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Changes in Distress

Changes in Distress of Women with Breast Cancer

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Running Head: Changes in Distress

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Changes in Distress of Women with Breast Cancer

Janis M. Petree

Abstract

In North America, breast cancer is the most common malignancy among women, it accounts for 29% of the cancers, for 18% (44,000) of the cancer deaths annually (Silverberg, 1990). Survival depends on the age at diagnosis, stage and type of Breast cancer. Treatment for cancer is often associated with significant physical and psychological distress. The purpose of this study was to describe the distress of women with Breast cancer over time. Secondary questions included the description of changes in distress between initial diagnosis and recurrence, age, education and marital status. The study is a secondary analysis from a larger study entitled: Coping and Self-Care of Cancer Families: Nurse Prospectus by Dodd, Lindsey, Musci, and Larson (1989), which is a descriptive correlational design. A subsample from this sample consisted of 48 women with Breast cancer, from three large institutions. The POMS (Profile of Mood States), a self-administered questionnaire, was completed at five time periods. Significant differences on tension, confusion, and depression subscales were reported over time. Married women reported more vigor, with more confusion reported in women that were not married. Women undergoing initial treatment of chemotherapy reported more anger. Age was significantly negatively correlated with anger and depression. At Times One, Two and Time Five increased education was associated with increased Vigor. Though many clinical practitioners think that Breast cancer chemotherapy is a relatively easy one, this report shows that these women do experience distress over time.

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Chapter I: Introduction

In North America, breast cancer is the most common malignancy among women, it accounts for 29% of the cancers, for 18% (44,000) of the cancer deaths annually, and for approximately 150,000 new cases this year alone (Silverberg, 1990). The risk of any American women developing breast cancer in her lifetime is ten percent, with the greatest risk being after age 65 (Devita, 1989).

Survival from breast cancer differs with the stage of the disease, type, and age (Casciato & Lowitz, 1988). Use of TNM (Tumor, Node, Metastases) classification helps practitioners predict the patients survival depending on the extent of disease or clinical stage. Age, is the third important factor in predicting survival outcome for patients, because it is considered a risk factor (anyone over age 40, has an increased risk of having breast cancer). Breast cancer is thought to be a relatively slow growing cancer, and survival is usually predicted at five and ten years.

In a large study (n=57,068) done in Sweden between 1960 and 1978, Adami and Malker (1986) report about the relationship of age and survival in breast cancer patients. Looking at the age groups (<30 to > 80) it was reported how survival diminishes over time with age. Many factors can add into this dropoff in survival including natural causes of death, but recurrence in disease in the most common factor. Breast cancer over a five, ten to fifteen year period tends to be a more indolent disease. Different studies (Adami, & Malker, 1986, Gelber, & Goldhirsch, 1986, Davis, & Gelber, 1986) report different rates of survival depending on the number in there studies, but overall effect of treatment is the same and does not really alter life expectancy. This study concluded that age should be considered as a prognostic factor in identification of patients at high risk for development of disease over the course of one's life.

Cancer treatment has been evaluated in light of increased life expectancy. Surgery is usually the first line of treatment (lumpectomy, modified radical or radical mastectomy), with radiation therapy and chemotherapy being used as adjuvant therapy. Standard chemotherapeutic agents used to treat breast cancer are CMF (Cyclophosphamide, Methotrexate, 5-FU), with or without use of other agents, such as Prednisone, or Adriamycin (Davis & Gelber, 1986).

Treatment for cancer is often associated with significant physical and psychological distress (Weisman, 1976; Romsaas, 1986). This has created a situation where quality of life becomes a key issue in deciding what is the appropriate treatment (Holland, 1982). One important factor affecting quality of life is distress or mood disturbance (Spitzer, 1981). The physical, psychological, and sociological stresses tax the cancer patients coping resources and skills. Coping effectively while undergoing chemotherapy may influence the effectiveness of therapy and quality of life (Welch-McCaffrey, 1985).

Little is known about the severity and extent of emotional distress associated with cancer survival (Quigley, 1989). Although many authors (Shanfield, 1980; Fobair, Hoppe & Bloom, 1986; and Cella & Tross, 1986) report the occurrence of significant levels of depression and anxiety in some patients, generally, the percentage of patients so affected has not been found to be statistically significant when compared to the controls (Quigley, 1989). Distress or changes in affective state may occur many times along the treatment course in women with breast cancer. The level of distress may affect women adversely in their personal life or in their decision making process, by altering her body image, sexual identity and self-esteem (Maguire, 1978). Distress has been described as anguish of the body or mind, a painful situation, the state of being in mental or physical anguish (Webster's, 1975).

'Distress of varying intensity may occur at multiple points along the continuum of care for the women with a suspicion of breast cancer' (Romsaas & Malec, 1986, p. 890).

'The emotional impact of breast cancer and its treatment is enormous, bringing irreversible change to the patient and to the family unit. Some women undergo the cumulative stresses of positive biopsy, mastectomy, adjuvant chemotherapy, recurrence, possible adrenalectomy, long-term chemotherapy with alopecia and 1 to 2 days of nausea and vomiting after each treatment, subsequent recurrence, and finally widespread disease and death. Fortunately, all patients do not have all of these stresses'' (Gates, 1988, p.257).

Derogatis, Abeloff, and Melisaratos (1979) found that in a group of 35 patients receiving chemotherapy for advanced breast cancer, those who survived the longest had a considerable amount of psychological distress, in the form of depression, anxiety, hostility and guilt, as measured by the SCL90-R Symptom Checklist and the Affect Balance Scale. Other investigators reported that women with breast cancer were more depressed than either women with fibrocystic disease or healthy women without breast disease (Jansen & Muenz, 1984). A serious and chronic illness such as breast cancer, usually involving loss of a breast, with its constant visual reminder of the illness, can change one's life forever (Silberfarb, 1978). 'The possibility that significant levels of distress may affect decision making at each critical point in breast cancer diagnosis and treatment, makes this an important issue for study'' (Romsaas & Malec, 1986, p. 890).

