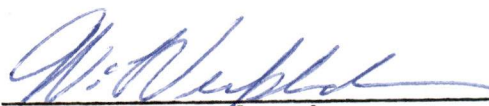


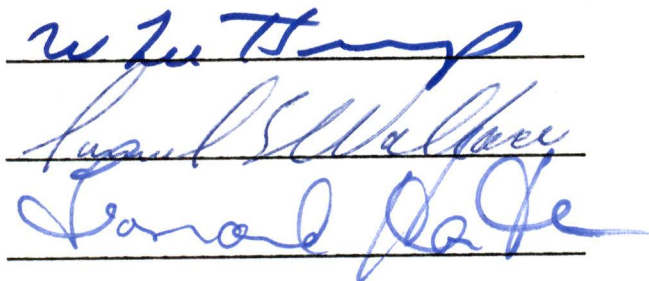
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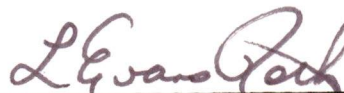


William Verplanck
Major Professor

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AN EXPLORATORY STUDY OF THE RELATIONSHIP BETWEEN
PSYCHOLOGICAL VARIABLES AND CHEMOTHERAPY
SIDE EFFECTS FROM CANCER TREATMENT

A Dissertation
Presented for the
Doctor of Philosophy
Degree
The University of Tennessee, Knoxville

Diana Scott Harrison

August 1979

1398054

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In memory of my parents, Frances Taylor Scott and
Irving James Scott, who, by example, taught me to always try
to make the best of what is available.

ACKNOWLEDGEMENTS

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ABSTRACT

The purpose of this study was to explore a relationship between cancer patients' reactions to their illness and its treatment and the experience of side effects from chemotherapy treatments. Twenty pre-chemotherapy patients served as subjects. They were interviewed before their treatments and again after treatment to obtain their evaluations of the severity of side effects. A physician also rated the side effects. Five months after the last pre-chemotherapy interview, hospital records were examined to find out which subjects were alive and which subjects had died from their cancers.

The subjects' and physician's evaluations of side effects as well as survival data were used to group subjects into high or low side effect groups and survival or non-survival groups. Interview data was analyzed to find items that subjects had discussed in their pre-chemotherapy interviews. The frequency of mention of these items was compared across subject groups.

The major findings of the research were that low side effect subjects reported coping mechanisms that helped them deal with the stress of cancer treatment more often than did high side effect subjects. Also, the low side effect subjects had continued to participate in their normal

activities and were optimistic about the outcome of their treatment. High side effect subjects were more likely to express resentment about the quality of their earlier treatment, had reduced their activity patterns and described their functioning as impaired. Survival was related to maintained activity patterns, report of coping mechanisms and optimism about treatment outcome.

Although this is an exploratory study and caution should be maintained when generalizing from the results, the findings suggest that cancer patients who are dissatisfied with the quality of their earlier treatment, are also likely to be critical of the impact of their chemotherapy treatments. Also, an optimistic attitude about treatment outcome, good stress tolerance and maintained activity patterns are associated with low side effects and survival.

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INTRODUCTION

Medical practitioners typically view physical illness as the consequence of physiological deterioration or as the result of some invasion of the body by a noxious foreign substance. Treatment modalities reflect an extension of the same reasoning when healing substances are introduced into an ailing system in order to effect a change. Although there is a long history of successful application of the above logic, this success may have obscured the importance of other factors which may also influence the course of a disease. The present paper will focus upon treatment response and explore the possibility that cancer patients' reactions to their illness and to its treatment may influence the experience of side effects from chemotherapy.

CHAPTER I

PROBLEM

Purpose of the Study

The various cytostatic drugs used in cancer treatment represent some of the most hopeful advances in cancer treatment. However, these drugs are associated with many side effects that range in severity from mild to life threatening. Drug intolerance may contribute to cancer mortality rates in two ways: (1) patients may die from chemotherapy side effects, and (2) patients may find chemotherapy treatments so uncomfortable that they stop treatment and refuse other types of cancer therapy. While drug intolerance has been related to the mode and rapidity of administration of the drug as well as to the physical condition of the cancer patient, these variables are not sufficient to predict the severity of side effects in any individual case.

