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Decision-making in breast cancer

Benevento, Anne, Ph.D.

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DECISION MAKING IN BREAST CANCER

BY

ANNE BENEVENTO

A dissertation submitted to the Graduate Faculty in Psychology in partial fulfillment of the requirements for the degree of Doctor of Philosophy, The City University of New York.

1989

This manuscript has been read and accepted for the Graduate Faculty in Psychology in satisfaction of the dissertation requirement for the degree of Doctor of Philosophy.

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Date

Irwin Katz
Chairman of Examining Committee

April 10, 1989
Date

Herbert D. Saltzstein
Executive Officer

Dr. Florence L. Denmark

Dr. Suzanne O. Kobasa
Supervisory Committee

The City University of New York

1989

Abstract

DECISION MAKING IN BREAST CANCER

by

Anne Benevento

Adviser: Professor Irwin Katz

Janis and Mann have developed a theory of decision making which suggests five different patterns of coping with threats. Four of these patterns should lead to defective decision making, while the fifth, which is called "vigilant information processing" should lead to adequate decisional consideration. This dissertation utilized the Janis and Mann guidelines to assess competent decision making practices among forty women who had chosen mastectomy as the treatment for their breast cancer.

The interviews were conducted in the New York Metropolitan area. The participants were women aged 29 through 72, with an average age of 46.6 years. All respondents had a mastectomy within the previous seven years. The average post-surgical period was two and one-half years. The interview consisted largely of open-ended questions, and was designed to cover the criteria considered by Janis and Mann to be important for adequate

decision making, as well as to be sensitive to the respondents' information gathering practices and their emotional and physical well being after surgery.

Findings supported the hypothesis that women who had adequately completed an informational search had less difficulty adjusting to the post-mastectomy period than did women whose informational search was found to be inadequate.

It was also found that the group of women who were merely open to receiving information fared better on the post-surgical anxiety items than did women who either did not search for alternatives pre-diagnostically, or who stated they were closed to receiving any information about breast cancer. Women who were told "not to worry" by their doctors before diagnosis and women who were found to be "closed to information" showed significant emotional distress after the mastectomy. Although the Janis and Mann model received considerable support from this study one of their hypothesized determinants of poor decision making was not found to be present. None of the women interviewed expressed regret about their decisions. All stated their belief that the mastectomy was the right choice in treating their cancer.

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Without the total support of Dr. Irwin Katz, this dissertation would not have been completed. When I found the topic emotionally draining, he offered encouragement. When I needed advice he was available. He was always kind, patient and insightful in his guidance. I can think of no other individual who so epitomizes everything a mentor should be.

I would also like to thank my other committee members. Dr. Florence Denmark has always been most helpful, enthusiastic and supportive of my work. Dr. Suzanne O. Kobasa has kindly offered her experience and insights in the field of health psychology.

I wish to acknowledge the courage of the 42 women, who allowed me to interview them about the most painful experience of their lives, and who expressed the hope that other women would benefit from this study. Without the input of these women, this dissertation would not have been possible.

Finally, I would like to mention the tremendous support I received from my family. My mother was encouraging. My daughter, Leigh, attempted to give help in whatever ways she could find. My husband, Tom, has always been there for me, and has always supported me. He did not fail to do so in this endeavor.

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INTRODUCTION

How much information a patient requires in order to make an informed decision about treatment of serious disease, the factors which effect the quality of informed decision-making, and the beneficial effects that increased control over health care may have for the patient, have long been issues in medicine. Regarding the disease of breast cancer, there has been a proliferation of information for both the lay public and the physician, and a growing belief that women should have more input into the choice of treatment. Therefore, a grasp of what constitutes competent decision-making in this disease is particularly relevant. It is also important to learn what type of patient effects, if any, can be traced to the patient's decision-making process during the disease.

In this paper, the Janis and Mann (1977) guidelines will be used to define competent decision-making. According to Janis and Mann (1977), inadequate decision making will inevitably occur when an individual does not consider all available alternatives fully and equally. The converse is also true. The individual who is engaged in adequate decision-making will, as much as is possible, attempt to

understand and consider the various factors and alternatives which are available, and continue to be receptive to new ideas until the time when a decision has been reached.

In attempting to understand the process of decision-making in breast cancer, there are, obviously, many areas which could be taken into account; however, in reviewing the research my focus will be limited to some factors which have been found to be germane to a patient's access to information, and are therefore believed to be most important to the topic.

One factor that is clearly relevant to patients' decision-making is the ongoing disagreement among medical experts as to what constitutes the best treatment for breast cancer. There has been increased publicity in the lay press about both the medical controversy which exists and the different treatment methods available. This has meant that over the past eight years medical information, which is often conflicting, has been more readily available to the breast cancer victim than ever before.

Another important factor in patients' decision-making is the tendency to perceive physician disclosure as insufficient. There has been a growing belief among patients that they should be fully informed by doctors, both

to protect their dignity as persons, and to allow them freedom of choice. Research findings suggest that the decision-making ability on the part of patients whose physicians underdisclose should be adversely affected relative to that of patients whose physicians are more forthcoming.

Related to the problem of underdisclosure are status differences between patient and physician, which, when emphasized by the physician, appear to further hinder communication and the development of a good patient-physician relationship.

A third relevant factor in decision-making is the patient's sense of control. Poor patient-physician communication has been found to affect adversely the future well-being of the patient by reducing her perception of control over her outcomes. Research has shown that the perception of control is beneficial to the individual, and the sense of being without control is injurious.

In reviewing research on the foregoing issues, I include material relating to post-mastectomy recuperation. Of particular importance here are those factors which have been found to influence the amount of time required for complete emotional and physical recovery.

Review of Previous Research

Factors Affecting Decision Making in Breast Cancer, Impact of changing medical beliefs and public information.

Some physicians believe that treatment of breast cancer has become more difficult because of the recent lay consumer focus on the disease (Lewiston, 1980). Certain of the new methods of treatment, which have been emphasized by the lay movement, have created a dilemma for physicians, because of what is viewed as a difficulty in comparing research or of assessing the adequacy of various studies (Kinne & Robbins, 1981). However, with the tremendous increase in innovative breast cancer research, many established beliefs about the mechanisms of breast cancer metastases and the most effective treatment for the disease have been challenged (Fisher, et al., 1985a, 1985b; Charlston, 1985; Bedwinek, 1984; Kettterhagen et al., 1984; Wilson, J.F., 1983; Legha, & Blumenschein, 1982; Letton & Mason, 1980; Frankl, G., 1980; Lewiston, E.F., 1980; Akins, et. al., 1972). A brief examination of recent research shows considerable variation in breast cancer diagnosis and treatment at this time. In particular, in the field of diagnosis, tremendous strides have been made, and tumors can be determined by mammography well before they can be detected by self-examination.

Unfortunately, as Lewiston (1980) has observed, the diagnostic improvements have not affected the death rate for breast cancer, which has remained constant over the past fifty years. Progress has only occurred when using the criterion of the five year survival rate. This finding gives credence to the claim of some researchers that breast cancer, in many cases, is a "systemic" (non-localized) disease. If the disease is systemic, a "uniform pattern of dissemination" would not occur (Charlson, 1985). Rather the disease would eventually be detected in the breast (Charlson, 1985; Ketterhagen, et al., 1984). In systemic cases a localized treatment, such as mastectomy, would not be effective in halting the cancer spread. Therefore, increased press coverage may actually be occurring because of a growing lay recognition of the treatment dilemma and may not be the root of the problem as Kinne and Robbins suggest.

A second possible reason for the increased publicity may be that breast cancer is the most common cancer found in American women and, despite treatment, causes the highest death rate as well (Cole, 1980; Lewiston, 1980). Some researchers believe that information about breast cancer discovery methods should be highly public because, statistically, 90 percent of all breast cancers will be discovered

by the patient. Through the use of ads and booklets, The American Cancer Society has tried to make the public more aware of the need for breast self-examination and through this type of examination, self-discovery of disease symptoms (American Cancer Society, 1982; National Cancer Care Foundation, 1986).

In attempting to determine adequacy of patients' decision-making, it is important to realize that in recent years, information has been freely available to women from sources other than the physician, such as television, newspapers or magazines. While it is as yet not known what effects this additional information may have on the choices women make, it clearly does present women with a way of discovering options for disease treatment other than staying with the physician who initially examines them. However, the option of changing physicians if that be necessary to receive the treatment of choice may not be utilized. It has been found that women are much more compliant than men in medical situations, and very reluctant to change physicians without advice from the present physician (Stone, 1979; Suchman, 1965).

As noted earlier, a gap is known to exist between how much information physicians believe patients desire and how much information patients state they require to make an

informed decision. Patients state they need more information than their physicians are willing to provide (Haug & Lavin, 1981; Hahn, 1979; McIntosh, 1974; Friedson, 1970). Further, patients of non-communicative physicians appear to feel that the physician does not truly care about their well-being. Individuals with this feeling have been found to recuperate more poorly than do other patients. Status differences between the physician and the patient, if emphasized, can also hamper effective communication (Waitzkin, 1985). In the next section the area of information disclosure will be presented. Of greatest interest is the way physician disclosure impacts decision making on the part of patients.

Physician disclosure and the patient-physician relationship. In 1965, Suchman found that the only decision made by patients in his study on decision making and health care was the initial decision to seek medical attention. Eighty percent of the time, this initial decision was based totally upon recommendations of friends or others who may have had as little knowledge as did the patient. (See also Sanders, 1982; Suls, 1982; Zola, 1973; Miller, 1973 for discussions of lay referrals.) Once Suchman's respondents entered the medical model, the physician made all the decisions.

Shane (1980) has also examined difficulties patients

experience while trying to receive complete information. She believes these problems are caused by faulty physician-patient interactions. She describes three typical patient-physician relationships. One type is similar to a parent-child relationship, and usually occurs when an individual is unconscious and therefore unable to make decisions. Shane feels this occurs occasionally even when the patient is alert. This type of relationship places decision-making entirely in the hands of the physician. The second, and Shane believes, the most common patient-physician relationship, occurs when the physician is considered to be benevolent and kind to the patient, but where the physician's opinion always seems to prevail if a disagreement in the treatment plan occurs. Shane's reflections lead her to suggest that the best relationship for the patient, but the most difficult to attain, occurs when the physician views the patient as a mutual participant in any interaction. As a mutual participant, the breast cancer patient would fully discuss all effects and risks of the various approaches to the disease, as well as positive or negative effects these approaches may have on the patient's life. Only after full mutual consideration of all alternatives would a decision be reached.

According to the Janis and Mann (1977) definition given

earlier, the third Shane category would be the only category of adequate decision-making, because the individual gives full consideration to all possibilities before coming to any conclusion. In their research, Janis and Mann have found that inadequate decision-making will most likely occur in areas where there is no stress (the decision is not important) or in areas where the stress is so intense as to render the individual unable to function adequately. Unfortunately, for the cancer patient in general and the breast cancer patient in particular, the most stressful times of the disease appear to coincide with those times when decisions must be made (see Massie, discussed below). Thus, according to Janis and Mann, unless the patient is vigilant about the decision-making process, inadequate decision-making will occur due to the increased stress.

A related factor, which appears to be relatively overlooked, is that of decision recognition on the part of the patients. The question is whether patients really comprehend that every time they sign a permission form, or contemplate changing treatments or physicians (i.e. when the internist recommends a surgeon, or the surgeon recommends an oncologist), they are making a decision. The cancer patient particularly is known to be in a highly stressful situation, and likely is unfamiliar with the medical arena. Therefore,

unless these individuals are actually alerted to the fact that they are making a decision, they may not be aware of this fact until it is too late.

Massie (1983) found that the Sloan-Kettering patients with whom she worked showed pronounced psychosocial and physical worries at specific times during their treatments: a) during diagnostic workups, b) upon being told of the diagnosis, c) when a new treatment was to start, and d) when a treatment failed. As one can readily see, three of the areas where Massie's patients were most stressed (b, c, and d), were actually periods when they must have been asked to sign consent forms or search out either a surgeon or oncologist to begin treatment, i.e., decisional areas. Area a, the first area, was also an area where the patients should have been considering what they would do should the tests prove positive, although a decision was not directly called for.

Massie further found that these periods produced difficulty in concentration, restlessness, sleep disruptions and changes in appetite or loss of appetite--signs of increased stress. Massie did not make note of the fact that patients were making decisions during these times. It may be that, as mentioned in the case of Suchman's respondents, the medical model frequently presumes that once a physician is

chosen, the physician will determine the course of the treatment.

Noting the prevalence of the idea among physicians that they should take over decisions for the patient, Friedson (1970) wrote that the last choice the patient made that was based upon the patient's conception of what was medically needed, was the choice of a first physician. "When that chosen practitioner cannot himself handle the problem, it becomes his function, not that of the patient or lay consultants to refer to another practitioner" (p. 209). Because choice is, at this point, taken away from the individual, the physician makes all further decisions. Freidson further remarks, "... indeed the client may be given services for which he didn't ask, whose rationale is beyond him."

The research of Rennie (1980) and Cassileth (1980) is in line with Friedson's observations. These authors found patients be either ill-informed or only slightly informed; nevertheless, these patients had signed consent forms. Thus these patients legally stated that their treatments were explained to them and the information they had received was fully understood by them.

Earlier research (Bard & Sutherland, 1955; Abrams, 1966) found that the point where the patient receives her diagnosis of breast cancer is not only crucial for the patient, but also difficult for the physician. Bard and

Sutherland state that "This information is never easily conveyed or calmly received..." (1955, p. 658). Bard (1970) found that the physician may experience distress and even confusion about what to tell the patient. The confusion may occur because, although it is the duty of physician to impart information about the seriousness of the disease and the impending bodily threat, the task frequently exposes the physician to the emotional upheaval of the patient and other traumatic effects that bad news brings. Haan (1979) has found that when people are distraught they "...tend to pull like behavior from others, so physicians find themselves in emotionally contaminating situations with many patients" (p. 122). The physician, therefore, has the additional tasks of being sensitive to the patient's plight, concerned for her welfare, and accepting of her distress, but at all times maintaining her dignity by regarding her as an autonomous human being who has intelligence and a right to fully take part in decisions which will change her life (see Sheldon, 1982; Breggin, 1980).

Katz and Capron (1975), in discussing the rule of informed consent, have stated that our culture expresses concern and expects respect for the power of human thought. It is this concept of "humanness" which requires that information be given. "By emphasizing the importance of involving

the patient in decision-making in a genuine fashion, this facet of the rule (of informed consent) gives further recognition to his (the patient's) status as a human being" (p. 83). Katz and Capron believe that a decision model which is based upon sharing of information between physician and patient is most beneficial for the patient, particularly in the therapeutic setting. The authors have found that in ordinary therapeutic settings physicians feel relatively free to use a common procedure or treatment without review; whereas, when a treatment is experimental, much more caution is used, and informed consent becomes extremely important. It is not unusual for patients in an experimental program to bring home the consent form, as well as a description of the treatment. They are expected to discuss side effects, problems, and possible benefits with their families. The authors believe that the patient in the ordinary therapeutic setting is entitled to just as much information. They state that using the term therapeutic to define "...interventions in which physicians are free to make decisions for their patients because they supposedly know what's best for them," is "fallacious" (Katz and Capron, 1975, p. 171). Similarly, Singleton and Singleton (1980) agree that if a physician wished to respect his patient's status in the relationship, the patient must be kept informed and allowed to choose her

treatment from whatever alternatives are available. Thus, there is a belief on the part of many medical researchers that in the therapeutic setting, despite the difficulties encountered, the doctor must be totally committed to involving and informing the patient, and also remain sympathetic and aware of the patient's emotional state. Along with this deep philosophical belief that it is important for individuals to maintain their dignity by being fully involved in their own medical decisions, a growing body of research is showing that this is also beneficial for the patient's physical health. Unfortunately, the reality of the situation for the patient is frequently quite different from the philosophical ideal.

It was found by Haug and Laven (1981) that of 81 physicians who indicated agreement with the statements that patients should be well-informed and should question their physicians about problems as they might arise, only eight percent stated they had actually acquiesced to a patient's demands. Waitzkin (1985) found in his research that refusal to share information and decision-making may be due to the desire of some physicians to maintain an unequal power base between patient and physician; that is, "information control may reinforce stratification" (p.83).

Certain medical specialists, in particular surgeons,

have been found to be highly authoritarian (Eisenberg, Kitz and Webber, 1983; Crane, 1975; Coser, 1968; Seaman & Evans, 1961). Since the treatment of breast cancer is usually surgical, this factor may be extremely important with regard to a patient's difficulty in obtaining information. Use of authoritarianism has also been found to increase where uncertainty exists, particularly in medical grey areas where insufficient knowledge exists about the disease, or/and the medical community makes decisions without full disclosure (Light. 1979).

Considering the debate that rages about the best treatment for breast cancer, one sees the disease does qualify as one where uncertainty exists. Physicians uncomfortable with uncertainty would, according to the Light findings, be expected to be more authoritarian.

Kirscht and Rosenstock (1979) also examined the effects of medical uncertainty and found another tactic used by physicians to increase their status. The authors found that physicians, when uncertain, used language and terminology which they believed patients would not understand. This tended to lead to reduced questioning by the patient and the viewing of the physician as the expert (McKinlay, 1975). It has also been found that the use of status by the physician creates difficulties in the physician's relationship with

the patient (DeMatteo, 1979; Taylor, 1979; Zander, Cohen & Stotland, 1959).