There are five emotional issues that are common to all cancer patients but in particular breast cancer patients: 1) the word cancer, usually is emotionally charged word, 2) the patient's perceived lack of control, 3) uncertainty about the outcome or future, 4) the treatment mode, usually treated like an acute illness, but ends up being more like a chronic illness; and 5) the debilitating nature of cancer treatments. All of the above factors disrupt normal activity, leading to distress in patients (Silberfarb, 1986). Silberfarb and his associates reported (1980) that at time of recurrence of breast cancer was more distressing for patients than at time of mastectomy or at time of first treatment. These

same patients also reported that ending current treatment was anxiety provoking as was the diagnosis of recurrent disease (Silberfarb, 1980). Wolberg and Tanner (1987) found that older women tended to select mastectomy more than younger women. Compared with women who elected for conservation of the breast, women who elected for mastectomy demonstrated more tension and anxiety ($P < .01$), and more depression ($P < .05$) as measured by the POMS. In a study by Maunsell and Brisson (1989) age and education appeared to modify the relation between type of surgery and psychological distress. Age, treatment course, diagnosis or histology of tumor all play a part in the distress that women have. Marital status and education have not been addressed as a factor contributing to or alleviating distress.

Distress, has been mentioned in other studies of women with breast cancer, to be a recurrent theme, yet little mention or even consistent ways of measuring distress have been reported in the literature. Distress may also include Tension, Anxiety, Depression, Confusion, Fatigue, and Vigor (six subscales of the POMS) (McNair, Droppleman, & Lorr, 1971). Age (Casciato & Lowitz, 1988; Adami & Malke, 1986; Maunsell & Brisson, 1989), education and initial diagnosis versus recurrence are themes or incidental findings that several of the above authors have mentioned. This study investigated the five variables mentioned above: 1) Distress (or the six subscales of distress as measured by the POMS), 2) initial diagnosis versus recurrence, 3) age, 4) education, and 5) marital status. The purpose of this study was to describe the distress of women with breast cancer over time. Secondary questions included: Is there a difference with women who are initially diagnosed versus those with recurrent disease; and is there a difference in distress by age, marital status or education? Marital status has not been reported to affect distress, in previous studies, this author evaluated marital status to see if it was associated with distress.

Chapter II: Review of Literature

A theory of coping by Lazarus and Folkman (1984) provides a conceptual framework for this study of women with breast cancer. They define coping as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p. 178). These coping functions serve two main purposes, emotion regulation and problem solving. Emotion regulation is a cognitive process directed at lessening the emotional distress. This can be done by using certain strategies such as avoidance, distancing, minimization, selective attention, positive attitude or comparison and trying to form a positive situation from a negative event. There are other ways to regulate emotions by first increasing emotional distress, for example, feeling worse before being able to feel better. These individuals like to dwell on self-blame or another form of self-punishment. Still others deliberately increase their emotional distress in order to get themselves into action, such as when athletes psych themselves up for a meet or competition.

Problem-solving skills include the ability to analyze the situation to identify the problem, to be able to search for information in order to look for alternatives and then be able to weigh these alternatives and implement the appropriate action. These problem-solving skills result from other resources or experiences, from a person's store of knowledge, and the ability to use cognition or ability to use that knowledge and self-control. The importance of the cognitive process of appraisal is to distinguish the potentially harmful stimuli, from the potentially beneficial stimuli, from the irrelevant stimuli (Lazarus, Averill, & Opton, 1974; Straus, 1987). "The way a person copes is determined in part by his or her resources, which include health and energy; existential beliefs (about God), or general beliefs about control; commitments, which have a motivational property that can help sustain coping; problem-solving skills; social skills;

social support; and material resources" (Lazarus & Folkman, 1984, p. 179). This cognitive appraisal can be further categorized into primary and secondary appraisal.

There are three kinds of primary appraisal: irrelevant, benign-positive, and stressful. When the encounter with the environment has no implication on the person's health or well-being it falls into the irrelevant category, and there is nothing lost or gained in the transaction. Benign-positive appraisals occur if the outcome of an encounter or problem is considered positive. These appraisals are characterized by positive emotions such as love, joy, happiness, and peacefulness. For some people there is always the feeling that something will go wrong, and that they must pay for the good feelings. So some benign feelings can generate guilt or anxiety. The third type of primary appraisal is called stress appraisal which includes harm/loss, threat, and challenge which calls for mobilization of coping efforts.

When we are in trouble or jeopardy, whether it be a challenge or a threat, something must be done to manage the situation. A further form of appraisal becomes evident and this is called secondary appraisal. Secondary appraisal is a crucial feature of every stressful event because the outcome depends on what can be done. Secondary appraisal is more than just an intellectual exercise in what can be done, but it is a complex evaluation of what coping options are available to the person. "Secondary appraisals of coping options and primary appraisals of what is at stake interact with each other in shaping the degree of stress and the strength and quality (or content) of the emotional reaction. For example, if the person is helpless to deal with a demand, stress will be relatively great because the harm/loss cannot be overcome or prevented" (Lazarus & Folkman, 1984, p. 35). If a person has a high stake in the outcome, then helplessness can be potentially devastating and produce considerable stress. Coping effectiveness depends on the match between secondary appraisal and the flow of events. Secondary appraisal can be faulty and this can lead to stress or distress in the case of breast cancer

patients. Therefore, this model makes an attempt to explain the variability of responses to the threatening event of breast cancer chemotherapy. The Lazarus model of coping has provided investigators (Weisman & Worden, 1976; Herth, 1989; Dodd, 1989) with a theoretical basis for studying coping behavior in the cancer population.

The diagnosis of cancer is stressful. Bridge and Benson (1989) studied whether stress could be alleviated in patients being treated for early breast cancer. One hundred thirty nine women with Stage I or II breast cancer, after being treated with mastectomy or breast conservation, were outpatients having a six week course of radiotherapy. The patients were seen once a week for six weeks (one half hour each week) by one of two researchers, and were randomly assigned (by random numbers table) to one of three treatment groups. The first group was a control group (n=46) with no intervention, except that patients were encouraged to talk about themselves. The second group (n=39) was taught relaxation techniques (taught to concentrate on certain muscle groups); the third group (n=43) was taught relaxation techniques and imagery techniques to enhance their own relaxation. The relaxation and relaxation/imagery group were told to practice their techniques at least 15 minutes per day. Two questionnaires were given to the patients: the Leeds general scales and POMS (65 item, with 6 subscales, and total Mood disturbance score) at the beginning and the end of treatment course (week one and week six). The study hypothesized that the relaxation/imagery group would have the most positive results, followed by the relaxation group. This hypothesis was supported, with the overall mood state, as measured by the POMS, significantly improved in the relaxation/imagery group, followed by the relaxation group, with the worst mood disturbance in women of the control or untreated group.