The medical oncology service of the University of Tennessee Memorial Research Hospital is annually referred approximately 300 new patients. Of those patients, about 75% are given chemotherapy. Medical personnel and clinical psychologists on the University of Tennessee oncology unit have noticed that patients' responses to chemotherapy seem related to their psychological state. It has been observed

that patients who appear to be relaxed and optimistic about treatment seem to experience fewer and less serious side effects than do patients who seem anxious or depressed. Although these observations have been clinically validated by their predictive accuracy in individual cases, they have not been formally investigated using controlled observation methods and systematic analysis of the data.

The present study has investigated a possible relationship between the experience of side effects from chemotherapy treatments and subjects' reaction to the cancer and the impact of the illness upon their lives.

Need for the Study

An extensive search of the literature has revealed no research that has related the incidence of the side effects of chemotherapy to a broad range of patient attitudes and reactions to having cancer. Much of the research by psychologists has focused upon the emotional factors that may contribute to the etiology of cancer. Thus, a gap in the literature exists primarily in the area of basic description of cancer patients and their reactions to having cancer. The present study will provide basic descriptive data about the feelings and attitudes reported by cancer patients and on the changes in their life that have followed diagnosis of cancer. These data will be related to the

patients' judgments of the severity of side effects from chemotherapy treatments.

Assumptions and Limitations

The present study assumes that "emotional states" may influence physiological reactions. More specifically, it is assumed that the attitudes and emotional reactions of cancer patients toward the disease and its treatment can influence their response to chemotherapy.

The study also assumes that the psychological methods used for data collection are valid; that is, the statements given by patients about attitudes, feelings and reactions to having cancer can be successfully used in predicting patient reactions to cancer treatment.

The generalizability of the present results is limited by the subject population. All subjects are residents of the East Tennessee region and fall within the lower-middle to upper-middle socioeconomic class range. Because of these sample restrictions, the present findings may not apply to cancer patients in other geographical areas or of other social and economic classes. Its results can be generalized by replication, using other identified groups of subjects.

The present study is descriptive in nature; it represents an exploration of a possible relationship between psycho-social variables and the experience of side effects

from cancer treatment. It is not an experimental study that attempts to test preconceived hypotheses.

CHAPTER II

LITERATURE REVIEW

Historical Considerations

Psychologists have investigated the complex relationships among physiological states, emotional responses and observable behavior from a variety of perspectives. Some researchers have demonstrated behavioral changes that are predictably associated with the physiological manipulation of various parts of the bodies of laboratory animals (Baker, 1953, 1955; Campbell, 1953; Delgado & Anand, 1953). These authors avoided making any inferences about the emotional state of their subjects. Thus, behavior and physiological response were linked but the mediation that is either expressed in or caused by emotional factors was ignored.

Other authors attempted to equate emotion with certain physiological reactions (James, 1884). This research failed to identify specific emotions that could be reliably identified by observing physiological reactions (Weller & Bell, 1965; Ax, 1953). Although it was not possible to identify individual emotional reactions that were consistently associated with certain physiological changes, other authors have demonstrated that gross levels of emotional

arousal can be reliably associated with patterns of physiological responses (Duffy, 1962; Leeper, 1965).

The above research has attempted to link up the emotions to the soma in a way that assumes that emotions are the result of physiological change. That is, when a person notices the feelings that accompany certain bodily changes, they learn to call those feelings by names such as "anger" or "fear." In contrast, the psychosomatic point of view has uniformly assumed that emotional states can influence physiological reactions. That is, the emotional reactions precede bodily response.

Psychosomatic theory has been applied to the study of many disease entities. Some of this research has utilized cancer patients as subjects and attempted to understand the contribution of psychological variables to the etiology of cancer. Etiological studies have produced two major hypotheses concerning the psychological precursors of cancer: (1) cancer may be a response to protracted tension and emotional stress, and (2) there are personality types that are predisposed to cancer (Hagnell, 1965). There is no contradiction between these two hypotheses as a response to stress and tension can emanate from the personality style. The major difference between the two hypotheses is in the relative emphasis placed upon stressful life events as opposed to psychic structure.

Stressful Events as Precursors to Cancer

The earliest articles that suggested an association between stressful life events and the onset of cancer appeared in mid-17th century publications. Kowall (1955) traced the contributions of 18th and 19th century authors to the psychological theories of cancer etiology. He quoted the case studies of two women cited by Gendron in 1701. Those studies showed a close temporal relationship between the experience of the loss of a loved one and the onset of breast cancer symptoms.