There has been presented here a variety of approaches used by researchers attempting to understand only one aspect of the patient-physician relationship. These approaches have been able to examine only a small, although important, portion of overall doctor/patient interactions. They do, however, point out the complexity of the patient-physician relationship. Because that relationship has been recognized for over thirty years as being crucial for the future emotional well-being of the breast cancer patient (Bard and Sutherland, 1955), it is important for those in the health care field to find ways to build up doctor-patient relationships of mutual respect.

DiMatteo (1979) has stated, "Confidence in the physician and the reduction of patient anxiety have been found to be inextricably intertwined..." (p. 17). The actual part information plays in creating this confidence and building up the patient-physician relationship is unclear; however, research has shown that it does definitely have an effect. It may be that the patient perceives a physician who is willing to take the time required to impart information as caring. This, in turn, may increase her sense of well-being. Also, the well informed patient is probably more

fully prepared to accept her treatment plan because she feels more in control of the situation and therefore less anxious.

Patient Control, Coping Ability And Well-Being.

Kubler-Ross' (1969) insights into pain control are helpful for understanding how much the patient's sense of dignity as a person is dependent upon being able to control one's own body. She found that dying or very ill patients, whose pain relief, freedom of motion, and even food selection were controlled entirely by the physicians and the nursing staff frequently became very angry, hostile and acted against their own best interests. If some control was restored, the individuals were more able to accept care, and in some instances had the added beneficial effect of experiencing less pain (Kubler-Ross, 1969; Mills & Krantz, 1979).

Kubler-Ross believes that control of one's body motion is a reaffirmation that one is human, alive and still in communication with the outside world. Hinton (1972) reported that cancer patients who were able to control their own pain medication required less medication than those who were not allowed this control, and they reported less pain and anxiety. Rodin and Langer (1977) and Schultz (1976) found that increased control, even over minor aspects of the day, also increased the individual's sense of well-being.

Taylor, Lichtman and Wood (1984) found that a belief in a sense of control over the course of the cancer was associated with adjustment. Also, independently related to good adjustment was a belief that some "other" could control the course of the disease. The authors note that "self generated feelings of control over a chronic situation are associated with the same beneficial effect" as has been shown in laboratory research on psychological control (p. 459).

It is known to be difficult to maintain individual control over decision-making throughout the course of the disease of breast cancer. One would still be dependent upon her physician for the professional evaluation of her symptoms. The physician has the duty either to recommend that the patient get follow-up testing (such as aspiration, mammography, and perhaps biopsy), or to complete the testing and inform the patient of the results. In investigations into patient attempts to maintain control in medical situations, Mullan (1979) found patients needed an ombudsman to help them through the process and intervene in the many areas where loss of control over the process occurred.

Miller's work (1981) has examined responses which individuals have used during stressful events and she hypothesizes that individuals either monitor or blunt to

cope with stressful events. Individuals who blunt have the ability to block out unpleasant events by utilizing other cognitive skills such as distraction, tuning out the danger, or denial. This mode of coping reduces their stress, but may not be related to the reality of the situation.

Although it seems obvious that cancer symptom discovery is highly stressful (Hinton, 1977; Meyerowitz, 1980), research has shown that the discovery of even insignificant symptoms can create reactions which are associated with stress, and cause reduced ability to cope (Pennebaker & Skelton, 1980; Mechanic, 1980). One long recognized problem connected to discovery of any symptom which could indicate cancer is denial, which can be dangerous should the symptom result in the disease (Cameron and Hinton, 1968). Miller's work points to ways that denial can effectively reduce the stress connected with a noxious situation such as symptom discovery. Peters-Golden, in her discussion of the attributes of cancer, discusses other factors which may cause individuals to deny the disease (1982). Treatment is a long process, and the side effects may appear more unpleasant than the disease itself. Cooperation with the doctor does not guarantee the success of treatment, and the victim must be prepared to deal with prolonged uncertainty and unknown outcomes. It is therefore possible that if the physician

does not clearly specify, any time when a cancer symptom is present, that the disease of cancer is a real possibility, the woman may opt to believe that she does not have the disease.

McIntosh (1974) states that some cancer patients experienced being told of disease in a rather oblique way. Physicians communicated information about the disease so indirectly that their patients were unclear as to their health status. It may be that the physicians believed they were making the uncertainty of the disease easier for the patient to handle. In actuality frequently, the patient was unprepared to face the reality of the disease.

In terms of breast cancer, the patient who receives an indirect communication may have difficulty deciding when the presenting symptom indicates danger, particularly if she hopes there is no cancer because she has been told "not to worry" by a physician prediagnostically. For example, a 1988 pamphlet on breast cancer detection advises that there are many "normal lumps," and that eighty percent of all lumps are not cancerous (The National Care Foundation, 1988). Therefore, although the possible effects of trying to communicate danger to the patient in an indirect fashion are largely unresearched, they would appear to be important,

particularly in view of the proclivity of many patients to deny their symptoms.

More is known about the effects of perceived lack of control occurring after diagnosis. Suchman (1965) sampled 137 individuals whose illnesses required at least three physician visits and either were incapacitated for five or more consecutive days or required hospitalization. He found that a full 81 percent of his sample felt they had not received adequate information. The solution for one-fourth of this group was to change doctors. Most of these changers were male, and the change took place covertly--that is, the patients did not discuss their dissatisfaction with the physician, but instead opted for the back-door solution to the problem. The study does not make clear why the respondents did not confront their physicians; however, according to Suchman the greatest problem for any patient at that time was the adjustment necessary in accepting the control and authority of the physician, which usually brought about feelings of dependency and loss of control over the medical situation. Suchman did not question the medical practice which caused the loss of control, but rather took it as a given. It is of interest, however, that even at a time when full disclosure was seemingly not expected and patients were to be fully under the control of

the physician, patients were disturbed by these practices.

More recently, Taylor (1979) and Raps, et al. (1982) have expressed the belief that patients are pressured to assume a role of compliance in health care. If they do, they are termed good patients. Although such compliance enables a hospital to function smoothly, the patients themselves are adversely affected. Taylor found that these patients may withhold information which could be helpful in their treatment plan. She states that the so-called good patient is often actually in a state of helplessness after an initial reaction of anxiety, denial or depression. McIntosh (1974) found that compliant patients who were unable to gain proper information from their physicians would turn to uninformed sources, receiving misinformation which caused them needless worry.

Morris, Greer and White (1971) showed that deleterious effects could occur months after treatment among breast cancer patients who felt they did not receive full information, and who also did not inform their doctors of the problems they were experiencing. Problems caused in this manner can also persist for years after the treatment ends. One hundred and sixty women who were suspected of having breast cancer were interviewed prior to surgery, and three times post surgery. Only 61 of the women were found to

actually have the disease. The authors wished to understand the women's perception of the adequacy of the information they received about the disease. One third of the women with breast cancer believed they had received inadequate information, and these women had great difficulty accepting the disease. For reasons not stated by the authors, these women never made their physicians aware of how deeply troubled they were. It is of interest, however, that the patient's perceptions, whether or not they are valid in terms of the amount of information they actually received, appeared to influence the outcome of their recuperation. It also may point out the difficulty of an indirect or other party evaluation of a patient. Presumably, if these physicians realized how distressed their patients were, they would have taken measures to attend to the problem.

A study by Wartman, Morlock, Malitz and Palm (1983) raises a similar question to the Morris et al. study. Patients and physicians were not in agreement about the amount of pain and mobility the patients were experiencing. Because these patients were actually experiencing more pain and less motion than their physicians believed to be true, the medication for pain relief was probably not considered to be adequate by the patient. Again, there would appear to be difficulties due to a medical assessment based upon the

conclusion of a second party. A second difficulty for these patients, according to the research of Mills and Krantz (1979), Hinton (1972), and Kubler-Ross (1969) is the increased pain they experienced. The ultimate effect of pain is to reduce the freedom of the individual--by restricting voluntary movement, and to reduce the individual's sense of control--by lowering his or her ability to relieve bodily pain. The frustration connected with this lack of control further exacerbates anxiety and pain, and makes the situation more difficult for the patient to manage. The difficulties which can occur when assessments are based upon the observations of a second party will be discussed further in the next section.

Lefcourt's (1973) observation is helpful in summing up the research presented in this section. He states that although control is an illusory perception independent of human action, it is extremely important when attempting to understand human behavior, particularly that behavior which occurs when the individual is trying to cope with a critical situation. The Taylor (1984) research presented earlier showed that a sense of control in the field is associated with the same effects noted in the laboratory. Specifically, laboratory studies have shown that a perception of control over the environment brought with it beneficial

effects. (See Staub and Kellot, 1972; Houston and Hodges, 1970; Corah and Boffa, 1970; Geer, Davison and Gatchel, 1970) Laboratory subjects were found to perform better under conditions of stress when they had control (Glass, Reim & Singer, 1971; Fosco & Geer, 1970). The overall effects of decision-making and control of the information process in the disease of breast cancer has not been fully researched. There is, for example, research which indicates that individuals who use blunting as a mechanism of coping would not desire more information (Steptoe & O'Sullivan, 1986). It is important to evaluate if an increased sense of control over medical processes actually would be beneficial to each patient's well-being and assist with readjustment problems, or whether this would be the case only for those patients who prefer to monitor information, while some other method of assisting adjustment would be better for those who prefer to blunt stressful situations.

There are many long term studies which show that mastectomy patients have difficulty readjusting to everyday life, post mastectomy. Although this research does not take into account how decisions were made, it has shown (Silberfarb, 1984) that hospitalized breast cancer patients, as a group, are referred for psychiatric consultation at "twice the expected rate," and that these patients have problems in

three aspects of their lives: psychosocial, somatic and the psychiatric (particularly depression and delirium).

Post-Mastectomy Health and Adjustment. Because the most usual treatment for the disease of breast cancer has been mastectomy the focus of this section will be on research on post-mastectomy health and adjustment. Once a patient has had mastectomy as a treatment for breast cancer, she must resume her everyday activities or readjust to long term rehabilitation. It is this type of adjustment that has proven difficult for many post-mastectomy patients. As already mentioned, Holland and Mastrovito noted that some women do appear to have adjustment difficulties. Adjustment difficulties for mastectomy patients have been referenced in other studies of cancer patients as well. Consider the two post-mastectomy studies cited by Silver and Wortman (1980, p. 306): One year post-mastectomy, 39 percent of the women showed severe psychological distress (McGuire, et. al. 1978); up to five years post mastectomy, the women remained significantly more depressed than groups of women without the surgery (Ray, 1978).

In the previously cited Morris et al. (1977) study, post mastectomy problems were multifold and included poor communication patterns, work disturbances, marital problems, difficulties in interpersonal relationships, and poor sexual

adjustments. The woman included in this study (mean age 48 years) were compared to women who were diagnosed at the same time, but whose growths were found to be benign.

Shottenfeld and Robbins (1970) compared a total of 826 women from two age groups (49-55 years and 56-62 years) of post-mastectomy patients and assessed activity levels and return to pre surgery living patterns. There were no significant differences between the age groups--sixteen percent of the younger group and thirteen percent of the older group did not resume their normal activities.

Schmale, et al. (1983) surveyed 103 cancer patients, three years post their last cancer treatment (which could include surgery, chemotherapy or radiation therapy). Fifty-eight of those surveyed were women, but the cancer type was not differentiated. The researchers found no major psychopathology or depression which interfered with everyday life; however, younger subjects expressed a loss of control over thoughts, real concern over every ache and pain and a "sense of sitting on a powder keg and waiting for it to go off" (p. 166). Years after survival, these subjects reported feeling vulnerable both physically and psychologically. They felt that they were less confident than they were pre-cancer. The authors noted that a sense of well being is a subjective and private experience, and that the things that determine

an individual's feelings of well being are highly personal.

In a study by Derogates, Abeloff and Melesarotos (1979), 35 women with metastatic breast cancer who were receiving chemotherapy were assessed using both psychological testing and self evaluative check lists. The results of the assessments were correlated with the victim's survival time of over or under one year. The results showed that survivors expressed significantly higher psychological distress levels and more negative affect--expressing less joy, contentment and affection--than those who survived less than one year.

The researchers also had oncologists rate the victims. Survivors were rated less well adjusted and more negative and resentful toward the illness and the treatments and they expressed poorer attitudes towards their physicians. The study had a major problem area because significantly more of the non-survivors had received two treatments of chemotherapy, which could well have affected the outcome; however, the study does indicate that clinical evaluations, even when carried out by experienced physicians, are not necessarily the most adequate measure of patient well-being.

From the descriptions of the patients it was apparent that those who died earlier in the disease process were less able to communicate hostile feelings than those who survived

longer. One might be able to describe them as helpless or not in control, because their manner was described as quiet, almost apologetic. They were perceived by their physician as better adjusted, but also to have less vigor. Kobasa, Maddi and Hahn (1981) found that stressful life events tend to have less negative impact on people with a constellation of personality traits they termed hardiness--which includes commitment or involvement, control--the sense that one is essential and influential, and challenges--the feeling that change is essential to growth. The authors believe that as stressful events mount in one's life, hardiness seems to be quite important. It may be that what the oncologists were terming "less vigor," in the Derogates et al. study (1979) was actually a lack of what Kobasa et al. term "hardiness."

In an earlier study by Derogates, Abeloff and McBeth (1976) it was found that depression was frequently identified by the physician as an indicator of poor prognosis. This was also mentioned in the previously cited Morris et al.(1977) study. In the Derogates et al. (1979) study, patients were described as depressed; however, they expressed this outwardly by externalizing the negative feelings. They did not appear, outwardly at least, to suffer loss of self worth through their communications. Further they did not appear intimidated by the medical

personnel but communicated their negative feelings freely. When they did not agree, they actively protested. Using the Taylor (1979) formulation, they could be termed "bad patients"; but they did not act out their anger in ways which were self-destructive. Rather they took it upon themselves to speak freely about their concerns and to refuse to capitulate when they disagreed with the physician. These same reactions have been noted in medical literature for over 30 years as beneficial to the patient. (cited in Derogates, 1979, p. 1507).

It is also possible, based upon the findings presented in the last section, to see the less than one year survival patients as behaviorally helpless. Once they had allowed the medical process to be decided for them by their physicians, they become almost bystanders in the process, observing from the outside rather than taking part in and being intimately connected with the medical decisions which were, in fact, changing their lives. Janis and Mann see the phenomenon of giving over control as occurring when the decision maker asks the question, "Is it realistic to hope for a better means of escape?" and receives the answer "No." This individual may then give up searching for a better solution and attempt to avoid any situation which will elicit painful feelings of helplessness. The individual

gives over the decision to another and ignores or avoids all information which goes against this choice. As noted earlier, this type of decision making has been accepted if not encouraged for many years in the medical model, and apparently it is still not considered unusual for patients to entirely give over decision making to their physicians.

Quint (1964) found that the 21 mastectomy patients she interviewed routinely had certain types of problems in recuperating post surgery. Most of these women had a continual dread that they were soon going to die, and many requested information from their physicians about their chances of survival. According to the patients, their discussions with the physician were limited, by the physician, to wound healing and therapeutic regimens. Quint's respondents also believed that they were receiving evasive or non-specific information from the physician, and some of the women changed physicians to get away from the evasiveness. Post changing physicians, however, the women found that they were getting varied information which was also, at times, contradictory to that told them by the initial physician. The inconsistency confused and upset them.

It seems probable that the problem of contradictory information in breast cancer would be more common today than at the time of the Quint study. Further, receiving contra-

dictory information post-decisionally should be more disruptive than receiving this information pre-decisionally. According to Janis and Mann, post-decisionally the individual would want to "bolster" or enhance the initial decision. Even in cases where the initial information search was complete, once a decision has been made, enhancement of that choice should occur. An incomplete initial information search can complicate the post-operative phase when the person opens herself to contradictory information at that point, because it is after the fact. In the case of the women in the Quint study, this should have been particularly damaging because the women changed physicians, and then learned that the second physician did not agree with the initial choice. Obviously, at that point, the woman can do little to change the situation. Had the women heard and evaluated all the information prior to surgery, they would have been exposed to contradictory information before the surgery. Then, if they so desired, they could have adjusted their therapy around the information.

Recent research has shown that utilizing experts, particularly the physician, who are willing to provide the patient and her family with complete information, will effectively reduce uncertainty and anxiety (Molleman, 1984), and both of these factors are characteristic of cancer. The

need to reduce anxiety through information was apparently the reason the Quint respondents wished to search out physicians who were more willing to disclose. It is certainly difficult to begin to complain or attempt to force the physician to change the established disclosure patterns after the surgery is completed. However, because cancer patients are followed by their treating physicians for many years after treatment, unsatisfactory disclosure patterns can, in addition to the problems with the initial decision, create problems while the patient is being followed. This may cause the complaint that the physician is uncaring. This complaint was not only found in the Quint study, but in the studies presented earlier in this paper.

Finally, it is important to understand what part the longevity of the disease plays in the desire for information. Breast cancer that has not progressed may never need further treatment past the mastectomy or lumpectomy. However breast cancer may also be the start of a disease process which then continues for many years. The individual involved in the process may later desire more information, or feel more information should have been imparted at the onset. This may be particularly true if the patient believed that the surgery was a "cure" for the cancer, and later finds chemotherapy or other more aggressive treatments

are necessary. The answers to these types of questions are important if we are to understand the variety of patient information seeking behaviors which exist.