This study was difficult to interpret due to the way the results were reported.

Results on the POMS showed a decrease in tension (p.043), decrease in depression (p.023), and a decrease in Total Mood Disturbance Score (p.036); all showing statistical significance with the relaxation plus imagery group showing the greatest decrease in all the above scores, followed by the relaxation group. The POMS scores also reported that the overall mood state of the women in the untreated group became worse. Both types of treatment were shown to be more effective on women 55 years or older, less tension and depression at the end of the six weeks. Women with low anger scores showed no difference, but women with high anger scores with relaxation and relaxation plus imagery showed more fatigue, less vigor, and greater total mood disturbances than the controls. The Leeds general scales showed no significant differences. There was no conceptual framework or any discussion on limitations of the study. This study had an adequate sample size for the treatment variables .

There have been many studies (Silverberg, 1990, Davis & Gelber, 1986) looking at breast cancer patients who are receiving treatment. In a study by McArdle and Cooper (1979), 56 patients were randomized to one of three groups. The first group of patients receiving chemotherapy (n=19) received the CMF regimen (Cytosin, Methotrexate, 5FU) on days one and eight, on a 28 day cycle for one year and all drugs were administered intravenously. Group two (n=22) consisted of patients receiving post operative radiotherapy (no dosage or time period given); and the third group (n=15) received a combination of both treatments (radiotherapy and chemotherapy). All patients had undergone mastectomy with axillary node dissection but no stages were given. No data were given on how the information was presented to the patients and if informed consent was obtained. The literature review was minimal. The purpose of this study was to define the incidence and severity of toxicity and to evaluate the extent of emotional

disturbance associated with this form of therapy . Psychological morbidity was measured by three self administered questionnaires: The General Health Questionnaire (GHQ), the Leeds Self Assessment of Depression (LSD) and the third was the Leeds Anxiety General Scales (LSA). The GHQ provides nonspecific estimate of the presence of psychiatric disturbance but does not indicate the underlying cause of illness. The Leeds scales measure the degree of pathological depression or anxiety. Results showed that four major toxic side effects were present: Leukopenia (< 4000) 84% of patients, Nausea and vomiting, moderate to severe 89%, oral mucositis, moderate 73% and severe 45% of patients and the fourth side effect was hair loss (alopecia) moderate 41% and severe 24% of patients. Severe nausea and vomiting by 89% of the patients caused dose reduction in therapy. Severe mucositis necessitating use of folic acid as a rescue from the methotrexate. Despite the degree of toxicity experienced by the majority of the women, most returned to work within three months of starting therapy. Since nausea and vomiting were so distressing a pilot study was started testing five treatment regimens: 1) placebo, ascorbic acid 50 mg tid, 2) metoclopramide, 10 mg tid, 3) cyclizine, 50 mg tid, 4) fluphenazine, 2 mg daily or 5) fluphenazine 1.5 mg and nortriptyline 30 mg daily starting two hours prior to treatment (chemotherapy) and continuing for five days. Metoclopramide, cyclizine and fluphenazine did not alter significantly the incidence or severity of side effects. The placebo group still had nausea and vomiting (83%) of the time, being severe 65% of the time. Only the fluphenazine and nortriptyline combination showed a highly significant reduction in the duration of both nausea ($p < .0005$) and vomiting ($p < .005$). Psychological morbidity by GHQ was present in 10 of 26 patients receiving chemotherapy, compared to 2 of 16 receiving radiotherapy alone. Depression occurred in seven patients receiving chemotherapy and two in the radiotherapy group. Anxiety was common in both groups. After 18 months the psychiatric morbidity was still prevalent in four of 19 patients receiving chemotherapy,

still scoring in the range of significant psychiatric illness and depression, as compared to none in the radiotherapy group. Anxiety was present in 10 of 19 patients receiving chemotherapy and two of eight in the radiotherapy group. The flaws of this study are the small sample size, poor reporting of details of the study such as interventions, bias, validity, reliability, no demographic data about the sample, no classification of disease, no conceptual framework and poor information about the design. This study would be very difficult to reproduce from the information given, but the results are interesting and it reports symptoms of distress (depression, anxiety which are symptoms of psychologic distress, and physical distress was reported on nausea/vomiting, alopecia, and mucositis) This author states he is measured psychological morbidity but he is also measuring physical morbidity.

Love and Leventhal (1989), studied 238 patients with the diagnosis of breast cancer (n=167) or lymphoma (Hodgkins and Non Hodgkins) (n=71), in four hospitals or clinics in the Wisconsin area. Multiple drug regimens were used including the following drugs: Adriamycin, Cytosan, Methotrexate, 5-Fu, Prednisone, Tamoxifen, Vincristine, Halotestin, Nitrogen Mustard, Procarbazine, Bleomycin and many others. Some patients (15%) were lost during the study due to death (n=16), disease progression (n=4), therapy change (n=14), or relocation (n=1) resulting in a sample size of 183 finishing the study. One group was assigned to five interviews, the first interview being prior to initial chemotherapy and the others scheduled at cycle 1,2,3, and 6 (n=214, 90% of participants scheduled for this intervention). The 24 remaining participants were scheduled for only an initial interview and an interview after cycle six. Of the 214 patients in the first group, 188 were assigned to do daily diaries of side effects, which was done by random assignment. The interviews were semistructured and administered by seven trained interviewers, 146 questions were asked covering the topics of side effects, management of side effects, details about chemotherapy, disruption,

