with each statement. Answer these questions based upon your recollection of your needs during the time period between diagnosis and beginning of treatment.

Code: 1 - Strongly disagree
2 - Moderately disagree
3 -Slightly disagree
4 -Slightly agree
5 -Moderately agree
6 - Strongly agree

	1	2	3	4	5	6
Family Related Needs—Continued						
8. I did **not** need reassurance from spouse/partner regarding changed body image.						
9. I needed to make my decision regarding treatment without help from my family.						
Emotional/Psychological Needs						
1.. I needed reassurance from someone who had a similar experience with breast cancer.						
2. I needed a close friend to talk with to express my fears and reservations.						
3. I did **not** need to talk with friends.						
4. I needed to talk with someone who had coped successfully with breast cancer.						
5. I did **not** need someone with me when I was given the results of the biopsy.						
6. I needed to have time by myself after being given the diagnosis.						
7. I needed friends to treat me the same.						
8. I did **not** need to talk with my pastor/priest/or religious leader.						
9. I needed someone to encourage me to express my feelings about my breast.						
10. I did **not** need to express anger.						
11. I needed others to realize the significance of my disease.						
12. I needed time for developing a personal coping strategy for dealing with the altered or loss of breast.						
13. I did **not** need time for psychological adjustment to recommended treatment.						
14. I needed my life to continue as normally as possible up to the time of treatment.						
15. I needed my health care provider to seem concerned.						

SURVEY

During the time between your diagnosis of breast cancer and your treatment, please indicate the importance of your need for information from your health care provider. regarding each of the following: Please rate on a scale of 1 (not at all important) to 100 (extremely important)

Disease Concerns:
1. **Diagnosis** _______
2. **Children** _______
3. **Treatment** _______
4. **Prognosis** _______

During the time between your diagnosis of breast cancer and your treatment, please indicate the importance of having your health care provider discuss with you the impact of your illness on the following: Please rate on a scale of 1 (not at all important) to 100 (extremely important)

Family Concerns:
1. **Spouse** ______
2. **Children** ______
3. **Siblings** ______
4. **Parents** ______

---

1. **From the time of diagnosis until treatment, what other needs did you have which were not identified in the survey?**

2. **How could your Health Care Provider have been more sensitive to your need?**

---

3. **Any other comments:**

Appendix E

Participants Agreement

Participants Agreement

My name is Barbara Collier. Thank you for agreeing to participate in this study. As I explained on the phone, I am a registered nurse and a graduate student at the Mississippi University for Women. I am doing a study to determine the needs of women from the time they are told they have breast cancer until treatment.

Your signature indicates that you understand that your participation is voluntary. Your care at the Oxford Clinic for Women will be unchanged. The information provided by the questionnaire and answers to the question will be analyzed and this information shared with professionals in both written and verbal form for scientific study. Your name will not be used. When you return this agreement with the questionnaire they will be separated by me. Analysis of the data will be done without any knowledge of which participant answered which questionnaire. Your identity will remain confidential.

Signature:____

Date:_____________

Appendix F

Demographic Data Sheet

Date ______________________

DEMOGRAPHIC DATA SHEET

Please complete this form and return it with the questionnaire in the enclosed envelope.

Date of Diagnosis_____________
Date treatment began_______________

Age at time of diagnosis: _______

Length of time since treatment _________ Months

Number of Children______________
Children's Ages___________

Employed before treatment___________ Yes or No
Employed now____________ Yes or No

Please put your highest level of education: _________________

Please Circle the
Type of treatment: Simple Mastectomy

Radical Mastectomy

Lumpectomy and radiation

Other ________________

Appendix G

Raw Data Responses to Open Ended Question 1

Raw Data
Responses to Open Ended Question 1

I had the best doctor... most caring person I know.

Needs were met through my Reach to Recovery Volunteer. I was made to feel that I could continue with my life and be a productive person. Because of the concern and caring shown to me, I have become very interested and dedicated to helping other women cope during this difficult time in their lives.