The Janis and Mann model applied to decision-making in breast cancer. The fact that breast cancer patients must make important and life changing decisions from the time of the initial symptom discovery to the recuperation period has already been discussed. One premise of this research is that many of the decisional points which occur during the course of the disease of breast cancer are not salient to the victim. She is therefore unaware of the gamut of alternatives available to her, and this decreases her capacity as a decision maker.

According to Janis and Mann (1977), a measure of decisional quality can be obtained by examination of the "quality of the procedures used by the decision maker in selecting a course of action" (p. 11). They have identified seven criteria which they believe define the adequacy of everyday decision-making. They suggest that if any of these criteria are not met, the quality of the decision-making is reduced. However, high scoring on these criteria does not ensure a good decision. This is particularly true in those cases where there is really no best path to follow, for example, during emergency situations. Thus while a certain amount of selectivity in decision-making is helpful, the decision maker must be careful not to hastily eliminate alternatives due to a perceived need to rush the decision.

The seven criteria are met when the decision maker (a) views a number of alternatives; (b) looks over objectives and values "implicated by the choice"; (c) checks both positive and negative consequences; (d) is open to new information and actually searches out this information; (e) assimilates new information correctly, even if it does not support a preferred choice; (f) reviews the consequences of all alternatives; and (g) carefully sets out to implement the chosen course of action while remaining aware that contingency plans may be necessary.

Janis and Mann believe inadequate decision making will likely cause the decision maker problems after the decision has been made. They particularly believe feelings of post decisional regret will be experienced. My search of the literature leads me to conclude that other stress-related types of difficulties may also occur for the decision-maker who does not complete an adequate information search prior to making the decision, and these difficulties will be related to the individual's loss of control over events as a consequence of the lost decision-making capacity.

Janis and Mann distinguish between ordinary daily decisions and emergency decisions by taking into account two factors. The first is how much the individual has at stake--i.e. the importance of the decision. The second is

the amount of time available to the individual--i.e. the decisional time period. Typically, emergency decisions occur over life and death matters and during a shortened time period. Janis and Mann have shown that emergency decisions increase stress, particularly when the choice which must be made creates a loss for the decision maker. This increased stress can weaken the person's ability to cope with decisional conflict.

Janis and Mann describe five coping patterns. Four of these patterns will generally lead to defective decision-making; the fifth, which they call "vigilant information processing" will likely lead to adequate decisional consideration. The authors believe that their decision-making theory makes it possible to "extend the analysis of decisional conflict by specifying the conditions that decrease the probability that a decision maker will meet the criteria for vigilant information processing resulting in low quality decision-making that leads to post-decisional regret and failure to adhere to the commitment he makes" (p. 52).

It is believed that the Janis and Mann conflict model can be adapted to determine the quality of decision-making utilized by breast cancer patients and other patients facing medical emergencies. Given the limitations of a

retrospective research design it would not be possible in this type of study to completely determine how adequately the individuals met the seven decision-making criteria. Nonetheless, it should be possible to ascertain whether or not the decision maker continued the decisional process to the point of vigilance. It should also be possible to determine what type of emotional and behavioral distress the patient has faced immediately post-mastectomy, and possibly, continues to face as she resumes everyday life. This post-mastectomy stress, occurring as it does post-decisionally, might well be related as much to inadequate decision-making and the resulting sense of loss of control as it is to the illness itself. Therefore, a comparison of adequacy of decision-making and post-decisional stress should show differences in stress related emotional and behavioral disruptions between those who utilize adequate decisional practices and those who do not, with those who have utilized inadequate decisional practices being adversely affected.

As has been presented, research indicates that both information gathering and the patient-physician relationship as it regards the information gathering process is important to the patient. Both areas are also intertwined with the decisional process. It seems likely therefore that if the patient experiences difficulty with

these areas she will have some difficulty with the decisional process as well, which should cause her to be more detrimentally effected than will other patients with more adequate decision-making processes. In particular, it is believed that patients of those physicians who either have tried to overly reassure the patient that she should not be concerned pre-biopsy (which would cause her not to think further about other aspects of the disease process), or those physicians who report their suspicions to the patient in such an oblique way as to allow the patient to feel there is no need for any further consideration, will show post-mastectomy emotional and behavioral damage.

As discussed earlier, the physician who uses this "not to worry" tactic tells the patient not to worry about the presenting symptom because in his opinion her presenting symptom does not indicate cancer. This may leave the patient momentarily relieved; however, it also prevents her from making adequate plans should she later prove to have a cancerous tumor. At a later point she must face both the reality of the disease and the necessity of planning for the disease at the same time. It may be that the physician may have the kindest of motives, and may desire only to spare the patient needless worry; however, the patient who has cancer may perceive the situation differently despite

the kindly intent of the physician.

The Janis and Mann conflict theory proposes five patterns of decision-making that may occur in emergency decisions. These determine the quality of a given decision about how to deal with the emergency. Associated with each pattern is a particular question which is posed for the decision maker as follows:

1. Does the danger signal or warning indicate a serious risk if no action is taken? If the answer is "no," a pattern termed "unconflicted inertia" occurs. The individual has no reason to alter the present course of action. For the breast cancer victim, the discovery of a danger signal would be finding some breast change which would indicate the possibility of a serious disease, i.e., discovery of a lump in the breast or some discharge, etc. Alternatively, the individual's physician may discover the symptom and tell her to seek further help. Most breast cancer patients would then proceed past this first question, and on to the next question in the decisional process. However, it is believed that patients whose physicians utilize disarming tactics would stop their informational search at this point. This occurs because the physician would have told them that the warning signal (i.e., a lump or other finding) was probably nothing to be concerned

about. Later, the individual must be told that the original signal did indicate some serious problem. But even if the patient then tries to institute an informational search she will probably have difficulty doing so, due to her initial loss of control over the process and the damage which occurs in the patient-physician relationship when she learns that her doctor had mishandled vital information.

2. Will serious risks occur if the most available protective action is taken? The conflict model asks if the individual will feel that the most available action will offset further serious risk. If it seems that the action taken will keep the person safe, the level of stress should remain low and the decision-maker should have no preference for any other course of action. Janis and Mann term this pattern of decision-making "unconflicted change." If it does appear that there may be some serious adverse effects despite the course of action taken, the person should move on to another level of decision-making.

The breast cancer victim may ask the physician about available treatment and be told only about mastectomy. If she believes that mastectomy totally removes all portions of the cancer and there is no chance of spread, her decision-making should stop at this level. However, research has shown that for most Americans the word cancer evokes a fear

of death. Due to the increased publicity about the disease, few breast cancer patients are likely to feel completely secure upon hearing that mastectomy is a total cure for breast cancer. Therefore most women should move on to the third pattern of decision-making.

3. Is it realistic to hope to discover a better means of escape? If the individual believes there is no better escape than the one originally discovered, Janis and Mann believe the person enters the pattern termed "defensive avoidance." Here pessimism about finding a better solution sets in, and although the original decision is perceived as unsatisfactory, no better one can be thought of. This individual should avoid any cue that might stimulate anxiety. The individual may keep very occupied, use alcohol, drugs or other diversions to keep her mind away from the situation. Another mechanism used by the individual in this pattern is to "buck-pass." This means that the she may believe that some other person knows much more than she does. She may then give over the entire situation and decision to that person, with the rationalization that the other person will make a better decision. This option has already been discussed in relation to the medical model. Bolstering is yet a third faulty method used in this decisional pattern. The individual avoids any knowledge of possible defects

associated with her choice and then rationalizes why her choice is best. Those who show this pattern are believed to maintain a variable level of stress with a "pseudocalm" exterior.

It is probable that this is the decisional area which will entrap most breast cancer victims. Rosser's research has shown that many breast cancer victims are seriously skeptical about the effectiveness of the treatment of mastectomy for the disease; however, these women may doubt that any other treatment offers them a better chance. Therefore, they may not search out other treatments due to their fears and pessimistic outlook. Most of these patients should utilize their pre-surgery time avoiding all cues about the situation. Some should bolster their decisions by ignoring all new information, including any detrimental information about their choice, or should rationalize that this is the only decision available to them because their doctor suggested it. However, according to the Janis and Mann theory, they should feel stressed whenever they think about the surgery, which would account for the variable level of stress.

When questioned, women caught in this pattern should give accounts of many time consuming events just prior to surgery which distracted them from thinking about their

condition or gathering relevant information. Examples of such events would be continuous shopping trips, lunches or dinners with friends which were out of the ordinary (during the week instead of weekends), or working overtime. It is believed that the women who remain with the third pattern will experience detrimental consequences post surgery due to their lack of decisional input.

4. Is there time to search adequately for alternatives and choose among them? If the individual believes that the choices must be made within a short time span, Janis and Mann suggest that the state of "hypervigilance" will be evoked. This state was discussed earlier, and will only be briefly presented here.

When an individual is made highly aware of the time factor in the decision-making process, she may feel pressured into accepting a solution she does not believe to be satisfactory, because she also does not believe she has the time to search for a better solution. Thus although she wishes desperately to find alternatives, and believes both that those alternatives do exist, and that there are serious risks from the present course of action, she also feels (due to the time pressure) that she is taking a risk using precious time in searching out any new solution. Hypervigilance, therefore, leads to poor judgment and inefficient

actions. The individual is under stress, and is always open to searching out new alternatives; however, the initially chosen course of action may not change, and the actual time available to the individual may not be used profitably. Janis and Mann believe the individual who is hypervigilant will fail to consider the long range effects of the chosen course of action.

Typically, the disease of cancer places people under time pressure, because they are urged to search out care rapidly whenever symptoms are discovered. It is possible, therefore, that a number of breast cancer patients will become hypervigilant. I believe that this decision-making pattern (of being highly aware of time passing) would occur during and after the treatment has occurred rather than before. But should the individual believe she has enough time to institute a search for a better solution, and also believe she may find a better solution, she will enter the next pattern of decision-making, which Janis and Mann call "vigilance."

5. Is there time to search adequately for alternatives and decide among the choices? If the individual believes she does have the time both to search and deliberate, she should enter the vigilant pattern. The individual who becomes vigilant recognizes that there are serious risks

involved in the current course of action as well as in any new course of action. She believes she may find a better solution, and takes the time to find and evaluate such a solution. Her level of stress varies "within the intermediate range," depending upon the communication she receives. She is willing to change her course of action should the information she discovers support such a change. It is possible that a very large number of breast cancer patients will become vigilant information seekers, because of the amount of information which is available outside of the medical model. These women would search out all available information and be open to various treatment options until they decided upon the treatment which was best for them.

The present study seeks to answer some of the questions raised about the consequences of using different patterns of decision making. Only women who have accepted mastectomy as their choice of treatment will be interviewed. There is much information available about the detrimental effects of mastectomy surgery, particularly about both psychological and physical effects which have lasted for years after the surgery. There is not as much information available about effects of the newer cancer treatments. Therefore, it should be very valuable to learn if the patient's control

over the decision-making process, and an openness to information in order to control the process, benefits the recuperative experience by reducing the post surgical physical and psychological after-effects of mastectomy.

Because in recent years most women have been exposed to new information about lumpectomy and radiation as alternative therapies, it is important to learn why a woman accepts the more damaging surgery. Does she actively choose this alternative because she truly believes it offers her more safety, or because she has given over the choice to her physician who has chosen this option for her? It is also important to learn how open women are to information, and whether being more open to information leads to greater control of the decision-making process.

Finally, the research will explore the possible adverse effects of attempting to lessen the impact of the disease on the patient, prediagnostically, by telling her "not to worry."

Hypotheses.

1. Women who fall into any of the four erroneous decision-making patterns as described by Janis and Mann will have more difficulty adjusting to their mastectomies than will those women who reach the final category termed vigilance.

1b Women who fall into any of the four erroneous decision-making patterns will verbalize more long term unresolved regret about the decision.

2. Women who are told "not to worry" by their physicians, and who attend to this communication, will exhibit the same amount of post-mastectomy adjustment difficulty as will those who fall into another erroneous decision-making pattern.

METHOD

Subject Selection: Forty women volunteers aged 29 through 72 were interviewed. They received no remuneration for participating.

To locate subjects the interviewer obtained the cooperation of six registered nurses from different metropolitan locations in and around the New York City area, a physician from a metropolitan hospital, and a Reach to Recovery volunteer from a New York City suburb. All of these were individuals who had worked with mastectomy patients. They were asked to gain permission from former patients to be referred to the interviewer.

The six cooperating nurses told each prospective respondent that a female registered nurse was conducting research on the experience of mastectomy, and was interested in speaking with women who had had this surgery within the past seven years. They were told the interview would be approximately two hours long, and would be totally confidential--even the recruiter would not know whether or not the prospective respondent agreed to take part in the study. If they asked about the interview content, the women were informed that it was about their own experiences after

discovering or becoming suspicious that they had breast cancer.

The Reach to Recovery volunteer arranged for the interviewer to speak to a group of women. The volunteer gave them the above information about the nature of the interview and asked if they would either provide names and addresses or call the interviewer at home if they decided to participate. The physician obtained the names and addresses of thirty patients who were willing to be contacted by the interviewer, and they were sent a letter containing the interview information.

Forty-six women agreed to have an initial contact. Once the subject either contacted the interviewer, or was contacted by her, the interview information was reiterated. The subject was told the interview would be conducted at her convenience, and at a location which would afford privacy. While almost all subjects chose to be interviewed in their homes, two chose a library. The women were told that they could withdraw from the study at any time before the interview by calling the interviewer, and could terminate the interview at any point once it got started. Respondents were also told they would not be expected to answer any question which they felt was too private or made them uncomfortable. Finally respondents were informed they would be

called at home one day before the appointment as a reminder. The points about confidentially and interview termination were repeated right before the interview began.

Of the 46 who had an initial contact, four later became doubtful about their ability to handle the interview emotionally, and withdrew. Of the 42 interviews conducted, two were not included in the data analysis due to the subject's misunderstanding of the criteria for inclusion in the sample. One of these women had actually had a lumpectomy which she mistakenly termed a mastectomy, and the other was ten years post surgery. Both did not wish to terminate the interview so that the data were gathered but not included in the study. Thus the results are based upon a total of 40 interviews. The 40 subjects had been admitted to a total of eight hospitals and had been treated by 33 different physicians. Demographic information and disease characteristics about the 40 subjects are given in Table 8 of the RESULTS Chapter.

Nature of the Interview: To test the hypotheses of the study, the attempt was made design an instrument which would (a) be sensitive to patient's information gathering and decision making occurring in connection with the disease of breast cancer, and (b) cover the seven criteria determined by Janis and Mann to be important for adequate decision

making, and (c) assess emotional and physical well-being post surgery.

The entire interview schedule is presented verbatim in the Appendix. It consisted largely of open-ended questions designed to insure recall of the illness. As much as possible, the items were arranged sequentially, to aid the respondent's recall of significant experiences from symptom discovery to the present time. The item topics are described below:

1. Variables relating to the discovery of the symptom before the actual diagnosis of breast cancer, including pre-diagnostic knowledge and the manner in which the individual began physician selection.

2. Diagnostic testing and post diagnostic treatment, including the subject's understanding of the diagnostic work-up which occurred, and the number of medical opinions and alternatives for treatment which were considered.

3. Follow-up treatment post surgery, with particular emphasis upon how post-mastectomy treatment was decided upon, how much information was gained, and how many opinions were obtained before treatment was agreed upon.

4. After effects of the mastectomy, including stress symptoms, how long it took to resume usual daily routines; difficulties encountered with household and job related

chores, and with telling others about the surgery, and the reaction of others.

Thus the interview attempted to measure, evaluate and understand the decision-making methods of the respondent within the framework of her perceptual viewpoint, exploring all nuances of her memories of the illness. The interview schedule was modified and revised after piloting the first version on nine mastectomy patients. The revision eliminated items found to be redundant, rearranged certain items to make them follow better sequentially, and shortened the questionnaire to a more manageable length without sacrificing study objectives. The revised interview took between one and one-half hours to two hours to complete and each interview was tape recorded. The tapes were transcribed by the investigator, and from that point the respondents were identified only by number.

Dependent Variables: Five stress symptoms which might have been mentioned by the respondent, formed an anxiety checklist. These were changes in appetite, difficulty in concentration, sleeplessness, sense of helplessness or inability to change the future, and depression. These checklist symptoms must have been experienced by the subject for five or more days, and not have been present prior to diagnosis. The score was the number of symptoms checked by

the respondent. Also analyzed separately were reports of the following: (a) changes in the use of alcohol or drugs, (b) resorting to some type of psychological counseling post surgery, (c) and positive or negative changes in the subject's life since the discovery of breast cancer. Finally demographic information was obtained.

Independent Variables: To measure the adequacy of the respondent's decisional behavior with respect to medical treatment, five categories were defined which were based largely upon Janis and Mann's five patterns of emergency decision making (described earlier). The five new categories are as follows:

1. Not To Worry (based upon Janis and Mann's pattern of "unconflicted inertia"). Any respondent who stated that after examination of her presenting symptom, her physician advised her not to worry about the symptom, was placed in this category. It did not matter what course of action she may have later followed, nor whether or not she believed the physician had only kindly intentions when he made this statement. (See "unconflicted inertia," page 40).

2. Passive compliance (based upon Janis and Mann's "unconflicted change"). Respondents reported that after hearing the physician's diagnosis and treatment recommendation (i.e., mastectomy) they were open to receiving new

information, but never actively searched for it, and perhaps were not really interested in receiving it (although they did not necessarily voice opposition to the idea). (See "unconflicted change," page 41).