difficulty (not described what type of difficulty), distress from therapy and disease. Each interview was recorded and lasted about 30 to 45 minutes. The symptom diary consisted of one data sheet with thirteen items, on an 11 point scale, such as chills, numbness, nausea, vomiting, pain, tiredness, hair loss, happiness, anger, sadness, nervousness, difficulty working, and appetite. Data were missing in 15 of the patients for symptom management, at one of their scheduled interviews. There was an increase in distress about receiving chemotherapy (nausea, vomiting, weakness, tiredness, diarrhea, mouth sores, and anticipatory nausea), these side effects were also used to correlate difficulty with chemotherapy, disruption of social life, and disruption of work life. Nausea, hair loss, and tiredness were experienced by 80% of the patients. Higher levels of distress, difficulty, and disruption were reported as the treatments progressed. Difficulty was the most pronounced (with $F=7.68$, and $P < .001$), with distress ($F=3.28$, with $P < .05$), and disruption of social life also increasing significantly ($F=8.76$, $P < .01$). The levels of distress, difficulty, and disruption were basically the same across the four patient groups (this author does not tell us how the groups are split up or what disease process fall into what group). Those patients treated with the CAF (Cytosin, Adriamycin, 5-FU) combination experienced the most difficulty ($P < .05$) and also had the most levels of disruption, both in social life and work, during cycle six. The MOPP regimen (Nitrogen Mustard, Oncovin, Procarbazine, Prednisone) showed the next highest level of difficulty (not operationalized). Factors enhancing distress were the presence of side effects, but were not the only factors related to distress; an inability to cope with side effects was also important. Those patients with a college education reported significantly higher levels of distress, difficulty, and disruption. With barriers of communication, 46 % of the patients thought of quitting their treatment but only a few communicated that to the medical staff (10 of 63 at cycle six). Many patients underestimated the side effects (eight percent reported tiredness, but 86% experienced tiredness) (the author does not let us

know if these side effects were reported in the interview or if in the diary). Barriers to complete communication were unchanged in regards to patients expectations of side effects, nor did they modify their response to the standard nursing preparation about side effects. Those patients whose initial interview came after the training session had expectations no different from those of patients whose interview preceded the training session. Since nursing preparation focused on the toxicities of treatment, (according to Love and Leventhal), it is reasonable to assume that the lack of effect does not reflect an omission in teaching, but as the lack of absorption of information. The second obstacle was complete communication in retrospective reports of side effects underrepresented the actual side effects experienced. There was definitely a need for constant open communication between the patient and the practitioner. Patients uniformly experienced side effects and for those with palliative intent, the side effects did not improve the quality of life. For those patients with a curative intent or preventative intent they were faced with a trade-off of side effects versus quality of life (not measured in the study). These authors did not offer any suggestions for future work, nor did they tell us of the limitations of the study, loss of 15% of the 238 patients did not complete the study. This sample size was not large enough for all of the treatment options (approximately 8) and would have been easier to interpret the data if results were reported according to disease entity.

Knobf (1986) studied 78 patients with breast cancer (stages not reported) who had all undergone mastectomy (modified 89%, radical 5%, simple 4%, breast conserving and radiotherapy 2%), with premenopausal (47%) and postmenopausal (49%) women . All patients received chemotherapy with CMF with or without Prednisone or Vincristine. At time of interviews 50 patients were on treatment and 28 had just completed a course of adjuvant treatment. The sample came from three private oncology practices and one university hospital outpatient clinic. Four patients were excluded from the study due to other primary cancers, depression, and severe learning disability. The purpose of this

exploratory study was to quantify the degree of physical (mobility, fatigue, bowel patterns, appetite, insomnia, nausea, and weight changes) and psychologic distress (diagnosis, loss of breast, survival, financial burden, appearance outlook, concentration and mood), experienced by patients and identify life-style changes. A semi-structured interview was conducted to obtain demographic data, distress and life-style changes by using the Symptom Distress Scale (SDS), the Psychiatric Status Schedule (PSS) and questions and scales developed by the investigator (reliability not reported). The SDS was modified by deleting two items (difficulty breathing and pain), and the PSS (normally 321 items) was reduced to 140 items. Validity of both of these tools was not affected, as stated by the authors. Informed consents were signed and a 45 to 60 minutes interview were conducted in the patients homes and patients were instructed to answer questions according to how they were feeling presently. Fatigue and insomnia were reported as causing the most distress ($P \leq .01$). Weight gain (5 to 16 lbs.) was correlated with mild nausea ($P \leq .01$) and 25% of the subjects reported that they had chronic gastrointestinal side effects that were relieved with food in their stomach, so they ate more frequently. Weight gain was also associated with decrease activity, increased appetite, change in taste buds, depressed mood, nausea, and metallic aftertaste from the drugs. Weight gain was also associated with a less happy mood ($P \leq .05$) and a more worried outlook ($P \leq .01$). Psychologic distress was rated on a five-point Likert scale with one being no distress, and five being great distress. Diagnosis was perceived as most distressful, followed by loss of breast ($P \leq .05$) and uncertainty of survival ($P \leq .01$) was greater for subjects not receiving therapy. The PSS evaluated depression and anxiety which was reported by 97% of the subjects but represented very low scores, indicating only mild distress. Depression and anxiety were correlated with uncertainty of survival ($P \leq .01$), change in appearance ($P \leq .01$), a less happy mood ($P \leq .01$), difficulty concentrating ($P \leq .05$), and a more worried outlook ($P \leq .01$). Fifty-six

percent of the premenopausal women reported a change in the frequency and quality of their sexual relationships versus 41% of the postmenopausal subjects. In this present study women receiving adjuvant therapy for breast cancer, primarily with a CMF combination, suggests that they experience only mild physical distress, mild to moderate psychologic distress that persists after therapy, significant weight gain, minimal alteration in lifestyle, and some changes in sexual relationships. Limitations of this study include a nonrandom sample of women with breast cancer, perhaps not representative of a larger population. The PSS tool may not provide an accurate representation of the impact of illness and treatment on the daily roles women perform. Thus a more sensitive tool to discuss role performance may be necessary. This study does provide the clinician with some findings to monitor physical and psychologic distress in the areas of weight control, nutrition, fatigue, insomnia and other symptoms.

Romsaas and Malec (1986) studied psychological distress among 339 women with breast cancer (five had biopsy proven cancer, 317 did not know their diagnosis yet, they were new patients [they had just come into clinic for an appointment], plus 17 inpatients with biopsy proven cancer) problems. Each women completed self-administered psychologic tests to evaluate mood disturbances (using the POMS) and responsibility and participation taken for overall health care (Health Locus of Control [HLCS]). Apparently a third test was administered called the Breast Cancer Information Test, which was a 16 item, true/false test and a brief rating of sources of information about breast cancer (the author does not tell us the source of this test). Results of these tests were compared to control populations of normal college women (n=516) and female psychiatric outpatients (n=650). Women seen in the breast cancer clinic were significantly less distressed on the POMS subscales ($P < .001$) than both the female psychiatric patients and the college women. The group of patients that already knew their diagnosis (n=5 outpatients, and n=17 inpatients) showed a significant difference on the Health