I had no needs which were not identified at that time.

I needed to know how to take care of my skin and wounds and I wasn't completely told how. Basically they covered everything to my knowledge

My breast cancer was very minor. She did a biopsy- my doctor operated on my breast, she took out the bad cells and I have most of my breast.

Needed to plan care for husband (household tasks) while I was recovering from surgery.

The post-op nursing care which was provided by my R. N. sister.

I needed a support system immediately. I needed a lot of love and understanding from my family and friends.

I went through a period of denial. It was so hard to believe I had reached the age of 73-had no symptoms-that is seemed un-real. It took me about 3 weeks to accept.

I needed to know where to buy bras. Need more information on breast reconstruction. Information on how to continue to take care of myself since surgery.

I wanted as much verbal and written information as I could get to make a wise decision about my operations. My doctor was very helpful and so was Reach for Recovery. I read EVERYTHING I could find. My husband and adult children did, too. I felt confident about my decision for lumpectomy and radiation. But I've talked to other breast cancer patients who felt rushed into surgery. I didn't.

I feel I should have had a Cat Scan and a Bone Scan, because I have recurrent and metastatic breast cancer involving my lungs.

I needed a lot of love from my family and church family.

I needed more time to think, get additional information and decide whether or not I opted to go with the radical mastectomy...than what my physician wanted which was come back next day and have the surgery.

Appendix H

Raw Data Responses to Open Ended Question 2

Raw Data

Responses to Open Ended Question 2

He was totally insensitive to the patient's need for time to develop a coping strategy to deal with her situation. I simply, but firmly stated that I needed time to think what I wanted to do.

By having more test done concerning other parts of my body.

I was very pleased with my Doctor. He knew how I felt and was very concerned about me.

My health care provider was very sensitive to my needs.

He couldn't have been more caring.

My health providers were excellent.

Everyone of my HCPs was sensitive in every way to my needs.

None. He was very sensitive to my needs.

They were very help and concerned. I think they did a great job. I was pulling for myself and that helped a lot.

Dr.____ was wonderful and sensitive to our needs.

My doctor was great-patient, king and understanding.

My health care provider was and is excellent.

My doctors were wonderful-nothing could have been added.

I think I had the best doctor. Dr. ____ is the most caring person I know.

Appendix I

Raw Data Responses to Opened Ended Question 3

Raw Data

Responses to Open Ended Question 3

My biggest fear was that I would die. I had a 15 year old daughter and the only thing I knew about cancer was a lot of people would die with it.

I am very active in the Oxford Unit of Reach to Recovery. My prayer is that through my volunteer work I can give to someone else the hope and positive outlook that I received.

My surgery was not bad at all. I had a caring doctor and a loving husband. I wish everyone could do as well as I did.

I didn't give up when the doctor diagnosed me. I immediately took it to Jesus and I'm not worried. I'm a cancer free patient because I have been healed through the hands of Jesus. Amen.

I was well pleased with the whole procedure; everything went well.

I lead a very normal life. I take two tablets which are Nolvadex a day.

I only had a small lump which was successfully removed. I am now recovering from radiation treatment which is doing fine.

It's important that I tell you that I'm a Christian and that my reactions are/were different from most people. I have a great attitude and I'm receiving excellent reports from my doctors. Praise the Lord.

Some of the questions was tricky I hope I answered them right.

I did not appreciate being called on the telephone on Memorial Day, because I was going through grieving process with the loss of my father, and to receive this type of information on that holiday did not make it any better.

This diagnosis changes your life completely and your future is uncertain. I needed a lot of emotional support more than anything. I will never be the same again. A part of me is dead and gone. It is much easier to die with cancer than it is to live with it.

My doctor said I didn't have to have any treatment after surgery that everything came back O.K. Thank "God" for that.

On the whole, my experience was good. My husband, children, friends, church and doctors were supportive and attentive. The wording of the survey questions was confusing.

I really did not have time to experience any of these emotion.