3. Closed to information (based upon Janis and Mann's "defensive avoidance"). Respondents reported that they wished to receive no information at all and actively avoided information. (See "defensive avoidance," page 42).

4. Open to information but not change (based upon Janis and Mann's "hypervigilance"). Respondents reported that they were receptive to new information (did not mind receiving new information) but felt they could not afford to reevaluate their situation, despite the information, due to time pressure. (See "hypervigilance," page 44).

5. Active information-seeking (based upon Janis and Mann's "vigilance"). Respondent stated that she actively attempted, in various ways, to gain information before making a decision regarding the disease. (See "vigilance," page 45).

Coding of Responses. Two judges, both registered nurses, were employed for independent coding of responses where required, and for checking the accuracy of precoded responses. The nurses were given the 40 transcribed interviews (See Appendix A, page 97). The interviews were transcribed from tape onto answer sheets, by the inter-

interviewer. To protect respondents identity, each answer page was identified by first name and interview number only. These sheets included those areas where precoding of answers was possible, as well as the hand written transcription. (See Appendix C, page 125, for copies of the answer sheets onto which interviews were transcribed.) Precoding was possible when a "Yes" or "No" response was expected, or when there was an area where one could expect a certain limited number of responses to the question. For example, Question 1 A asks, "Did you notice some sign or symptom either through self examination or some other method that made you aware a problem might exist." Since the answer of either "Yes" or "No" was expected, these responses were already printed on the answer sheets. If the respondent added more information, after the "Yes" or "No" response, this too was added to that individual's answer sheet.

The coders were asked to utilize the interview schedule with each answer sheet. They were asked to check the accuracy of the precoded responses against any further statement made by the respondent and also to look for any statements which might prove contradictory to any other information given. They were asked to determine the number of respondents who carried out adequate decision making, based upon their own medical expertise and the Janis and

Mann guidelines, and then to perform counts for the dependent variables. They were asked to discuss any areas of disagreement for resolution.

It was determined by the two registered nurse coders, after reading the Janis and Mann guidelines, that at the very minimum, a complete information search on the part of a breast cancer victim should have included the following: 1. That the individual not have stated either that she did not wish information or that she regretted receiving information. It was believed this type of answer (see Question 7) indicated difficulty with the basic premise of openness to new information, set forth by the Janis and Mann criteria. 2. That the individual not be aware of a tremendous time pressure (hypervigilant), as this would prevent her from openly examining information. 3. That the individual had gained at least one independent second surgical opinion. (Independent meant an opinion from a second surgeon not in any way connected with or recommended by any other physician seen; for example, not an opinion from a different physician in the same group practice, nor a physician recommended by the first surgeon even though this physician might be in a different practice). 4. That the individual had shown by her responses that she questioned at least one physician about her treatment options, asked about her prognosis, and

about any contingencies she might have should the mastectomy treatment fail. 5. That the individual have indicated in her answers to the various questions on searching for information, that she searched to the best of her own ability. (This did not mean that the individual was successful in gaining the desired information, only that she attempted in various ways to gain it.)

The coding of the categories was quite straightforward, as the majority of the responses were either precoded or consisted of items to be counted.) Coding for the decision-making categories was performed as follows:

1. Not to worry. The woman's answer to Question 4 A stated that she was told by the initial physician that her presenting symptom probably indicated nothing, or was nothing to worry about, and also, in answer to Question 4 B, she said she was told not to worry. Thus, the Not to worry category was a simple count of all women who gave these two responses. Women judged Not to worry were also later analyzed in terms of the other decision-making categories, but despite any category of decision-making they might have obtained through later action (once they realized they indeed had cancer), they were placed this category based upon their answers to Question 4 A and B. The not to worry statement is felt to coincide with the answer "no" to the

first Janis and Mann question. That is that the individual actually believed the initial warning sign (presenting lump, breast skin change, etc.) did not indicate a need for them to change their present course of action. Thus, the action they took upon signal discovery was the determining category placement.

2. Passive Compliance. If in answer to the information seeking questions (questions - 5 A, E, G, I, J; 9 B, C; 10 B, C, D; and 13 H) the woman indicated that she would have liked to have received information, but never sought out any information, she was placed in this category. The exception to this placement occurred if she also indicated that she was aware of time pressure, and thus also believed she did not have time to search for information. Therefore, time pressure awareness removed the individual from this category and placed her in Category 4.

3. Closed to information. If in answer to Question 7 the woman stated that she intentionally did not want information, and her answers to the information seeking questions (Questions given in Category 2, above) were consistent with this response, she was placed in the "closed to information" category.

4. Open to information but not change. If in answer to Question 13 F, the woman stated that she was worried

about the amount of time passing, and that she believed she did not truly have time to think about alternatives, she was placed in this category.

5. Active information seeking. Women in this category were judged to have made a complete information search based upon the criteria as explained above. Thus, the raters decided that these women actively sought information based upon their responses to the information seeking questions given above; had received at least one independent second surgical opinion (Question 8); and showed by questions to the various physicians (Question 3 D; Question 5 A, B, C, D, E, F, G; Question 8 C 2, 3; Question 9 B, C; Question 10 A) that they truly wanted to know about treatment options, and pressed to gain this information.

RESULTS

Independent Variable The decision-making categories used in this study are described fully in the METHOD Chapter and are presented only briefly here. Forty interviews were analyzed by two raters (registered nurses). The raters independently assigned each respondent to one of the five decision-making categories on the basis of her reported information-seeking behavior before undergoing surgery. Criteria for all but the last category were straightforward. The raters agreed on all but five cases, all of which involved the final category (as explained below).

Due to small sample numbers, the five categories based on Janis and Mann that are described in the METHOD Section were reduced to four by collapsing Categories 2 (Passive Compliance) and 4 (Closed to Information) as follows:

1. Not to worry (N = 10) Women who were told by their physician that the presenting symptom was nothing to worry about (or probably nothing to worry about). These patients believed the tests were routine and precautionary. The tests and the doctors' statements were accepted without any additional information search. Each woman in this group reported she was stunned to learn later she had cancer.

Statements made by these women indicate how fully they

attended to their doctor's "not to worry" statement regarding the presenting symptom. For example, at the time of her symptom discovery, one woman in this group was breast feeding her infant daughter. She noted a strange greenish-tinged discharge both in-between and during breast feedings. After seeing her doctor she returned home and continued breast feeding the baby until after her visit to a second doctor (recommended by the first) who informed her of the cancer diagnosis.

Another woman, who was told "not to worry" about a lump she discovered in her breast, felt completely relieved. According to her report, her doctor stated she should return in about a month for reexamination. Her husband who noted the same lump a few weeks later, insisted that it was of serious concern to him, if not to her, and he felt she needed immediate testing. She stated she did so to placate him and was not prepared for the diagnosis of cancer.

2. Closed to information (N =11) These women were aware that they did not want information. Five of the 11 expressed anger at well-intentioned individuals who unwittingly gave them information. They were clear in their desire to avoid any type of written information and declared they would not have read anything which went against their

decision, had it been provided. In fact, they went to great lengths to avoid exposing themselves to any information about breast cancer. (For example, two women mentioned turning off the television during a highly publicized news feature on breast cancer innovations, and three mentioned refusing to buy any magazine which featured, on the cover, a story about breast cancer. One woman stated she became annoyed when she discovered the newspaper she was reading had an article on breast cancer.)

3. Open to information (N = 10) While seven of the subjects in this category did not actively search out information about the disease, they did not mind if they gained information. Also included in this group were three subjects who stated they did not search out information because they were very aware of time pressure--of the need to have surgery "before the cancer spread." These three women stated they would have preferred to have searched out information, but because of what they believed about the rapidity of spreading cancers, they were not able to do so. (These three were placed by the two raters in the original Category 2, as described in the METHOD chapter, and would have been termed hypervigilant by Janis and Mann.) Due to the small N's, and the fact that the two groups appeared to belong together conceptually (both open to but not actively searching out information), the original Category 2 subjects

were placed in this category.

4. Seeking Information (N = 9) The final group was initially conceptualized as made up of patients who had completed their full information search. However, only four women were judged to have done this. All of these women received at least 2 independent opinions. There were 5 other subjects who were judged by the raters to have actively searched for information to the best of their ability, although they were not judged to have satisfactorily completed the information search according to the criteria. Four did not gain an "independent" second opinion, and one had unanswered questions which she did not pursue. These five women were quite different from the Category 3 ("Open to information") group, because none of the women in that group had in any way attempted actively to search for information. These five were actually closest in profile to the group judged to have completed their information search. Therefore, they were included for analysis in this group, which was then termed "Seeking Information."

Hypothesis 1

Hypothesis 1 stated that women in the highest category (now Category 4--Seeking information) as compared with those in the other decisional categories would (a) have less difficulty adjusting to the post mastectomy period than

women in the other categories, and (b) exhibit less of the feeling of "regret" about the decision which Janis and Mann predict is encountered by individuals making incomplete decisions.

Specifically, it was predicted from Hypothesis 1a that subjects in Category 4 (Seeking information) would have more favorable scores than subjects in the other decisional groups on each of the following five measures: anxiety checklist, positive life changes, negative life changes, alcohol/drug use, and resort to psychiatric or psychological assistance.

Results for Anxiety Checklist The internal consistency of the anxiety checklist scale as estimated by Cronbach's coefficient alpha was .71, indicating that reliability was adequate. Next a one-way analysis of variance (ANOVA) was carried out, in which the four decisional categories were the independent variable and anxiety scores were the dependent variable. For this analysis, F (3, 36) = 4.15, p < 05. To compare, a priori, the differences between Groups 1, 2 and 3 combined and Group 4, a t test was used. Table 1 shows that, as hypothesized, Groups 1, 2 and 3 were significantly different from Group 4 in post-operative anxiety scores, with Group 4 showing significantly less anxiety. (t = 2.98, p < .01).

TABLE 1

Comparison of Groups 1,2 and 3 with Group 4

On Post Surgical Anxiety Scale

Group	N	Mean Anxiety Score[a]	t	df	p
1,2,3	31 (10+11+10)	2.2			
4	9	.66	2.98	36	<.01

[a] Scores could range from 0 (lowest anxiety) to 5 (highest anxiety)

Table 2 shows the means of each of the four groups on the Post Surgical Anxiety Scale. Looking at the group means, it can be seen that anxiety scores diminish progressively from the two lowest levels of information search (Groups 1 and 2 to the highest level (Group 4). To appraise these between-group differences, a posteriori, the Tukey test with a Bancroft modification for unequal Ns was used. Table 2 shows that Groups 1 and 2 reported significantly more signs of anxiety than Group 4 (ps both < .01); while Group 3 was not significantly different from Group 4.

Overall, the results for the anxiety scale do support Hypothesis 1, however, as Table 2 shows, there does also appear to be a beneficial effect (in terms of lower anxiety) to the mere fact of being open to information, even if that information is not actively pursued.

TABLE 2

Comparison of Decisional Group 4 With Other Groups on Post-Surgical Anxiety Scale

		Comparison with Group 4		
		Mean	Tukey	
Group	N	Anxiety[a]	WSD	p
1 (Not to worry)	10	2.9	2.24	<.01
2 (Closed to information)	11	2.5	1.84	<.05
3 (Open to information)	10	1.2		ns
4 (Seeking information)	9	.66		

[a] scores could range from 0 (lowest anxiety) to 5 (highest anxiety)

Further testing was then carried out to see if the scores of Group 3 differed significantly from those of Groups 1 and 2. The Tukey test for a posteriori data, was used for this comparison as well. Group 3 was found to have fared better in terms of post-operative anxiety than Group 1 (Tukey = 1.7, $p < .05$), and Group 2 (Tukey = 1.3, $p < .06$), showing that Group 3 was closer in profile to Group 4 on this measure.

Results for Positive Life Changes Post Surgery Positive change scores were derived from responses to Interview Item 23-D8 (see Appendix B, page 120), which asked an open ended question about any positive life changes that may have occurred because of the breast cancer. Coder agreement on the number of positive life changes mentioned by each subject was perfect except for slight disagreements regarding responses of two subjects. See Appendix B for a more complete description of how the positive life statements were counted, as well as for selected respondent statement (Appendix B, 121). The two disagreements were reconciled through discussion. The four decisional categories were the independent variable, and the number of positive changes mentioned was the dependent variable. For the one-way ANOVA, F (3, 36) = 7.72, $p < .01$. An a priori comparison of differences between Groups 1, 2 and 3

combined, and Group 4 was completed usinga t test (t = 3.00, $p < .01$). As Table 3 shows, Group 4, the "Information seekers," mentioned significantly more positive post-surgical changes than did the three other groups (t = 3.00, $p < .01$).

TABLE 3

Comparison of Groups 1,2 and 3 with Group 4
On Post Surgical Positive Life Changes Noted

Group	N	Mean Number of Positive Changes	t	df	p
1,2,3	31 (10+11+10)	.83			
4	9	2.1	3.00	36	<.01

Mean based upon a count of the number of positive changes noted by the respondent post mastectomy. The higher the mean the more positive changes noted.

As Table 4 shows, there were marginally significant tendencies for Group 4 the "Information seekers," to mention more post surgical positive changes than each of the other three groups, (Tukey Test).

TABLE 4

Comparison of Decisional Group 4 With

Other Groups On

Post Surgical Positive Life Changes

		Comparison with Group 4		
Group	N	Mean Number of Positive Changes[a]	TUKEY	p
1 Not to worry	10	.9	1.2	<.09
2 Closed to information	11	.99	1.11	<.10
3 Open to information	10	.7	1.4	<.08
4 Seeking information	9	2.1		

[a]Mean based upon a count of the number of positive changes noted by the respondent post mastectomy. The higher the mean the more positive changes noted.

Results for Negative Life Changes Post Surgery As with the positive life changes, the negative life change statements mentioned were based upon responses to Question 23-D8 (See Appendix). Coder disagreement occurred about the count on two statements made by the respondents. These disagreements were reconciled through discussion. (For a

negative life changes statements, see Appendix B, page 122. For sample statements see Appendix B 123). The four decisional categories remain the independent variable, and the number of negative changes mentioned was the dependent variable. The mean number of negative changes mentioned by group were: Group 1 = 2.5; Group 2 = 1.45, Group 3 = 1.2; Group 4 = 1. The higher the mean, the more negative changes mentioned. The means are in the predicted direction. However the results of the one-way ANOVA fell just short of significance, $F(3, 36) = 2.38$, $p < .06$. The t test between Groups 1, 2 and 3 versus 4 was not significant. As Table 5 shows, there was a significant difference between Group 4, the "Information seekers," and Group 1, "Not to worry," (Tukey Test).

TABLE 5

Comparison of Decisional Group 4 with other Groups on Post Surgical Negative Life Changes

	Comparison With Group 4			
Group	N	Mean Number of Negative Changes [a]	Tukey WSD	p
1 Not to worry	10	2.5	1.5	<.05
2 Closed to information	11	1.45		ns
3 Open to information	10	1.2		ns
4 Seeking information	9	1		

[a]Mean based upon a count of the number of negative changes noted by the respondent post mastectomy. The higher the mean the more negative changes noted.

Results for Use of Alcohol and Drugs Post Surgery

Respondents were asked whether or not they were using alcoholic beverages or tranquilizers more than they had before the illness (see Appendix, question 23D5). A one-way analysis of variance (ANOVA) was carried out, in which the four decisional categories were the independent variable and an increase of alcohol or drug use (over pre-surgical

levels) was the dependent variable. For this analysis, F (3, 36) = 4.66 $p < .01$. Although the t test of Group 4 versus the other three groups combined was not significant, it can be seen that the group means were in the predicted direction (Group 1 = .6; Group 2 = .09; Group 3 = .03; Group 4 = 0). When Tukey tests were done between Groups 1, 2 and 3 separately, and Group 4, none of the differences were significant.

Other Hypotheses Hypothesis 1b stated that women who fell into any of the four erroneous decision-making patterns as described by Janis and Mann (my Groups 1, 2 and 3) would verbalize more long term unresolved regret about the decision than would women in the highest category (Group 4). This was not found to be the case in this study. In answer to Questions 12 C, D and E, (see Appendix) all the women in this study indicated that they were satisfied with their decisions, that they believed they had made the correct decision, and that they would not change the decision in any way. They expressed no regrets either for the decision or the way in which they made it. Many of the women voluntarily stated that they were still alive and that was enough. It is interesting that women who reported the most adequate pattern of decision-making, Group 4 (Information seekers), did not appear to view their decision as more

positive than did the other groups of decision makers. All of the women tended to view their mastectomy as a positive factor in ridding their bodies of cancer.

Hypothesis 2 Hypothesis 2 predicted that the women who were told "not to worry" by their doctors, would experience the same amount of post-surgical adjustment difficulty as other groups of women who did not complete the decision making process. This hypothesis was correct. As Tables 1, 2, 3, 4 and 5 have shown, these women were highly affected by the disarming process, just as much, if not more, than either of the other two erroneous decisional groups.

Comparison of other cancer-related variables Certain cancer-related problems could have impacted greatly on the results of this study. As Table 6 shows, there were no significant differences among the groups in the following: (a) Number of women who had experienced a relapse at the time of the interview; (b) Number of women who had been found with positive nodes (more advanced stage of disease at time of discovery) and then received either chemotherapy or radiation therapy; (c) time that had elapsed between the cancer treatment and the interview date.