Locus of Control Scale ($P < .01$). The inpatient group scored lower than the outpatient group on the HLCS, but were combined into one group for all further analysis. The diagnosis known group was compared to the diagnosis unknown group on the POMS subscales; with the diagnosis known groups scoring significantly higher on tension, depression, anger, confusion and Total Mood Disturbance Scores ($P < .001$). The diagnosis unknown group scored significantly higher on the vigor subscale ($P < .05$). The diagnosis known group when compared to the college women and to the psychiatric women did not differ significantly on any of the POMS subscales. The diagnosis unknown group versus college women scored significantly lower on the depression, anger, fatigue, and confusion subscales ($P < .001$), and were the same on the tension and vigor subscales. This same group when compared to the psychiatric women scored lower on the tension, depression, anger, fatigue, and confusion scales and significantly higher than the psychiatric women on the vigor subscale ($P < .001$). The diagnosis known group did not differ significantly in level of distress from either the college students or the psychiatric groups. This leaves interpretation difficult, and that there might be some mood disturbance of psychiatric proportions with cancer patients. It is difficult to compare 22 patients (known diagnosis) to a group of 650 patients (psychiatric women), or to compare them to a group of 516 (normal college women). The author makes no attempt to explain where she collected her information on the control groups, no demographic data were presented and a poor explanation of the procedure was given. There is a big difference in the two groups of patients: diagnosis known ($n=22$), and the unknown diagnosis group ($n=317$) and is probably not the most even way of comparing the two groups. There is no insight into limitations or future research given.

McCorkle and Quint-Benoliel (1983) did a longitudinal (short term, over 2 months) study looking at newly diagnosed lung cancer patients ($n=56$) and newly diagnosed myocardial infarction patients ($n=65$) who completed two interviews post diagnosis at one

and two months. Data were obtained using the modified version (13 item) of the McCorkle and Young Symptom Distress Scale, the Weisman and Worden Inventory of Current Concerns and the Profile of Mood States. The aims of the study were to describe the level of symptom distress, current concerns, and mood disturbances in persons with a diagnosis of lung cancer or myocardial infarction (MI); secondly, to test for mean differences of symptom distress, current concerns, and mood disturbances associated with disease type and time since diagnosis; and thirdly, to test the association of self-reported symptom distress, current concerns and mood disturbances in the two samples at two occasions. The interviews were conducted by five pre-doctoral university students; with lung cancer patients interviewed at the radiation therapy department of one of the four medical centers used. The MI patients were interviewed in their homes. Symptom distress was defined as the degree of discomfort reported by the patient in relation to his/her perception of the symptoms being experienced.

The Symptom Distress Scale by McCorkle and Young was a 13 item scale which was expanded from 10 to 13 symptoms (nausea [frequency], nausea [intensity], appetite, insomnia, pain [frequency], pain [intensity], fatigue, bowel patterns, concentration, appearance, breathing, outlook and cough). The items were summed to provide total symptom distress ranging from 13 to 65. Higher scores denote greater levels of symptom distress. (Alpha reliability was 0.82 and validity was established).

The inventory of Current Concerns is a 72-item self-administered scale that measures potential sources of distress that are sometimes concerns (health, self-appraisal, work, finances, family, religion, friends, and existential concerns) of people with serious illness. Responses were answered on a three point scale (0-not true, 1-somewhat true, 2-true). The items in each category were totalled, and the scale ranges were 0 (low) to 144 (high concerns). The POMS was the third scale used, a 65 item scale using the six

subscales of Tension, Depression, Confusion, Anger, Fatigue, and Vigor. The Total Mood Disturbance Score was obtained by summing the scores of the factors (ranges from -32 (low disturbance) to 204 (high mood disturbance), and was judged to be valid and reliable.

Lung cancer patients showed significantly more symptom distress, with fatigue as the most distressing symptom on both occasions. Other troublesome symptoms for cancer patients were pain frequency, cough, lack of appetite and insomnia. MI patients reported outlook, sleep patterns, pain and concentration to be troublesome symptoms. Both groups reported significantly fewer concerns at the second occasion. Mood disturbance was greater for cancer patients than for MI patients, and greater at the first interview than at the second. The cancer patients were less vigorous and more fatigued than the MI patients. The lung cancer patients suffered from more symptom distress than did persons with an MI (this was true for symptoms of pain, fatigue and insomnia). Symptom distress contributed to increased Mood disturbance for cancer patients at both interviews, this may have occurred due to increased symptoms.

These six studies provide some interesting information, unfortunately each study has some limitations either in sample size, study design, or statistics and results reported. One factor that seems to emerge from this data is that the POMS subscales seem to measure distress in patients. Some studies have looked at distress (Romsaas and Malec, 1986), distress over time (Bridge and Benson, 1989), psychological morbidity, extent of emotional disturbance, showing depression and anxiety; and physical distress: such as nausea/vomiting, alopecia, and mucositis (McCardle & Cooper, 1979). Distress, disruption, and difficulty in handling chemotherapy were reported by Love and Leventhal (1989), looking at breast cancer patients and lymphoma patients. Knobf looked at breast cancer patients and degree of physical and psychological distress (1986); Romsaas and

Malec (1986) studied psychological distress among women with breast cancer, and those not yet diagnosed, using the POMS. McCorkle and Quint-Benoliel (1983) looked at symptom distress among lung cancer and myocardial infarction patients. Wolberg and Tanner (1987) looked at factors influencing options in primary breast cancer treatments. This study used the POMS to measure distress in 206 women with breast cancer. The study reported that older women (over 55) tended to select mastectomy more than younger women. Compared with women who elected conservation, women who elected mastectomy demonstrated more tension-anxiety ($p < .01$) and more depression-dejection ($p < .05$) as measured by the POMS. In another study by Maunsell and Brisson (1989) looking at psychological distress in women with breast cancer ($n=227$), found that patients that had partial mastectomy tended to be younger and had a slightly higher education level than women who had a total mastectomy. Age appeared to have a modifying effect on the relation between type of surgery and psychological distress especially at three months but also at 18 months. Education level seemed to have a slight modifying effect: those women who underwent partial mastectomy had higher levels of psychological distress when compared to total mastectomy patients. Distress or subscales of distress have been reported in the previous six studies, age, education, and initial versus recurrent disease have also been discussed this author was also interested in looking at marital status in relationship to distress. Therefore the purpose of this study will be to look at the distress in women over time, and will describe any differences in women with initial diagnosis versus those with recurrent disease; and is there any difference in distress by age, marital status, or education level ?