TABLE 6

Comparison of Decisional Groups on Selected Cancer Characteristics [a]

Group	N	Mean Number of Months Post Surgery	Relapsed Prior To Interview [b]	Required Chemotherapy [b]
1 [c]	10	24	1	5
2 [d]	11	31.3	1	5
3 [e]	10	40.8	3	6
4 [f]	9	23.5	2	4

[a]Note: F for one-way ANOVA was nonsignificant. [b] Number of Subjects. [c] "Not to worry," [d] Closed to information, [e] Open to information [f] Seeking information

Comparison of decisional groups on questions related to time passage from symptom discovery to treatment Question 1E of the questionnaire asked the respondents how long they waited from the time of symptom discovery until they sought medical treatment. There were no significant differences among the groups on this question. All of the women in this study sought immediate (as soon as they were able to get an appointment with their physician) medical attention once the

symptom was discovered. The longest waiting period was under two weeks.

There was, however, an interesting and significant finding related to the amount of time which actually passed from symptom discovery until treatment occurred. Question 4D was framed to have the respondent explain how long the time period was between symptom discovery and treatment. In Question 4F, this time question was again presented for increased clarification.

As can be seen from Table 7, Group 1 women reported having a significantly longer period of time pass before they received cancer treatment (mastectomy) than did the other three groups. For this analysis, F (3, 36) = 18.44, $p < .01$. To appraise these between group differences, *a posteriori*, the Tukey test with a Bancroft modification for unequal Ns was used, $p < .01$.

TABLE 7

Comparison of Decisional Group 1 With Other Groups on Time Passage from Symptom Discovery to Mastectomy

		Comparison with Group 1		
Group	N	Mean Weeks of Time Passage	Tukey WSD	p
1 Not to worry	10	21.2		
2 Closed to information	11	2.27	18.9	<.01
3 Open to information	10	2.5	18.7	<.01
4 Seeking information	9	3.67	17.5	<.01

It is obviously impossible to determine from the respondent's statements whether or not the doctors clearly told these Group 1 women that there was an urgent need for them to either seek out further diagnostic work-ups or to return to the office for this type of diagnostic work-up. The study is retrospective in nature, and therefore quite limited in this respect. It may be that the patient did not perceive the doctor as stressing the need for immediate diagnostic work-up based upon her attention to the "not to worry" statement. It is also possible that these patients' doctors actually did not stress the importance of rapid follow-up because they sincerely felt that the presenting

symptom was benign. It does seem clear that each woman in this study, upon discovery of her symptom, was concerned about the symptom, and took the precaution of seeking out medical intervention. Further, after this medical intervention, only those women who remembered hearing a "not to worry" statement were delayed in receiving cancer diagnosis and treatment. The reasons for this delay are not clear, but do warrant further study.

Demographic information The women who took part in this study were highly educated, with an average of 14 years of schooling. Years of education was not significantly different among the groups. Although the age of the study participants ranged from 29 to 74, only two women who took part in this study were in their 70's and one was under 30. Ages were not significantly different among the four groups. Other factors found not to be significantly different among the groups were religious orientation, income levels, and marital status. Table 8 presents this Demographic information.

TABLE 8

Selected Demographic Information

Factor	Group 1 (N = 10)	Group 2 (N = 11)	Group 3 (N = 10)	Group 4 (N = 9)
Mean Age	41.3	48.6	48	48.4
Religion: [a]				
Protestant	3	3	4	1
Catholic	3	3	2	3
Jewish	4	5	3	5
Other	0	0	1	0
Marital Status: [a]				
Married	8	9	8	6
Widowed	0	1	1	2
Divorced	2	0	0	1
Single	0	1	1	0
Income Level: [a]				
Above $30,000	3	7	8	6
Below $30,000	2	4	2	3
Years of Education:	14.4	13.2	15	13.6

[a] Note: Numbers refer to number of women in the category

DISCUSSION

The main hypothesis of this study received support. Women who went through an informational search and reached a more informed decision regarding mastectomy as the best treatment for their breast cancer, had significantly less post surgical anxiety than did women who had the same surgery but either did not carry out any informational search or who were informed by their physicians at the start of the disease discovery process that they need not worry, causing them to halt any type of decisional process until after the results of the diagnostic tests. These results were predicted on the basis of the Janis and Mann theory.

Unexpectedly, the data also suggested that while the decisional process is important, utilizing the optimum decision-making pattern may not be quite as relevant to the patient's overall post surgical well-being as was originally hypothesized. This statement is made for two reasons. First, not all of Category 4 subjects (Information seekers) made what would be considered an adequate medical decision (some, as mentioned, lacked an independent second opinion, which is considered by most medical consumer advocates to be a minimal requirement). Yet the entire group did score

significantly better in the measures of post surgical adjustment. The second reason involves the Category 3 women, who were merely receptive towards receiving information, but who did not search it out in any way. These women also fared better on the post surgical anxiety scale than did those women who, at the start of the process, either resisted information or were encouraged not to worry.

The question arises as to why the act of searching out information, or even of simply being open to information, might have a beneficial effect on the emotional recovery of breast cancer patients. Understanding of this point is particularly important if one considers that all of the women involved in this study reached exactly the same conclusion about the treatment for their breast cancer (i.e. they decided to have surgery). In considering this study, it is important to realize that recovery from the disease may not be related to the amount of understanding the individual gained about the disease because successful breast cancer treatment, from a medical point of view, is judged in terms of the length of time the individual remains free from disease reoccurrence. A few disease free years do not indicate a cure or a correct decision. Actually knowing whether the chosen procedure halted the disease may take seven to ten years; and thus what may have seemed to be the

right decision at one point, may prove to have been incorrect just a few days or months later when symptoms reappear. Many cancer victims (see Schmale, et al., 1983) have been quoted as stating that this fear of reoccurrence causes them years of anxiety. Therefore, it is not profitable to view the woman's decision in favor of mastectomy only in terms of information gained about possible disease treatments, which then led to the choosing of this particular surgical treatment. This is not what caused the women "seeking information" to fair better on post treatment measures. Rather, as suggested by Janis and Mann, a good decision must take into account any possible outcomes of the entire process under consideration. In the case of a decision about the disease of cancer one must understand that knowing eventual outcomes may take years.

In conjunction with this point, it must be understood that some of the women in this study, who took the time to seek information (Group 4), still had the need for chemotherapy after surgery. Others had relapses before the interview. Either outcome would certainly indicate to the patient that the surgery was not a cure, and possibly might lead them to believe that surgery might not have been the best course of action. Still, "Information seekers" were not only found to suffer fewer post-surgical emotional after

effects, they also were able to see the noxious event more in terms of the positive changes it brought into their lives and less in terms of negative changes. Interestingly, this finding carried through for those who were only "Open to information" (Group 3). Being open or receptive to new treatment ideas, even if they are not actively searched out, may be one way of keeping control over a stressful medical situation. The open mindset may encourage the individual to continue to think about the disease process, which in turn may lead to better preparedness if one must later cope with disease continuation after surgery.

It may also be helpful to reconsider some of the issues which surround patient information seeking, already discussed in the first chapter, and to understand how they may relate to the present study. The central theme in the literature concerning patient information seeking appears to be the importance of full disclosure in the overall well being of the patient (Friedson, 1970; Katz & Capron, 1974; McIntosh, 1974; Rennie, 1980; Cassileth, 1982; Sheldon, 1982; Breggin, 1982). However, there is also a long held belief that full disclosure may not be best for every patient (Bard & Sutherland, 1955; Friedson, 1970). This belief places the burden on the physician of determining how much information each patient can handle at each point of

the medical treatment. Research suggests that the withholding of information may be unsatisfactory for both physicians and patients.

Because the present study was retrospective in nature it was not possible to analyze any of the actual information imparted by the respondents' physicians, or even to comment on how much or how little information was actually received by the respondent, either from the physician or from any other source. Under consideration are the respondents' perceptions about the type and amount of information they desired pre-decision making, the type and amount of information which they stated they actually obtained, and the receptiveness they stated they felt towards receiving information at that time. The women's perceptions, when considered along with the literature on information seeking, do give clues as to what may be occurring when physicians impart information to patients facing serious disease. While the information may not be pleasant, it does give the individual a chance to accept the fact that there may be future problems, and to begin to think about possible solutions or at least about ways of handling these problems. This may be why patients state they are so intent on seeking information, and why they are so afraid that physicians are withholding information from them.

Studies show that many physicians insist that they have imparted full information, but that their patients somehow have not absorbed what was said. It must be considered that there may be differences in the way in which patients are able to take in various types of information at the time it is relayed. Although this study did not examine personality differences among the women interviewed, it is quite possible that the differences found among the groups were related to personality factors. Perhaps patients who tend to blunt unpleasant situations (Miller, 1981) do not take in information as readily or fully as those who tend to monitor them. Not attending to information may serve a positive function in the face of an unpleasant but minor office or hospital procedure, but may actually hamper the individual's ability to attend to information during serious illness. It is therefore important to know if monitoring behavior is actually related to pre-decisional information gathering, and also to carefully distinguish between pre-decisional monitoring and post-decisional monitoring. Information gained about a process before the decision has been reached should prove to be beneficial. However, some studies have focused on individuals who are actually monitoring information post decisionally. One example of this type of monitoring would be asking questions about a

procedure and attending vigilantly to a procedure while it is being performed or even after it has been performed. This type of monitoring should only increase anxiety because no decisional changes can take place at that point.

If it is found that certain patients, due to personality differences, cannot absorb all the information that is imparted regarding serious disease after only one or two visits to the physician, there are ways to get around this problem. Medical regulations routinely insist that "experimental" treatments as well as any related options, must be fully explained, both verbally and in writing, in terms that the lay person can understand. This practice is successfully being carried out in hospitals across the country. Many experimental treatments, which are frequently of a complicated pharmaceutical nature, cannot take place until the patient is made aware of all the consequences and side effects of each drug being administered. That this type of disclosure is used in experimental programs, indicates that patients can tolerate and absorb full disclosure when for reasons of legality, it must be given before treatment. It is therefore inconsistent to think that this type of complete disclosure could not be utilized for patients who are receiving the more accepted and well-established medical treatments (such as those for breast cancer).

Because this type of disclosure requires both time and contact with medical personnel, it may also encourage more questions. Further, if information is given by auxiliary personnel, there may be enhanced disclosure, with no one treatment featured more than any other. This type of disclosure could be made at the hospital on an outpatient basis, well prior to any surgical date. Time could be required to pass before any treatment is chosen, to ensure that all possibilities are considered. The only instance in which such disclosures would not function would be true emergencies, such as heart failure, where immediate treatment is necessary. This type of disclosure would also make it obvious that an individual was avoiding all information, and needed more time to adjust to the situation.

In the present study, both the Group 1 (Not to worry) women and the Group 2 (Closed to information) women apparently did not receive (or were not aware of) full information about their symptoms and the possible treatment options. While it would seem that the reasons for limited disclosure were different between the two groups, the outcomes in terms of emotional well being of the patients, post surgery, were similar.

The patients in Group 2 (Closed to information)

appeared to believe that they should follow what the physician recommended as the best or safest treatment for their illness and that they should not dwell on either alternatives or adverse outcomes. These women were strongly opposed to receiving any type of controversial information, particularly if it caused them to question their already chosen course of treatment. Possibly they could be described according to Taylor's (1979) description as "good patients," simply following their doctor's suggestions. This does seem improbable, however, because these women were cognizant of not wanting information, and of becoming angry or frustrated when faced with receiving information. It would seem that as the Janis and Mann theory suggests, these women avoided controversial information to reduce stress while going through the decisional process.

Problems arose for them when they were faced with information which did not support or bolster their decision, even though they could still change their minds. Therefore, some of these women mentioned closing magazines or turning off the television if the topic of breast cancer arose. Some were unwilling to even discuss the disease with family and friends before treatment, aware that they did not wish to receive adverse information about their choice of treatment. They tried, as much as possible, to avoid

information both pre and post mastectomy. While not stated overtly, it was almost as if these women could deny that the disease existed if they did not think about it. However, they were not able to avoid the emotional after-effects.

In cases such as this, if no third-party auxiliary help can be gained, it may be that gentle guidance from the physician would be helpful in preventing too hasty a choice of treatment. In fact physicians should probably not allow a patient to make a decision about a serious disease until they are sure the patient has truly thought through the consequences. It seems that to reach a thoughtful decision the decision maker must not only consider the options, but also take time to adjust to the disease. This can probably best be determined if the patient shows herself to be open in discussions about the disease and possible disease consequences. Pre-surgical cognitive activity may actually be the most important factor in post disease emotional well being. It should also be noted that this type of cognitive activity may not take increased time in terms of achieving treatment. Actually Groups 2, 3 and 4 were very close in the amount of time which passed from symptom discovery to mastectomy. Although it is possible that patients who are similar to my Group 2 "Closed to information" women, may need more time to adjust, it is more probable that they need

more guidance in how to make choices and view alternatives.

With the proliferation of breast cancer informational material today, it is increasingly difficult for the individual to remain totally uninformed. The "Closed to information" group was exposed to increased stress and worry every time they were in a situation which might present information which went against their decision. Their mindset was to block anything which was different from their decision, or which presented them with new alternatives. It is not surprising, therefore, that maintaining this type of defense created problems both before and after the surgical process.

Group 3 women were open to information, and therefore were able to think about the disease and its consequences. This is important, because even though they may not have had complete information, they were willing to consider options which were made known to them. They also probably gained information not altogether positive, but helpful on thinking realistically about the future. Because Group 4 women were actively searching for information, they were made aware of both the possibility of treatment failure and possible alternatives open to them. Of all the groups, this group was most able to adequately assess what the disease could bring. They did not have to fear gaining untoward

information in the future, because they had already considered such an alternative. This type of mindset should, in the long run, reduce emotional upheaval, because it has enabled the patient to consider and prepare for possible emergency situations before they occur.

The results for the "Not to worry" patients (Group 1) are the most difficult to understand. These results point toward some possible long term problems for a patient whose physician tries to dull the impact of the onset of serious illness. The long delay time between symptom discovery and treatment is troublesome as well. It is hard to know if the physician actually misdiagnosed the woman, or if she misunderstood what she had been told.

It is possible that there were individuals in the other three groups whose physicians told them "not to worry" until they were adequately diagnosed. However, the women who comprised Group 1, (the "Not to worry" group) tended to take this type of message far more seriously. It is possible that the women who comprised the other three groups in this study may have been more aware of the serious nature of their symptom, or more likely to think that a statement telling them they need not be concerned was a platitude. This does not seem probable, because the "Not to worry" group was similar in profile to the other three groups, in

terms of age, education and income. Nevertheless, it must be considered as one possible explanation of Group 1 behavior.

What is the best way for a physician to tell a patient that there is a possibility of a serious disease? Is it necessary to be somewhat blunt about the possibility of serious disease? It may be that whenever the possibility of serious disease exists, the physician must be very explicit, saying, for example, "I don't want you to become overly alarmed, but we must check this symptom out in the following ways..." At the same time the physician might offer further verbal and written information to the patient about the types of treatments which are available should the symptom warrant it after testing has taken place. The importance of testing the symptom, and the methods of testing, could be fully explained as well. This would give the patient time to adjust to the idea of the possibility of disease, and also to do some cognitive work in terms of thinking about solutions or at least about coping strategies. The physician could further temper the information by presenting one or more of the American Cancer Society's booklets which clearly state that in many cases the symptoms prove negative. Thus the patient could be hopeful without being totally unconcerned. This type of approach would encourage

the patient to follow up on the symptom, no matter how benign it appears. It would also encourage the physician to follow up on every symptom as well, even if he or she thought that the symptom was benign.

If a patient is told to return to the office for a further check-up of a serious symptom, and that patient does not return, the physician probably should have some mechanism for recording this event. A phone call to a patient would remind the patient that it was necessary to follow through on the second check-up, even though the symptom might be found to be benign. Alternately, the physician could set a date for a second appointment before the patient left the office. Obviously, this study points to the need for clarifying best methods of warning an individual that danger may exist without also being unduly alarming. Since the majority of patients who present with breast cancer symptoms find their symptoms to be benign, physicians may feel that they are being needlessly cruel if they encourage women to think about the possibility of having breast cancer before diagnosis. Indeed, the majority of the Group 1 women stated they felt their physicians were being kind by not causing them to worry about the possibility of cancer before it became a reality. Still, if even one woman delays treatment until her cancer has reached

a less treatable stage that would appear to be a high price to pay for reducing pre-diagnostic worry.

There are, of course, many possible reasons why the Group 1 women adjusted so poorly post surgery. It may that what was hypothesized at the start of this study is correct: the woman's belief in the "not to worry" message ended her need to think about making a decision. She entered into the pattern described by Janis and Mann as "Unconflicted inertia," causing her to fail to recognize that the danger signal which sent her to the doctor still represented a serious warning. She could have actually received an oblique message from the doctor, or she could have falsely perceived that the doctor suggested her symptom was benign.

Another possible explanation, based upon the research literature is that Group 1 patients may have felt they were betrayed by their physicians, even though this feeling was not verbalized. That the "not to worry" statement turned out to be untrue may have caused them to lose their trust of physicians, and thereby disrupting their ability to form a patient-physician relationship (noted in Chapter 1 to be detrimental for patients).

A third possibility is that the patient thought the physician was only trying to be kind, and then felt guilty about having negative feelings towards him or her. This

could also have interfered with the patient's ability to properly prepare herself for the reality of the disease.

Finally, Group 1 patients had all discovered their own symptoms. The idea that the symptom was not as dangerous as the woman initially thought it was may have, in some way, caused her to doubt her own perceptions regarding her body. She may have then worked at denying both the "worry" and the symptom rather than dealing with it. While it is interesting to consider why these women reacted as they did, it is very important to understand that the reaction would probably not have occurred if the women had attended to the symptom promptly. It must be ensured that every patient who sees a physician about a serious symptom be aware that the symptom must be fully diagnosed before their can be an assumption of no danger. In the case of breast cancer, this should probably mean that the person be examined by a physician who actually specializes in this type of cancer.

Lastly, it should be noted that none of the women in the present study expressed regret about the decision. Janis and Mann view regret as a major indicator of poor decision making. Perhaps when one is involved in a decision that makes the difference between life and death, the reality that one is still alive makes the decision a "good" decision. All of these women took life-saving measures to

cure their cancer. Under these circumstances, patients may consider it improper to express regret about the decision. This is not to say that in some instances the women might not have wished they had made some other decision. It is possible that there is another, more subtle way of testing the regret concept, than was employed in the present study.

APPENDIX A--QUESTIONNAIRE

INTRODUCE SELF -- FIND OUT NAME RESPONDENT WISHES TO BE CALLED

I UNDERSTAND YOU HAVE RECEIVED TREATMENT FOR BREAST CANCER, AND THAT TREATMENT CONSISTED OF A MASTECTOMY IS THAT CORRECT. WHEN WAS YOUR SURGERY?

AS A NURSE I HAVE WORKED WITH MANY WOMEN WHO HAVE ALSO BEEN TREATED FOR BREAST CANCER. iN THIS STUDY i AM TRYING TO GET A MORE THOROUGH UNDERSTANDING OF THE EXPERIENCES WOMEN FACE WHEN THEY HAVE BREAST CANCER IN THEIR OWN LIVES OR IN THE LIFE OF A LOVED ONE.

PLEASE FEEL FREE TO NOT ANSWER ANY QUESTIONS WHICH MAKE YOU FEEL UNCOMFORTABLE. ALSO, IF YOU WISH YOU MAY STOP THE INTERVIEW AT ANY POINT. TO DO SO, JUST TELL ME THAT YOU WISH TO STOP THE INTERVIEW.

I KNOW THE QUESTIONS MAY BE STRESSFUL AND I DO NOT WANT YOU TO BE UNCOMFORTABLE

I WOULD APPRECIATE IF YOU WOULD ADD ANY INFORMATION YOU FEEL MIGHT BE HELPFUL, BUT WHICH WAS NOT COVERED.

I HOPE IT WILL NOT MAKE YOU UNCOMFORTABLE IF I TAPE THE INTERVIEW. NO OTHER PERSON WILL EVER LISTEN TO THE TAPE, AND YOUR IDENTITY IS CONFIDENTIAL. IT JUST MAKES IT EASIER FOR ME TO MAKE SURE THAT I DO NOT MISS ANY PART OF YOUR RESPONSE.

FINALLY, BEFORE WE START THE INTERVIEW, I WANT YOU TO KNOW THAT YOUR PARTICIPATION IN THIS INTERVIEW IS GREATLY APPRECIATED.

(TURN ON TAPE)

For the first few questions I want you to think back to before the time that the cancer was discovered. Some of the questions will seem to be repeated from time to time. Please bear with this. This was done to assure that I gather all the necessary information. The repetition also may help you to remember some situations more clearly.

1. INTRODUCTORY QUESTIONS

1 A. Did you notice some sign or symptom either through self examination or some other method that made you aware a problem might exist. What did you notice? How did you notice this sign/symptom?

1 B. What did you think about when you noticed this sign?

1 C. What did you do at this point? (If not clear -- did you speak with anyone about what you noticed -- whom -- what did you discuss)

1 D. If she didn't speak with anyone Did you think about speaking with anyone -- If yes -- was there a reason why you didn't?

1 E. How long did you wait before you sought medical attention?

1 F. What exactly did you know about breast cancer at the time you discovered your symptom (explore pre knowledge: probe background if not given (medical); did she practice BSE; did she read or see tv specials)

QUESTION 2 (SKIP--if respondent answered Question 1)

2 A. How was it discovered that a problem existed. (Probe MD exam, routine mammography, etc.)

2 B. What did you think about when you were told of the problem. (once thoughts clear go to 1 F above)

2 C. What did you do at this point?

The next few questions are about your exam and medical visit (after you noticed the symptom) (where your symptom was discovered).

QUESTION 3

3 A. How did you select the physician?

3 B. Did any accompany you on your first office visit. If yes: Who -- was it helpful. If no: Would it have been helpful to have someone with you.

3 C. What did this first visit consist of (probe: symptom check only, physical, tests.) How long would you say this visit lasted? Did you feel comfortable with this doctor?

If yes: In what ways did he/she put you at ease?
If no: Why do you think you felt uncomfortable with this doctor?

3 D. Did you have many questions? Can you remember what types of questions you asked. How did you feel the doctor answered these questions.

(IF NO QUESTIONS -- did you feel comfortable asking questions -- explore)

3 E. ONLY IF ACCOMPANIED. You said you were accompanied by -----. How did you feel about this. Did ----- go into the office with you. Did he/she ask questions. (if not, go to

3F) How did you feel the doctor reacted to --------'s questions. Were they adequately answered. What types of questions were asked by --------)

3G. IF ----- DID NOT ASK QUESTIONS. Was --- at all encouraged to ask questions? Why do you think he/she did not ask any.

QUESTION 4 (Disarming and Time Frame)

4 A. What did the doctor tell you about your symptom?

4 B. Did this doctor ever tell you not to worry about the symptom? How did the doctor tell you this. What did you think about what the doctor told you. How did you feel about this information.

QUESTION 4 (Continued)

C. Were you told by the physician that the symptom might be something to be concerned about -- what exactly were you told?

4 D. Time Frame: Can you tell me how long was the period of time from when you discovered the symptom until your actual surgery.

4E . Would you recommend this doctor to a friend -- why, why not.

4 F. (Clarification of testing and time frame) After the initial visit, what further testing was done to determine your diagnosis? Were these tests ordered by the first physician you saw -- (the one we've been discussing) or the same medical group. Did this physician have a medical specialty -- what was it? (ASK IF NOT CLEAR FROM TIME FRAME GIVEN) Now, just to clarify, you said the period of time from symptom discovery to treatment was (go over time frame again)

These next few questions are about the testing you may have had.

QUESTION 5--(UNDERSTANDING OF PRE-DIAGNOSTIC TESTS, REFUSAL OF TESTING, ESTROGEN/PROGEST. RECEPTOR ASSAYS, UNANSWERED THOUGHTS, INFORMATION SEARCH ABOUT TESTS)

5A. What tests did you have? Did you feel you fully understood the need for these tests? Were there any tests you did not understand? Did you clarify these tests with the doctor who ordered them?

5 B. At any time did any mention anything to you about a progesterone or estrogen receptor assay. If yes -- what do you remember being told? If no: Do you remember anyone speaking about the benefits of your knowing whether a tumor would respond to hormonal treatment.

5 C. Did you ever feel any of the diagnostic tests were totally unnecessary. Did you have these tests anyway? (explore)

5 D. Did you refuse any test or procedure suggested to you.

5 E. Did you check with anyone, for example relatives or friends before agreeing with any procedure (who -- what did you learn)

QUESTION 5 (con't)

5 F. Did you check with anyone else, for example a doctor or nurse or other medical personnel before agreeing to any of the tests (who -- what did you learn)

5 G. Can you remember having any unanswered thoughts or questions which you decided not to ask about the testing.

5H. Do you remember giving permission for any of the tests
Which tests (how feel about giving permission)
How was permission given

If forms were used -- was there anything about the permission forms which made you uncomfortable.
Did you speak with anyone about this

5I: Were any books or pamphlets offered to you about the procedures you underwent.

If yes: Did you read them? (probe why/why not)
If read them: Did you find them helpful.
If none offered: would you have liked to have received this type of information (why/why not)
5J. Did you on your own search out any additional information about the tests done to determine breast cancer: (for example, did you speak with a friend who had a similar experience, nurses or doctors, or go to a library, etc)
If yes: was this helpful?
If no Was there any particular reason you did not search out any further information? (explore)

QUESTION 6 (HOW MUCH INFORMATION DESIRED FOR OTHER'S SERIOUS MEDICAL PROBLEMS vs. OWN SERIOUS MEDICAL PROBLEM)

6 A. Before your diagnosis of breast cancer, did you ever go to a doctor with a family member (for example your child, husband or parent) or with a very close friend, who had what you considered to be a somewhat serious medical problem. Who did you go with? What was the problem? How much information would you say you requested from the doctor at that time? (Show information scale--)

6 B. Also before your diagnosis of breast cancer, did you ever go to the doctor for your own medical care about something which you considered to be a somewhat serious medical problem? What was the problem? How much information would you say you requested from the doctor at that time? Show information scale --

SCALE

LITTLE INFORMATION,1..2..3..4..5..COMPLETE INFORMATION

QUESTION 7 (INTENTIONALLY NOT WANT INFORMATION)

7 A. Do you think that at any time during the illness that you intentionally did not wish to receive information about the disease? (if yes) Can you tell me why?

7 B. Do you remember any times that you regretted having information given to you about this disease?

If yes: How did this occur? What type of information had been given to you? How would you have preferred to have had this situation handled if you had been asked beforehand?

QUESTION 8 (INFORMATION ABOUT THE PHYSICIANS THIS PERSON SAW RE ASK QUESTIONS FOR EACH PHYSICIAN SEEN. CLARIFY PHYSICIANS)

The next few questions are about the different physicians you may have seen regarding your illness

QUESTION 8 (PHYSICIAN INFORMATION -- SECOND OPINIONS)
We've talked about the first physician you saw, (whose specialty was ----------) or who was a -------. and I asked you about the different physicians who may have ordered testing for you. Now I want to go back and talk about any physicians you may have seen.

8 A. Outside of the first doctor you saw, who was (---------) how many other physicians did you see?

I would like to go through how you contacted each physician you saw.

8 B. First, I want to talk about the surgeon who did your surgery. How did you contact this doctor. Was this the first surgeon you saw? (if YES see below)
IF NO -- How many physicians did you see before you saw this physician? What were the specialties of these other physicians?

IF YES How did you find out about this physician? Did you see any other physicians after you saw this doctor?

Now, for each physician you have mentioned, I want to ask you some questions.

QUESTION 8 (CONTINUED -PHYSICIAN CLARIFICATION)
(Start with first doctor mentioned)

For first physician:

8C1. Just to clarify about the first doctor you mentioned. He/she was a (specialty). You said you went to this doctor because (clarify).

IF CLEAR --this doctor recommended that you see another physician. Did you go to see this physician? (Ask physician questions below)

IF NOT CLEAR: What did this doctor recommend? What did you do then? Probe until clear about how got to see surgeon (unless surgeon was first/only physician seen -- if so, go to Alternatives 8 C. 3)

8 C. 2 PHYSICIAN QUESTIONS: You said you saw Dr. -- (who was recommended by the first doctor you saw) -- (who you found by -----) Did you feel comfortable with Dr. -- In what ways do you think Dr. -- made you feel comfortable? How long would you say you met with Dr. -- Did you have many questions -- Can you remember some of the questions you asked Were these questions answered adequately? Was anyone with you when you met with Dr. --
If yes: who was with you -- Did you find this helpful (why/why not) Did (name person) get to speak with Dr -- as well? How did you feel about this? How do you feel Dr. -- reacted to this person. What exactly did Dr. -- recommend.

If needed to clarify, ask: Was this the physician who did your surgery?

ALTERNATIVES

8 C. 3 (ALTERNATIVES PRESENTED) Were there any other alternatives presented to you at the time of this recommendation? Probe: what were you told about these alternatives (name them) Did you, yourself, inquire about any alternatives?

OPINIONS

You said you received (give number) other opinions, is that correct: Now I want to discuss these other physicians. (go back to 8 C. 2)

QUESTION 9 (MASTECTOMY KNOWLEDGE)

ONE STEP/TWO STEP

9 A. I want to discuss the type of surgery suggested to you. Did you have the surgery and biopsy all at one time as a one-step procedure. This means you gave permission for the surgery to be done if the biopsy was positive without awakening and finding out the results/ or/ Did you have the biopsy and surgery in two separate steps -- that is, first a biopsy and then the surgery. If two step: Was the biopsy done in the hospital or in the doctor's office. If hospital (was this a separate admission)

9 B. Did you feel you were freely able to ask questions about the biopsy and the possibility of the mastectomy before you agreed to the (biopsy) (biopsy/mastectomy)? Did you ask many questions? If yes: What type of questions did you ask If no: Was there a reason you did not ask questions.

9 C. Before the surgery did you discuss the type of mastectomy you were to have? What were you told about the type of surgery you had? (probe extent of knowledge) Were you told if any lymph nodes were to be removed? What were you told about the way the disease was classified. Did you ask any questions about this.

Was the surgery you decided upon given a name -- what was it called? What type of information was given to you about the recuperation period prior to surgery? Was anything mentioned about further treatment after surgery? Was this type of treatment ever mentioned

(If yes, state Then, I would like to discuss that later, if that's ok).

If surgery was not named, probe again: What exactly did you remember about the type of mastectomy you had?

A. Radical mastectomy (pectoralis muscle destroyed)
B. Modified radical (2 types -- Patey resect pectoralis Auchenclass retain pectoralis)

QUESTION 10 -- (Surgeon reassurance -- Hidden Information -- Searching Information)

10 A. Can you think of any times your surgeon was particularly helpful or reassuring - can you tell me about these times?
Was there any time you felt the surgeon could have been either more helpful or more reassuring? Can you tell me when this happened.
Was there any time you felt that either you were not given full information or where the answers were not adequate?

10 B. Were any books or pamphlets offered to you about the various medical and surgical opinions in the treatment of breast cancer?
What was offered?
Did you wish to read this type of material? Why/why not
Did you actually read it? why/why not

10 C. Did you yourself search out this type of material
If Yes: Were you able to find it readily Where did you go to get the information.

10 D. Would you have liked to receive (some) (some other) literature about the various medical and surgical opinions in the treatment of breast cancer.

QUESTION 11 (ANXIETY RATING SCALE)

11 A. Can you rate how you felt before the biopsy -- (biopsy/mastectomy) (Show scale 2)

11 B. Can you rate how you feel normally (every day) Show scale 2

SCALE 2

CALM..1..2..3..4..5..ANXIOUS

11 C. Why do you think you felt (calmer at this time) more anxious at this time.

11 D. What type of thoughts were you having at this time.

QUESTION 12 (EASE OF ONE-STEP -- TWO STEP)
FIRST, CLARIFY WHICH WAS HAD. I ELIEVE YOU SAID YOU HAD THE BIOPSY/MASTECTOMY (ALL IN ONE STEP--IN TWO STEPS)

12 A. Are there any ways in which a (one step/two step) mastectomy procedure is easier on a woman?

12 B. Are there any ways in which a (one step/two step) mastectomy procedure is more difficult on a woman?

12 C. Looking back now do you feel you made the right decisions about your breast tumor?

12 D. Are there any changes you would make if you had this decision to make over again? 12 E. Are there ever any times that you regret the decision or the way you made the decision?

QUESTION 13 (TIME PRIOR TO MASTECTOMY/HYPERVIGILANCE/OPEN TO INFORMATION)

13 A. How long was the period of time from when you decided to have the (biopsy/mastectomy) until you actually went into the hospital?
13 B. What did you do during this period?

13 C. Were you ever very anxious--How did you handle this?

13 D. Did you ever, even after you had agreed to have the mastectomy think about not having it / or about changing your mind
13 E. Did you ever worry about your decision during this period of time? If yes, how did you handle this?

HYPERVIGILANCE

13 F. Did you ever worry about the amount of time that was passing? Did you ever feel that you didn't have enough time to think about alternatives to the surgery?

13 G. Did you have any other tests, which we have not discussed, while you were awaiting hospital admission or upon hospital admission. Did you feel you understood the need for these tests? Were there any tests you did not understand? Did you refuse any hospital tests?

13 H. Did you receive any literature from the hospital or from anyone connected with the hospital on your admission -- on the procedure? Was it helpful

If no literature received: Would you have liked to receive any literature?
Were any classes held in the hospital? Was this helpful /or/ Would this have been helpful?

QUESTION 14 BEFORE SURGERY QUESTIONS

14 A. Can you tell me about the night before your surgery? Was it difficult for you to get through that night?
What did you do ?
Would anything that you can think of have made that night easier.

QUESTION 14 BEFORE SURGERY (CONTINUED)
14 B. How was the morning of your surgery? What did you do before going to surgery? What is the first thing you remember after you awakened from anesthesia? Tell me about this period?

14 C. How long were you in the hospital prior to the biopsy and then mastectomy? (biopsy/mastectomy)

14 D. Which doctors visited you before your surgery?
What did you discuss with these doctors?
How long would you say these visits lasted?
Did you feel these visits were sufficient to answer any lingering questions and fears you might have had.

QUESTION 15 (AFTER SURGERY)
15 A. When did you first see your doctor after surgery? What did he/she have to say to you at this time? How did you feel your doctor handled this visit?

15 B. What about when your dressings were removed? Many women say this is a particularly difficult time -- would you agree with this? How did you deal with this? Did your doctor do anything to make this time either easier or more difficult for you?

15 C. Was there anything that your doctor could have done to make this entire post surgical period easier for you -- (in terms of pain medication, dressing changes, early exercises, teaching, etc.)
15 D. Are there any areas of your relationship with your physician which I have not mentioned?