Chapter III: Methodology

This research report is a secondary analysis of a larger study entitled Coping and Self-Care of Cancer Families: Nurse Prospectus, Dodd, Lindsey, Musci, and Larson (1986-1989). The purpose of this descriptive correlational study was to determine the coping strategies and self-care behaviors of patients and family members over a six month period during their cancer chemotherapy treatment. A longitudinal comparative design was used with 100 patients with breast, lung, colorectal, gynecological cancer or lymphoma. A subset of the patients with the diagnosis of breast cancer were used in this report. The purpose of this study was to describe the distress of women with breast cancer over time. Secondary questions included: Is there a difference with women who are initially diagnosed versus those with recurrent disease; and is there a difference in distress by age, marital status or education ?

Sample. The breast cancer patients (n=48), were in one of two groups: 63% of the breast cancer women were undergoing initial treatment and 36 % had recurrent disease. The majority of the patients were caucasian women (81%), with the majority either working full time (31%) or not working at all (31%), married (52%), and living with their spouse (50%) (see Table 1). The mean age of the patients were 47 years (SD 10 years), well educated, on average 14 years (SD 2.27 years), having had no previous chemotherapy before (64%).

Setting. There were three research settings used for the sample accrual (University of California, San Francisco; Veteran's Administration Medical Center, San Francisco; and Stanford University Hospital) with large outpatient chemotherapy clinics. The patient data were collected by research assistants who scheduled appointments with the patient over five collection periods. The research assistants were graduate nursing

students and the investigators who underwent extensive training to assure standardization of the interview procedures.

Instrument. The instrument, POMS consists of a 65 item self-administered questionnaire that measures six affective states. These states or subscales include: (1) tension-anxiety, (2) depression-dejection, (3) anger-hostility, (4) vigor-activity, (5) fatigue-inertia, and (6) confusion-bewilderment. The patient response to a five point Likert scale ranging from 0 (no feeling) to 4 (extreme feelings) related to each emotion on the subscales. The patient was asked to circle the number that best described their mood state for the past week.

To obtain a score for each of the factors, "the sum of the responses is obtained for the adjectives defining the factor" (McNair, Droppleman, & Lorr, 1971, 1981, p. 9). All items defined in each factor are keyed in the same direction, except for two items, relaxed (in tension-anxiety scale) and efficient (in confusion scale), these two items are weighted negatively in the factor scores. A Total Mood Disturbance Score may be obtained by summing the scores (with vigor weighted negatively) on the six primary mood factors. The higher the score, the greater the mood disturbance. The raw scores for the subscales were Tension (0-36), Depression (0-60), Anxiety (0-48), Vigor (0-32), Fatigue (0-28), and Confusion (0-28), with 0 being low and 60 being high.

Reliability for the POMS. A study was done at Boston University Medical Center Psychiatry Clinic with 350 male and 650 female outpatients between October 1966 and July 1969. POMS data for each of these samples was analyzed by a multigroup procedure. All of the reliabilities were highly satisfactory. Test-retest reliability was done on 100 psychiatric patients. Estimates of reliability (stability coefficients) ranged from 0.65 for vigor and 0.74 for depression (McNair, Droppleman, & Lorr, 1971).

The alpha reliabilities for this study are listed for the six subscales of the POMS

(see Table 2) and the five time periods. There is no combined alpha for mood state.

Validity. Validity of the POMS was done with 100 psychiatric patients, which provided predictive and factor-analytic support for the specificity of POMS subscales (Haskell, Putagatch, & McNair, 1969; Lorr, McNair, & Weinstein, 1964, Sacham, 1983).

Procedures . The informed consent was obtained after participants were given an explanation by the primary nurse or another nurse clinician, and an information sheet was left for the patient and the family to review. The consent forms were approved by the Committee for Human Subjects at University of California, San Francisco.

The patients completed the POMS, at five collection points over a period of six months (the timing depended on when their next round of chemotherapy was scheduled, for example, every three weeks or every four weeks). The questionnaire was filled out before or after seeing the doctor, it takes five to ten minutes to complete, and is based on a seventh grade reading or education level (McNair, Lorr, & Droppleman, 1978,1981).

Definitions. Distress is operationally defined as : the state of being in mental or psychological anguish, with a lack of quality of life (Webster's, 1975) as measured by the Profile of Mood States.

Coping: " constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person " (Lazarus & Folkman, 1984).

Chapter IV: Results

Interpretation of the POMS subscales was done by using Independent t-tests, group t-tests, and repeated measures analysis of variance over time. The repeated measures analysis of variance (ANOVA) of the POMS subscales was not significant. However, using this procedure, the sample size dropped dramatically from 48 participants to only 33-35 (data were missing from some of the time periods), thus decreasing the power of the test to determine differences. A sample size of 40 could be obtained if Paired t-test were used. Tension $t = -3.32$, $p = .002$, Depression $t = -2.69$, $p = .011$, and Confusion $t = -2.43$, $p = .020$, (see Table 3) were significantly increased at Time One and decreased by Time Five. The Anger, Vigor, Fatigue, and Total Mood Scales were not significantly different over time.

Independent t-tests were used on 2 factors: Initial treatment versus others, and married versus others. In examining the relationship of cancer recurrence to affective state, independent t-tests of the POMS subscales were conducted by initial treatment status. Anger emerged as the only subscale that showed any significant difference. At Time One, those patients undergoing, initial treatment reported more Anger than the recurrence group $p = .045$. At Time Five, there was no significant differences by group in the Anger subscale.

To explore the relationship of marital status to the affective states of these women, independent t-tests of the POMS subscales were conducted with the groups of married versus others (see Table 4). At Time One, Confusion was more prominent with those who were not married $t = -2.62$, $p = .012$, versus those that were married, but Confusion showed no significant difference at Time Five. At Time Two, Tension $t = -2.05$, $p = .046$, and Mood $t = -2.02$, $p = .0495$, were both increased in the other group, but by Time Five, Tension and Mood had showed no significant difference. Vigor

subscale showed that there was more vigor in those that were married $t=2.55$, $p= .015$, versus those that were not married at Time Five.