15 E. If you had designed your own care plan, what would you have preferred during this period of time?

QUESTION 16 (HOSPITAL STAFF EXCLUDING INDIVIDUAL PHYSICIAN)

16A. Which staff members visited with you before your surgery
Go through questions then re-ask for after surgery?

VISIT QUESTIONS

What did you discuss with these staff members?
How long would you say these visits lasted?
Did you feel you were visited frequently enough at this time to take care of your needs both physically and emotionally?

16 B. AFTER SURGERY: (helplessness) How was your nursing care after surgery? Can you remember any times that you felt the care was somewhat inadequate? If Yes: How did you handle these situations? (For example, were there times your call light was not answered for a long period, or where you had increased pain without adequate relief?)

16 C. How did you handle these situations? Is there any area regarding your care in the hospital which I have not discussed? If you had designed your own care plan at the hospital what would you have preferred during this period of time.

16 D. Did you also have family members visit with you before your surgery? (After your surgery?) If yes: Who visited you? What did you discuss? How did these visits go?
Can you think of anything that could have made these visits better for you. if you had been able to make changes to suit exactly what you needed at that time

ASK ONLY AT END OF AFTER SURGERY QUESTIONS

Was there anything more difficult after surgery about having visitors.

16 E. (Helplessness response) Sometimes in a hospital you have to wait long periods for something you really need. (for example, a bed pan or water or even for someone to set up your dinner tray which is just sitting a few feet away getting cold) Did you have any of these types of situations occur while you were in the hospital? (if yes) Can you tell me about how these types of situations made you feel? How did you respond? (explore anger, helplessness.

QUESTION 17 SURGICAL FOLLOW-UP CARE

17 A. How long ago was your surgery?
After surgery, was any further treatment such as radiation therapy, chemotherapy or other type of therapy suggested to you.

17 B. I want to ask you about the post surgical care you received?

After your mastectomy how often did you visit the surgeons office? During these visits did you have follow-up examinations related to the surgery and breast cancer?
Are you still being followed by this doctor.
If yes: How often do these examinations take place.

17 C. What were you told about the possibility of reoccurrence?

17 D. Was any other information given to you about your own care which I have not covered.

IF NO FOLLOW UP THERAPY TOOK PLACE

GO TO FINAL QUESTIONS NOW

QUESTION 18 (FOLLOW-UP THERAPY)

18 A. You said that follow-up therapy was suggested. What form of treatment did you receive:
1. Irradiation
2. Chemotherapy
3. Dietary

18 B. Who suggested this follow-up care?
When was the need for some sort of follow-up care first mentioned to you?
How was this presented to you?
Did you talk about this aspect of treatment with any other doctors?
With a nurse or some other hospital staff member?
Was any literature given to you, or did you attend any type of classes regarding the need for further care?
Did you, on your own, search out any information regarding follow-up treatments for breast cancer?

18 C. Was anyone with you when you consented to your follow-up care plan or, did you talk this plan over with anyone before agreeing to it. (With whom, was this helpful?)

18 D. Are you still receiving treatments?

QUESTION 19 (IRRADIATION)

19 A. How did you choose the doctor who was (is) responsible for your radiation therapy? Is this doctor a radiologist?

19 B. How frequently did you meet with the radiologist before starting therapy?

What were you told about radiation therapy, in terms of duration of treatment and about side effects?

Did you have many questions? Were they answered satisfactorily?
How would you say the doctor was about receiving questions?

19 C. What would you say were your major concerns at this time? Are any of those concerns still bothering you today? Have you talked about these matters with anyone?

19 D. Have you had to make any changes in your life since receiving radiation? What were they?

19 E. If you were to speak with another woman, who, after mastectomy, was told she must consider radiation therapy, and she asked for your advice, what would you tell her to do?
Is there anything you might like to add?

QUESTION 20 CHEMOTHERAPY

20 A. How did you choose the doctor who was (is) responsible for your chemotherapy? (Was) Is this doctor an oncologist?

20 B. How frequently did you meet with him/her before starting therapy? Did you feel the course of treatment was explained fully?

20 C. What were you told (or have you been told) about the type of chemo agents that were used?
Do you know the names of the drugs you were using? What have you been told about side effects?
Did you have many questions? Do you feel they were answered satisfactorily? How would you say the doctor was about answering questions?
Did you feel comfortable talking with this doctor?

20 D. What would you say were your major concerns at this time?
Are any of those concerns still bothering you today? Have you talked about these matters with anyone?

20 E. Have you had to make any changes in your life since receiving chemotherapy? What were they?

20 F. If you were to speak with another woman, who, after mastectomy, was told she needed follow-up care, and she asked for your advice, what would you tell her to do?
Is there anything you might like to add?

21. DIETARY THERAPY

21 A. How did you decide upon a dietary therapy? Who suggested this form of therapy.
How did you choose the person who was (is) responsible for your dietary therapy?
Is this person a medical doctor, a nutritionist, or some other specialty? (If applicable: Did you speak with your surgeon or MD about this form of therapy? (Why/why not) How did they feel about it?

22 B. How frequently did you meet with him/her before starting therapy?
What were you told about dietary therapy, in terms of duration of treatment and about side effects?
Did you have many questions? Were they answered satisfactorily? How would you say the doctor (nutritionist, etc.) was about receiving questions?

22 C. What would you say were your major concerns at the time you started therapy?
Are any of those concerns still bothering you today?
Have you talked about these matters with anyone?

22 D. Have you had to make any changes in your life since beginning this type of therapy? What were they?

22 E. If you were to speak with another woman, who, after mastectomy, was told she must consider follow-up therapy, and she asked for your advice, what would you tell her to do? Is there anything you might like to add?

FINAL QUESTIONS

QUESTION 23 (FINAL QUESTIONS)

23 A. Approximately how long after your mastectomy would you say it took before you were able to resume your everyday routine?

Did you have much difficulty with work about your home?

Did you receive any extra help during this period?
If yes: From whom? For how long a period of time?

Could you have used help (have used even more help)?

23 B. Do you work outside of your home as well?
If yes: Did you have any difficulty getting back to work?

What things at your job did you find most difficult?
For how long a period of time?
Did your employers and the other employees know of your mastectomy?
If yes: How did they respond?
If No: Was there any particular reason you did not wish them to know.
Were there any neighbors or friends whom you also did not tell about your mastectomy?
If yes: Was there any particular reason you did not want them to know.
If no: Did you find it difficult to tell people.

23 C. Sometimes after an illness, some people notice that other people treat them differently, or behave differently around them. I will ask you about your relationships with some other people, and, in particular, please tell me if you have noticed any changes since your discovery of breast cancer.

Husband, Children, Parents, Siblings, Friends, Neighbors

23 D. I would also like to talk about how the illness might have affected you. Frequently after an illness, people notice that they feel differently from they way they felt before the illness.

23 D1. - Since the discovery of breast cancer, have you ever had two weeks or more during which you felt sad or depressed, or when you lost interest in the things and people around you.
Had you ever experienced these types of feelings, for this period of time before your illness?

23 D2 - Have you had any difficulty either going to sleep, or remaining asleep, or any other changes in your sleeping pattern since the start of the illness?
How about changes in your appetite?

How frequently have these changes occurred?
How long do they last?
Had you noticed these type of changes in sleep or appetite before the start of the breast cancer?

23 D3 - Have you had any times, that you have felt you mind has gone blank, or that you just can't concentrate as well as you once did?

How frequently have you noticed this happening?
Had you ever noticed this before your illness?

Do you think this is at all related to some aspect of your illness?
What, if anything, have you been able to do to alleviate this?

23 D4 - Have you had any periods where you felt helpless to do anything to change your future?

How often has this occurred?
Had this ever occurred before your illness?
Do you believe that this feeling is related to your illness?

23 D5 - Since your illness, have you ever used any type of tranquilizers or alcoholic beverages, more than you did before the illness?

23 D6 - I would like to ask you about your religious beliefs since the illness:
Have they changed in any way?
How much do you think these changes were due to your illness?

23 D7 - Have you ever wondered why you yourself, rather than some other woman developed breast cancer?
Have you been able to answer this question?
How did you answer this question?

23 D8 - Overall, how would you say the development of cancer has changed your life?

Have there been any positive changes?

Have there been any negative changes?

QUESTION 24 (WORRY SCALE)

24. I am going to read three statements. Please indicate how often each statement is true for you.

24-1. Although it makes me feel bad, I cannot avoid thinking about all kinds of catastrophes in the future. Would you say this is:
1. Never true of me. 2. Rarely true of me.
3. Sometimes true of me. 4. Often true of me.

24-2. I worry that something bad will happen to me.
1. Never true of me. 2. Rarely true of me.
3. Sometimes true of me. 4. Often true of me.

24-3. I worry that something bad will happen to my loved one?
1. Never true of me. 2. Rarely true of me.
3. Sometimes true of me. 4. Often true of me.

25-A. Over their lives most people have something good happen to them or to someone they love. By "something good" I mean things like receiving an honor or award, or getting a good grade in school, getting a promotion or raise, or going on vacation. Or like, when someone does something nice for you or a good friend comes to visit. Or maybe just something important you wanted to happen did happen. compared to other people you know, how often have things like this happened to you?

1. hardly ever
2. not very often
3. sometimes
4. pretty often
5. almost all the time

25-B. When good things have happened in your life, how much do you feel that you have typically been able to appreciate or enjoy them?

1. hardly at all
2. just a little
3. some
4. quite a bit
5. a great deal

25-C. Compared to most other people you know, how much pleasure have you typically gotten from good things that have happened to you?

1. hardly at all
2. just a little
3. some
4. quite a bit
5. a great deal

25-D. When something good happens to you, compared to most other people you know, how long does it usually affect the way you feel?

1. not long at all
2. not very long
3. for a short while
4. for a pretty long time
5. for a very long time

That is the final question of the prepared interview, and I want to thank you again for taking part.

At this point, I would also like to ask you a little about yourself. These questions are not related to the breast cancer, but are needed just to get an overall picture of the women I interviewed.

(Ask demographics - (show card) age, years of school completed, religion, income

I would also like to know if you believe there is an area that you feel was important to you that I have not covered in the interview.

APPENDIX B

CODING OF POSITIVE AND NEGATIVE CHANGE STATEMENTS

Coding for Positive Change. Coding for the positive statements consisted of counting the number of positive statements made by each individual. The raters were asked not to read into the statements, but to perform a simple count of what was given. The mean number of positive statements for the entire group was 1, and thus the coders had high agreement on the count.

Only in two cases did disagreement occur, and in each case the count was off by 1. (These disagreements occurred where respondents mentioned 4 and 5 positive changes respectively.) The coders, upon discussion, adjusted the count downward to 3 and 4 positive changes.

To give an example of how positive change statements were given by the respondents, and how the coders made the count, two statements of respondents from each group will be given, with the count in parenthesis) It should be noted that the coders were also asked to categorize the positive changes as they counted them. Here, there was virtually no agreement. After discussion the coders only agreed on the categories of religious expressions and greater appreciation of life.

SAMPLE POSITIVE STATEMENTS

Statements from Group 1, "Not To Worry"

Respondent 3 I found out that some people turned out to be more supportive than I ever would have imagined.
(Counted by both raters as 1)
Respondent 6 My husband was so kind and I think it actually improved our relationship in some ways.
(Counted by both raters as 1)

Statements from Group 2, "Closed to information"

Respondent 13 I had been fighting with my sister for a long time, but when I developed breast cancer we both put our differences aside and grew closer again. I also think I am more reflective and less frantic now. I realize that life goes on whether or not I feel hectic and force myself to do more or whether I go at my pace, I and I think that's a positive aspect of the disease. Also I make sure that I enjoy things now, especially the kinds of things I took for granted before.
(Counted by both raters as 3)
Respondent 39 I think my attitude is better than it ever was before. I look at everything with a very positive attitude now.
(Counted by both raters as 1)

Statements from Group 3 "Open to information"

Respondent 12 I was supposed to be getting married right at that time, but I wanted to let him out of it after I decided on the mastectomy. He said he didn't care. He was marrying me not just my body.
(Counted by both raters as 1)
Respondent 25 I was going to all different doctors, thinking every pain was a new cancer, when I started to notice the kinds of problems other people in the different waiting rooms had. All kinds of bone problems. People who couldn't walk. I looked at myself and thought breast cancer isn't the worst thing. Since that day I've felt more positive about my life than I ever did even before the cancer.
(Counted by both raters as 1)

Statements from Group 4 "Information Seekers"

Respondent 22 I'm more self-centered and less sacrificing, and I think that's good. I'm not ridiculous about it, but I think about me more and about enjoying my life more.
(Counted by both raters as 1)
Respondent 23 My relationship with my husband has really improved. Maybe it's because he realizes my mortality, but we spend more time and better time together now. I also think I'm a stronger person than I realized. I used to see other people with cancer and think I could never handle that, but I realize that I can.
(Counted by both raters as 2)

Coding for Negative Changes As with the positive life changes, the negative life changes mentioned were based upon Question 23-D8. Negative statements were coded similarly to positive statements. The two disagree- ments on the count were discussed by the raters and adjusted downward. (The mean number of changes mentioned by respondents was 1.5 overall).

Attempts to categorize the statements, except for categories of "fear of death," and "depression", were not successful as there was virtually no agreement on the categories. The raters did attempt to discuss these differences, but the task was time consuming due to the amount of coder variance, and the idea of categorizing the statements was abandoned.

To give an example of how negative changes counts were coded, the responses of eight respondents, two statements of respondents from each group, will be given.

SAMPLE NEGATIVE STATEMENTS

Statements from Group 1, "Not To Worry"

Respondent 9 I've had a lot of negative changes. I knew I was going to die from cancer, and every pain and ache I had I believed was another type of cancer. Sometimes I still feel this way. I also have been very depressed, and this has not changed since the surgery. I just get depressed very easily. I was always a positive person, but now I find I am very negative, and this has affected my life. I try to hide these negative feelings from others, but I can't escape them. I also think that I am somehow different, less connected, with my family and friends than I was, and I feel distant from people in general. I was never like this before the cancer.
(Coded by both raters as 4 negative changes.)
Respondent 31 "Since the discovery of cancer I am almost always depressed."
(Coded by both raters as 1 negative change)

Statements from Group 2, "Closed to information"

Respondent 10 I am a very bitter person now--not better just bitter, I'm bitter about the cancer, about everything, I never enjoy anything anymore. I believe also that I lost whatever belief in God I had. If God is good how could this happen? I always think about dying and death. I go about every day thinking I am going to die. For example my husband thought it would cheer me up to fix the house, but I said why bother when I won't be here to enjoy it. Also, my relationships with other people don't seem to matter anymore either. I just don't want to be involved with others, and I used to be very close with my friends. I hate the scar on my body, too. I can't get used to it.
(Coded by one rater as 5 negative changes and the other as 6, after discussion placed at 5 by both)
Respondent 20 I still get upset with my body even though it's two years since the surgery. I hate getting up and seeing the scar. Once I'm moving it's better until that night. Then it starts again when I have to look at the scar all over again. I didn't think the disease itself was too bad, because I thought the mastectomy would cure it, but I hate what it did to my body.
(Coded by both raters as 1 negative change)

Group 3, "Open to information"

Respondent 1 I had a very hard time adjusting to using the prosthesis. For a long time I really hated it. Sometimes I still do, but I try not to think about it, and when I do, I say "well, you're still here."
(scored by both raters as 1 negative change)
Respondent 29 I became very suspicious of my friends and how they felt about me. I don't really know if they felt different, but I dropped friends because I thought they were looking at me differently and treating me different socially. This was especially true of my husband's friends, but even some of my long time friends too. I don't know if I could say this was real. Maybe it was in my mind. Another thing I found really hard was adjusting to the scar. I really don't know if I've done that or not, but I try not to think about it too much. I also find now that I don't enjoy some things as much as I used to. For example, I can remember looking forward to reading a really good book, but now I don't. I don't know why this is so, but it is.
(Coded by both respondents as 3 negative changes)

Group 4 "Information Seekers"

Respondent 2 I think I've noticed a difference in the way some women treat me. I think they have more difficulty handling it than men, maybe because of their vulnerability, but I think this does diminish my relationships with some women.
(Coded by both raters as one negative change)
Respondent 11 I find that I worry somewhat more about my appearance now. If I let myself think about the prosthesis, I'd never feel secure. I try to focus on other things, and not dwell too much on how I look. If I catch myself doing that--like making little adjustments or staring in the mirror to see if I can see a difference--I stop myself.
(Coded by both raters as one negative change)

APPENDIX C--ANSWER SHEETS

PAGE 1 INTERVIEW #
DATE OF INTERVIEW

FIRST NAME

YEARS OF SCHOOLING under 10 11 12 13 14 15 16 over

INCOME LEVEL below 25,000 above 25,000

RELIGION: Cath, Pros. Jewish Other:

MARRIED DIVORCED OTHER
INTRODUCTORY QUESTIONS

1A Notice sign Y N What noticed

1B. What think

1C Do something Y N
Action taken:

Spoke with

Waited to see if went away

Other:

1 D. If didn't speak with anyone:
Think of it Y N

Why didn't speak with someone

1 E How long waited

PAGE 2 INTERVIEW

1 F Pre Knowledge
Med Background (Nurse RN Prac. Med Tech
Med Sec. Other:

Family member with B. Ca. Other Ca.