In examining the relationship of age and education to affective state, correlations of the POMS subscales were conducted. At Time One, there were a number of significant negative relationships between Age and Anger and Depression; and a significant positive relationships between Education and Vigor. This latter correlation was demonstrated at Time Two and Five, as well. Similarly the significant negative correlation between Age and Anger was observed at Time Two as well, but not Time Five (see Table Five).

Chapter V: Discussion

Since breast cancer is the most common malignancy among women, and the risk of developing breast cancer in our life time is ten percent, how women handle the distress of the diagnosis and treatment of breast cancer is of interest to nursing. Because the course of the disease process is relatively a slow one, in most cases, we need to turn our attention to the quality of life women can have without distress in their lives, caused by the breast cancer or side effects of the treatment. If we can not prevent the distress, then perhaps we can help these women increase their coping skills, by being able to manage specific distress elements of the experience.

Significant differences on the Tension, Depression, and Confusion subscales reflect that patients are more tense, depressed, and confused after initiation of chemotherapy at Time One. Anger, Vigor, Fatigue, and Total Mood Scores did not emerge as being significantly different at this time. This corroborates with the findings of Romsaas and Malec (1986), who reported that there is more distress with diagnosis on the tension, depression and confusion subscales. The tension subscale looks at many factors (tense, shaky, on edge, panicky, relaxed, uneasy, restless, nervous, and anxious), and one would expect that the tension from not knowing what is going to happen in the future, in relationship to the diagnosis or knowledge of recurrence of cancer, would decrease over time. Thus the tension scores in our breast cancer sample did decrease over time at six months.

With the independent t-tests, it showed that there was more confusion in the group that was not married at Time One only $p = .015$. Perhaps the predictability and structure in the breast cancer women's life who was married, helped with the understandable confusion and bewilderment that was present initially but dissipated in time.

The confusion subscale is composed of the following items: confused, unable to concentrate, muddled, bewildered, inefficient, forgetful, and uncertain about things. None of the studies cited in the literature review, discuss why confusion is associated with distress. Vigor is identified at Time Five, showing that married women have more vigor than those who are not married $p = .015$; perhaps because the spouse is helping do other chores that the patient would normally be doing or the spouse allows the wife to get more periods of rest because things will be taken care of. Women who are not married, do not always have this kind of live in support. In the study by Knobf (1986), fatigue was considered one of the most distressful symptoms, but in this analysis fatigue was not identified as a problem, but with the assistance of a spouse perhaps fatigue can be lowered.

The independent t-tests of patients with initial treatment (chemotherapy) versus others, Anger was the only subscale that showed a significant difference. At Time One, patients undergoing initial chemotherapy reported significantly more Anger, but did not at Time Five. In the study by Romsaas and Malec et al (1986), the Diagnosis Known group scored significantly higher on Anger and Total Mood Disturbance corroborating these data.

Increase in age, was associated with decreased anger and decreased depression. Bridge and Benson (1989) reported that in women over age 55 there was less tension and depression. One might ask why age is an important factor here or is it just an incidental finding. Despite prognostic realities, cancer is perceived to be most lethal. Perhaps a person's response to this news is less distressing the older she becomes. Frequent comments are: I have led a full life and rich life. A younger person may not have this perspective at all, but my life is just beginning.

This study has reported that patients get more angry, confused, and tense which contribute to distress in their lives. Many clinicians imply that cancer chemotherapy for

breast cancer is easy (less toxic), and that women will tolerate it well. This may be true for some women but this study demonstrates that women with breast cancer do get distressed about their diagnosis and therapies. Can we help women increase their coping abilities and thus decrease their distress? Once women recur there seems to be an increase in distress, perhaps because the hope of a cure is diminishing. Silverfarb (1980) reported that women with recurrence had more distress than those with initial diagnosis.

Limitations of the study include a small sample size due to missing data and that this was a secondary analysis of the data. This author chose to define distress with only the psychological components, but the physical components have also been reported to increase the distress of women with breast cancer. Quality of life was mentioned as an important variable in the distress of women, but was not measured for in this study. There was no measure of the stage, type or histology of these women with breast cancer in the larger study.

This author is satisfied that the POMS did measure distress in women with breast cancer, but there is a lack of consistent ways to measure distress (i.e. symptom distress, psychological distress, physical distress) in all the studies looking at distress in women with breast cancer.

There is a need for a study with larger populations of breast cancer women. There were many confounding variables when discussing distress, such as: stage of disease, histology of disease, long term disease free survival, a patients environment, social structure, support mechanisms, state of physical and mental health, what information the patient was given and what was actually heard, as well as our ability to lump the word distress into one broad category and measure it in many different ways. Age is an important factor in diagnosis and long term survival, we need to have additional studies conducted to demonstrate the contribution of age in understanding the cancer experience.

In this study, increased educational level correlated with increased vigor across three data collection periods. Better educated women may have done more problem solving on energy conservation measures or in buying assistance since increased education usually means increased income. In a study by Maunsell and Brisson (1989), educational level correlated with women who tended to be younger and have more partial mastectomies rather than radical mastectomies. In this same study, lower education level correlated with more psychological distress. Marital status and vigor, were also two variables that were related.

The use of the POMS helps us identify distress in patients by the specific subscales and by obtaining a Total Mood Disturbance score. By having this information about our patients, it may clue the clinician in, to be able to support a patient through a treatment course of chemotherapy for breast cancer. By recognizing that breast cancer patients will have a potential for distress, we can help them explore the best way of coping with these new internal and external demands. In turn, better coping will eventually decrease their distress.

It has been reported that distress is relative to the individual, and that chemotherapy is distressing. By recognizing this distress, hopefully, staff can open up lines of communication with the patients, that may not have been opened before so that these patients can tell staff what their concerns or problems are.