Close friend with B. Ca Other Ca
Prac. BSE
Read a lot / watched TV specials
Other:

QUESTION 2 (Skip if 1 answered)

2A. How discovered
MD Exam: Mamo. (routine) (other)
Other:

2B. Thoughts

2C. Action

QUESTION 3 FIRST MD SEEN

3A. How select MD

3B Accompanied 1st visit: Y N Person:
Was it helpful Y N Why

3C Visit consisted of:
symptom check only full physical exam
partial phy. exam
Testing also:
Symptom check and talk (long/brief)

PAGE # 3 INT.#

QUESTION 3 CONTINUED

Estimated length of visit:
Very brief Moderate (10-20)
Long (over 20 min)
Comf with Md Y N Why

3D Have many quest. Y N

Which remember:

How did MD respond:

3E ACCOMPANIED by whom: Husb. Friend Child Parent
Other:
Other go in to speak with MD Y N
Respondent. comf with other Y N
Other Ask Questions Y N (If No see 3F)
Md appear comf. with other Y N
Md reaction to questions:

Adequately answered Y N

Types of others questions:

3F Was other encouraged to ask questions Y N
Why think didn't ask

QUESTION 4 TIME FRAME & NOT TO WORRY

4A. What told about symptom

4B Told NOT TO WORRY about symptom Y N (IF YES, READ ANSWERS ON BACK OF SHEET)
How told:
What did you think about:

How feel about this information:

PAGE # 4A INT #

QUESTION 4 CONTINUED

TOLD SYMPTOM SOMETHING Y N
What told

4D Time Frame Time from symptom discovery to surgery
days weeks months

4E Rec. Md Y N Why

4F CLARIFICATION What else done to clarify diagnosis
Something

Nothing

Tests:

Other:

Md from first group mentioned Y N
Specialty:

Md. from other group Y N
Specialty:

Clarification - Compare with 4D)
4F. Time Frame: days weeks months

PAGE # 4B INTERVIEW #

5. UNDERSTANDING OF PRE DIAGNOSTIC TESTING,
ESTROGEN RECEPTOR REFUSE TESTS UNANSWERED THOUGHTS
INFOR. SEARCH RE TESTS

QUESTION 5
5A. Tests had: Phys. exam of symptom; Mammography;
Aspiration; Biopsy; Others:
Additional Info:

Any didn't understand Y N

Clarify: Y N

With Md: Y N

With other: Y N

Who

5B: Mention Estrogen/Progesterone receptors:
Est. Pro.

Both

None

PAGE 5 INTERVIEW

QUESTION 5 CONTINUED

5B. What told:

Anyone ever mention hormonal benefits Y N

5C. Feel diagnostic tests unnec. Y N
Have anyway Y N
5D. Refuse any tests Y N
5E & F Check with others re tests before agreeing to them:
Y N
Who: Friend: Relative: RN
LPN MD Other Med. Pers: Other:
What learn non-med personnel Med Personnel:

5G Unanswered thoughts Y N (if yes, may be continued on back)

5H Permission remembered Y N
How given: Form Verbal Other:
What remember:

5I Remember info. offered Y N - Books Pamphlets
Other:

Read them Y N
Helpful Y N

None offered: Would like to get them Y N

Reason:

PAGE 6 INTERVIEW

5J Search out info on own: Y N

How: Talk to friends Talk with other md's
Talk with other med personnel (Rn LPN Aide Tech Other:
Go to Library Buy books or magazines
Watch TV specials Phone other med institutions
Call Cancer Hotline

Other:

Was it helpful:

Any reason not wish further information: (answer may be continued on back)

QUESTION 6 SERIOUS ILLNESS (OWN VS OTHER SERIOUS PROB)
6A Go with other Y N Child Husb. Moth. Father
Friend Other: Problem:

How much info requested: 0 1 2 3 4 5 6

Go for self with serious problem Y N
Problem:

How much info requested: 0 1 2 3 4 5 6

QUESTION 7 INTENTIONALLY NOT WANT INFO.
(IF YES ANSWERS SEE BACK IF NEEDED)
7A Aware of not wanting information Y N
Why:

7B Ever regret getting information Y N
Explain:

PAGE # 7 INT#
CIRCLE EACH PHYSICIAN PAGE; 8A-2ND PHYSICIAN;
8B-3RD PHYSICIAN; 8C-4TH PHYSICIAN; 8D-5TH PHYSICIAN;
8E-6TH PHYSICIAN; 8F-7TH PHYSICIAN (CONTINUE)

QUESTION 8. PHYSICIAN SORTING First Physician was:

Specialty was:

How many seen in total 1 2 3 4 5 6 7
(see separate physician sheets for each physician seen)
Surgeon who did surgery was: First surgeon seen Y N

See others after Y N
How find surg:

Alternatives presented: Y N
(CONTINUE ON BACK IF NEEDED)
List Alternatives:

Ever inquire re alternatives Y N

What happened when inquired:

PAGE # 8 (8A; 8B; 8C; 8D; 8E; 8F; 8G INTERVIEW #

PHYSICIAN #
NUMBER OF PHYSICIANS SEEN IN TOTAL 1 2 3 4 5 6 7 8

THIS IS ABOUT NUMBER

SPECIALTY OB/GYN INTERNIST FP GEN MED SURGEON
ONC. OTHER:

How found physician: Md Rec (independent)
(already seen)
1 Hosp Rec 2 Phonebook 3 Clinic 4 Family md
5 Friend Rec. 6 Other:

Feel comfortable Y N
How made comf.:

How long met:
very short 5 min 10 min 15 min 20 min long
Have questions Y N
What asked: (over if needed)

Answer adequately Y N

IF NO; WHY (SEE BACK)
Did the other ask questions Y N

What asked:

How did you feel about other asking questions:

How did MD react:

Clarify if necessary: This doctor was specialty:
This doctor did surgery: Y N

This doctor was the First, Second, Other: seen:

Did this doctor recommend you see another doctor: Y N
Did you follow this recommendation Y N

What MD did this doctor recommend:
What was specialty:

PAGE 8A-2; 8B-2; 8C-2; 8D-2; 8E-2; 8F-2; 8G-2; 8H-2
PHYSICIAN

In talking with this doctor: were you comfortable Y N

How made comf: 1. MD manner 2. MD Reassuring
3. MD gave time 3. Other:

if not comf: how handle

Did you ask many questions: Y N

What asked:

What exactly did Dr.# recommend

Were alternatives presented to you at this time by Dr. #

What told about alternatives

SECOND OPINION

If not clear: You said you received other opinions about the surgery Y N

PAGE 9 INTERVIEW #

QUESTION 9 MASTECTOMY KNOWLEDGE

9A ONE STEP TWO STEP SURGERY

9B Able to ask questions: Y N

Ask many questions: Y N

What type of questions did you ask:

Was there a reason that you did not wish to ask questions:

9C Before the surgery did you discuss the type of mastectomy you were to have Y N

What told:

Told anything about Lymph Nodes: Y N

Removed?

Know Classification: (staging

A. Radical

B. Modified radical (2 types -- Patey resect pectoralis Auchenclass retain pectoralis)

PAGE 10 INTERVIEW #

QUESTION 10 -- (Surgeon reassurance -- Hidden Information -- Searching Information)

10 A. Times your surgeon was particularly helpful or reassuring?

Time when could be more helpful or more reassuring? Y N

when this happened.

Time you were not given full information or where the answers were not adequate? Y N
When

10 B books or pamphlets offered? Y N

What was offered?

Did you wish to read this Y N
Why/why not

Did you actually read it? Y N
why/why not

10 C. search Y N

If Yes: Were you able to find Y N

Where go to get the information.
Friend
Library
Hospital Library
Medical Center
Md. (who)
AC Society
Other:

PAGE 11 INT #

10 D. Would you have liked to receive (some) (some other) literature
Y N
Explain:

QUESTION 11 (ANXIETY RATING SCALE)

11 A. Can you rate how you felt before the biopsy -- (biopsy/mastectomy) (Show scale 2)
0 1 2 3 4 5 6

11 B. Can you rate how you feel normally (every day)
Show scale 2 0 1 2 3 4 5 6

11 C Why feel that way

11 D. What type of thoughts having at this time.

QUESTION 12 (EASE OF ONE-STEP -- TWO STEP CIRCLE RESPONDENTS SURGERY)

12 A. ways easier on a woman?

12 B. ways more difficult on a woman?

(FOR LONGER RESPONSES SEE OVER)

12 C. Looking back now do you feel you made the right decisions about your breast tumor? Y N

12 D. Changes you would make?

12 E. Are there ever any times that you regret the decision or the way you made the decision? Y N
WHY:

PAGE 12 INTERVIEW #

QUESTION 13 (TIME PRIOR TO MASTECTOMY/HYPERVIGILANCE/OPEN TO INFORMATION)

13 A. How long time from when you decided to have the (biopsy/mastectomy) until hospital?
DAYS WEEKS MONTHS

13 B. What did you do during this period?

13 C. anxious-- YES NO

How handle this?

13 D. Did you ever, even after you had agreed to have the mastectomy think about not having it / or about changing your mind YES NO

13 E. Did you ever worry about your decision during this period of time? YES NO

If yes, how did you handle this?

HYPERVIGILANCE

13 F. worry about time passing? y n

Did you ever feel that you didn't have enough time to think about alternatives to the surgery? y n

13 G. other tests not discussed Y N
List Tests:

PAGE 13 INTERVIEW #

QUESTION 13 CONTINUED

13.G Understand need for these tests? Y N

What do if did not understand?

Did you refuse any hospital tests?

13 H. literature from hospital or med personnel Y N
on your admission -- on the procedure?
Was it helpful

Would like it Y N

Classes Y N

Helpful Y N Why

QUESTION 14 BEFORE SURGERY QUESTIONS

14 A. night before your surgery difficult Y N

What did you do ?

How make easier

14 B. morning of surgery
(Answer questions on back)

What did you do before going to surgery?
What is the first thing you remember after you awakened from anesthesia?
Tell me about this period?
14 C. How long in hospital prior (biopsy and then mastectomy) (biopsy/mastectomy) days

PAGE 14 INTERVIEW #

QUESTION 14

14 D. Which doctors visited you before your surgery?

What did you discuss with these doctors?
Reoccurrence
Need for further Therapy
only wound healing
emotional difficulty
scar
extent of cancer
other:

How long would you say these visits lasted?
brief minutes 1/2 hour longer

sufficient time? Y N

QUESTION 15 (AFTER SURGERY)

15 A. When did you first see your doctor after surgery?

What say to you

How did doctor handled this visit?

15 B. dressings
(Use Back if needed)
Was it difficult time Y N
How handle

Anything could make easier of dsg change Yes see over No

of hosp period Yes see over No

Anything md could do Yes (see over) No
What if design own care plan (Make changes see over) (No change)

PAGE 15 INTERVIEW #

QUESTION 16 (HOSPITAL STAFF EXCLUDING INDIVIDUAL PHYSICIAN)

16A.staff members visited before your surgery

VARIOUS RN'S LPN'S HOSP/OWN MD'S NONE OTHER;

VISIT QUESTIONS

What discuss with staff members?

How long? TOO SHORT MINUTES LONG ENOUGH

Did you feel you were visited frequently enough at this time to take care of your needs both physically and emotionally?
Y N

16 B. AFTER SURGERY: (helplessness)
How was your nursing care? POOR FAIR GOOD EXCELLENT

Was the care was somewhat inadequate? Yes No

How handle these situations?

Add anything Y N

Change Anything Y N

16D Family visit Before Y N After Y N
Who: (Answer over) Husb. Child Friend Workers Other

What Discuss Serious Light Other: (See Over)

How visits: Poor Fair Good Excellent (See over)

Anything to change:Yes (see over) N
Was there anything more difficult after surgery about having visitors. Y (see over) N

16E Anything make feel helpless Yes (see over) No

PAGE 16 INTERVIEW #

QUESTION 17 SURGICAL FOLLOW-UP CARE

17 A. How long ago was your surgery?
(DATE OF SURGERY / /

_____DAYS _____MONTHS _____YEARS

After surgery RADIATION CHEMOTHERAPY OTHER;

post surgical visits

Follow up exams Yes No

Still Followed Y N How frequently see

17 C. What told about reoccurrence

;7 D. Receive other info.

PAGE 18 INTERVIEW #

QUESTION 18 (FOLLOW-UP THERAPY)

1. Irradiation
2. Chemotherapy
3. Dietary

Who suggested:

When

How

Talk with others Yes No
(# of opinions_____)

Talk with RN Hosp Staff Other:

Get literature Y N
Attend Classes Y N
Search on own Y N
Accompanied Y N With whom: Helpful Y N

Still being treated Y N

QUESTION 19 (IRRADIATION)

19 A. How choose the doctor?

Is this doctor a radiologist? Y N

19 B. How frequently did you meet with the radiologist before starting therapy?

PAGE 19 INTERVIEW #

RADIATION
What were you told about radiation therapy, in terms of duration of treatment and about side effects?

Did you have many questions? YES NO
Were they answered satisfactorily? YES NO
COMMENT;

How would you say the doctor was about receiving questions?

19 C. major concerns?

Are any of those concerns still bothering you today?

Have you talked about these matters with anyone?

19 D. Make any changes Yes No

What:

19 E . Tell Another

Add Anything

PAGE 20 INTERVIEW #

QUESTION 20 CHEMOTHERAPY

How choose Chemotherapist? Is doctor Oncologist? Y N
If no: specialty

What were you told about chemotherapy therapy, in terms of duration of treatment and about side effects?

How often met with Md before:

Did you have many questions? YES NO
Were they answered satisfactorily? YES NO
COMMENT;

How would you say the doctor was about receiving questions?

20. C. major concerns?

Are any of those concerns still bothering you today?

Have you talked about these matters with anyone?

20 D. Make any changes Yes No

What:

20 E . Tell Another

Add Anything

PAGE 21 INTERVIEW #

21. DIETARY THERAPY
How did you decide upon dietary therapy?

Who did you speak to

What were you told about dietary therapy, in terms of duration of treatment and about side effects?

Did you have many questions? YES NO
Were they answered satisfactorily? YES NO
COMMENT;

How would you say the therapist was about receiving questions?

21 C. major concerns?

Are any of those concerns still bothering you today?

Have you talked about these matters with anyone?

21 D. Make any changes Yes No

What:

21 E . Tell Another

Add Anything

PAGE 22 INTERVIEW #

FINAL QUESTIONS

QUESTION 23 (FINAL QUESTIONS)
23 A . How long before resume health

days months year(s) not yet

Much difficulty Y N

Extra Help Y N
From Whom:
How Long days months still

Could have used it Y N Need More help Y N

23 B. Work outside Job Y N

What things at your job did you find most difficult?

For how long a period of time? days months still

Did your employers and the other employees know of your mastectomy? Y N

If yes: How did they respond?

If No: Was there any particular reason you did not wish them to know.

Were there neighbors or friends whom you did not tell If yes why:

If no: Did you find it difficult to tell people.

PAGE 23 INTERVIEW #

23 C. differently treated, or behave differently Husband,

Children,

Parents,

Siblings,

Friends,

Neighbors

Others

23 D. Did you notice that you feel differently from before the illness. (ANXIETY SCALE)

have you ever had two weeks or more during which you felt sad or depressed, or when you lost interest in the things and people around you. Y N

Had you ever experienced these types of feelings, for this period of time before your illness?

23 D2 - Have you had any difficulty either going to sleep, or remaining asleep, or any other changes in your sleeping pattern since the start of the illness? Y N

How about changes in your appetite? Y N

How frequently have these changes occurred?

How long do they last?

Had you noticed these type of changes in sleep or appetite before the start of the breast cancer?

PAGE 24 INTERVIEW #

23 D3 mind gone blank, or can't concentrate Y N

How frequently have you noticed this happening?

Had you ever noticed this before your illness? Y N

Do you think this is at all related to some aspect of your illness? Y N

What, if anything, have you been able to do to alleviate this?

23 D4 - Have you had any periods where you felt helpless to do anything to change your future? Y N

How often has this occurred?

Had this ever occurred before your illness? Y N

Do you believe that this feeling is related to your illness? Y N

23 D5 - Since your illness, have you ever used any type of tranquilizers or alcoholic beverages, more than you did before the illness? Y N

23 D6 - religious beliefs since the illness:
Have they changed in any way? Y N

How much do you think these changes were due to your illness?

PAGE 25 INTERVIEW #

23 D7 - Have you ever wondered why you yourself, rather than some other woman developed breast cancer? Y N
have you been able to answer this question? Y N

How did you answer this question?

23 D8 - cancer has changed your life?

Have there been any positive changes?

Have there been any negative changes?

QUESTION 24 (WORRY SCALE)
24-1
1. Never true of me. 2. Rarely true of me.
3. Sometimes true of me. 4. Often true of me.

24-21.
I. Never true of me. 2. Rarely true of me.
3. Sometimes true of me. 4. Often true of me.

24-3.
1. Never true of me. 2. Rarely true of me.
3. Sometimes true of me. 4. Often true of me.

25-A.

1.	2.	3.
hardly ever	not very often	sometimes

4.	5.
pretty often	almost all the time

25-B.

1.	2.	3.
hardly at all	just a little	some

4.	5.
quite a bit	a great deal

25-C.

1.	2.	3.
hardly at all	just a little	some

4.	5.
quite a bit	a great deal

25-D.

1.	2.	3.
not long at all	not very long	for a short while

4.	5.
for a pretty long time	for a very long time

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