Appendix A Table 1
Patient Demographic Information

Variable	Percent (%)
<u>Ethnic Background</u>	
Asian	6.3%
Black	4.2%
Caucasion	80.8%
Hispanic	2.1%
Other	6.3%
<u>Employment Status</u>	
Full time, no change	31.3%
Part time, no change	8.3%
Part time, change	4.2%
Disability	10.4%
Not employed	31.3%
Other	14.6%
<u>Marital Status</u>	
Married, or Partner	52.1%
Separated, or Divorced	25.0%
Widowed	4.2%
Single	18.8%
<u>Living Arrangements</u>	
lives with spouse	50.0%
lives with other family	18.8%
lives with significant other	4.2%
lives alone	12.5%
other	14.6%

**Appendix B
Table 2****Standardized Alpha's of the POMS**

Subscale	Time 1	Time 2	Time 3	Time 4	Time 5
Tension	0.904	0.893	0.914	0.941	0.911
Depression	0.925	0.936	0.918	0.951	0.925
Anger	0.924	0.939	0.932	0.936	0.926
Vigor	0.881	0.895	0.884	0.876	0.878
Fatigue	0.937	0.882	0.933	0.958	0.957
Confusion	0.809	0.825	0.846	0.878	0.863

Appendix C

Table 3

Paired T-Test for the POMS Subscales at the First and Last Interview (6 month apart)

Variable	Time 1		Time 5		T	P
Tension	N	40	N	40	-3.32	.002
	Mean	12.34		9.33		
	SD	8.03		7.03		
Depression	N	40	N	40	-2.69	.011
	Mean	12.18		8.45		
	SD	11.85		9.43		
Anger						NS
Vigor						NS
Fatigue						NS
Confusion	N	40	N	40	-2.43	.020
	Mean	7.75		6.34		
	SD	5.15		5.19		
Mood						NS

Appendix D

Table 4

T-Test Married versus Others

Variable	Married		Others	T	P
Confusion (Time 1)	N	25	22		
	Mean	5.72	9.36	-2.62	.012
	SD	3.92	5.56		

Tension (Time 2)	N	23	21		
	Mean	8.19	12.66	-2.05	.046
	SD	5.04	9.01		

Mood (Time 2)	N	23	20		
	Mean	20.78	45.34	-2.02	.0495
	SD	27.87	49.97		

Vigor (Time 5)	N	20	21		
	Mean	19.05	14.33	2.55	.015
	SD	6.99	4.71		

Appendix E
Table 5

Correlations of Age and Educational Levels with POMS Subscales

Time 1						
Variable	Tension	Depression	Anger	Vigor	Fatigue	Confusion
Age	NS	-.307*	-.317*	NS	NS	NS
Education	NS	NS	NS	.363*	NS	NS
Time 2						
Age	NS	NS	-.305*	NS	NS	NS
Education	NS	NS	NS	.324 *	NS	NS
Time 3						
Age	NS	NS	NS	NS	NS	NS
Education	NS	NS	NS	NS	NS	NS
Time 4						
Age	NS	NS	NS	NS	NS	NS
Education	NS	NS	NS	NS	NS	NS
Time 5						
Age	NS	NS	NS	NS	NS	NS
Education	NS	NS	NS	.346*	NS	NS

*<.05, **<.01, ***<.001

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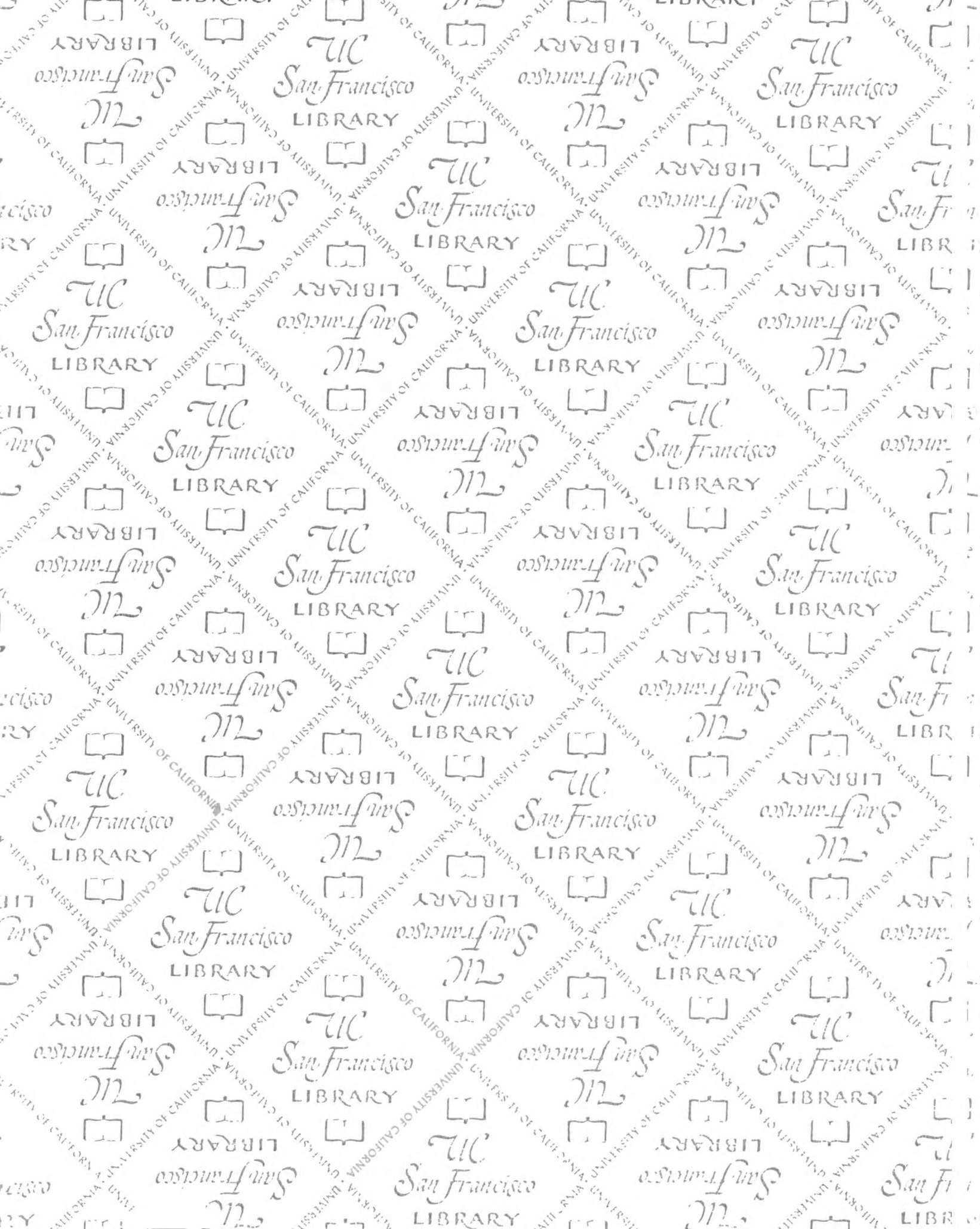
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