In 1870, Herbert Snow published the first statistical study of cancer etiology. He observed 250 outpatients and inpatients with cancers and in 156 cases found that the cancer had been preceded by death of a loved one, serious financial hardship and loss of status or physical injury. Although Snow's research might have represented a major breakthrough for psychosomatic theory building, his study had little impact upon the research that followed. By the beginning of the 20th century, cancer was viewed as an organic disease with no etiological relationship to psychological variables.

A resurgence of the psychosomatic hypothesis occurred in the late part of the 1920's after psychoanalytic theory had made an impact upon western medical thinking. In 1928, Groddeck wrote The Book of the IT, in which cancer was

viewed as a bodily response to severe psychological frustration.

Elida Evans (1926) also advanced the idea of psychological precursors in cancer in her study of 100 cancer patients. Evans interviewed these subjects and reported that, in most cases, the cancer patient had lost a significant relationship before the onset of cancer symptoms. The work of E. Foque (1931) is a typical expression of the theoretical position of these early writers:

. . . cells first have to be in a receptive state before the cancerous process could start . . . and . . . it is necessary to study the role of sad emotions as activating and secondary causes in the activation of certain human cancers [p. 839].

Reflecting the idea that life stresses and loss may be the precursors of cancer, recent studies have utilized modern statistical techniques for the analysis of data as well as recently developed psychological instruments, techniques and theories. Researchers who have used such methodologies have had limited success in their attempts to demonstrate a statistically significant relationship between traumatic life events and the onset of cancer symptoms.

For example, Muslin, Gyarfas and Piper (1965) related the onset of breast cancer to a separation experience. These authors administered a questionnaire to all breast biopsy patients who entered a Chicago hospital. The questionnaire inquired about close relatives and friends and

attempted to find out when any separation between the patient and these people had occurred. An investigator with no prior knowledge of the questionnaire results placed the women in two groups on the basis of biopsy results. The group with benign biopsies were matched with members of the cancerous biopsy group in terms of age, race, marital status and socioeconomic status. Muslin, Gyarfas and Piper did not find a significant difference between the two groups in their experience of separation from a significant relationship.

Leshan and Worthington (1956) also investigated the frequency with which cancer patients had experienced the loss of an important relationship. They found that their subjects were significantly more likely to have experienced loss prior to the onset of cancer symptoms.

Personality Variables as Precursors to Cancer

The authors of other studies noted that the experience of loss, grief, anxiety or depression doesn't always result in cancer. Therefore, they reasoned that cancer patients may have a unique reaction to stress that produces cancer. That is, stress may be necessary but not sufficient for its occurrence or detection. This viewpoint focused attention upon the psychological makeup of the cancer patient rather than upon the stressful life events experienced by the patient.

Utilizing the Rorschach Test, Tarlau and Smalheiser (1965) studied 11 women with breast cancer and 11 women with cancer of the cervix. The data suggested that both groups had negative attitudes about their sexuality. This study is limited by the small number of subjects, the absence of a control group and by the fact that all subjects were administered the Rorschach after the onset of cancer. Therefore, the results may have reflected attitude shifts that were stimulated by the cancer and therefore may not have contributed to the onset of the cancer.

Bacon, Rennecker and Cutler (1952) utilized case history data to study 40 women with breast cancer. They reported that 35 of the 40 women exhibited a masochistic style in their interpersonal relationships. This research may have been influenced by the bias of the researchers who tested a hypothesis by looking at data on women whom they knew were breast cancer patients.

A highly developed theoretical explication of a relationship between personality type and cancer etiology is provided by Bahnson. Bahnson and Bahnson (1965) observed that cancer patients often display an interpersonal style that is controlled, rigid and conventional. However, psychological tests and interviews revealed that this interpersonal style covered feelings of deep despair and hopelessness. They hypothesized that a personality style

that produces conscious denial of feelings of despair and hopelessness may permit an unconscious expression of these feelings on a deeply regressed level of the personality.

Bahnson and Bahnson hypothesized that:

. . . the psychobiological effort to regenerate in the face of frustration, guilt and despair takes place on an archaic biological level . . . on the deepest and most archaic level of primary process fantasy, the creation of a tumor may be as important and meaningful to the cancer patient as is the creation of a symphony to the musician [p. 844].

The etiological focus of all of the above research has acknowledged the psychological pain that may contribute to the onset of cancer symptoms. However, the research has uniformly ignored the experience of the cancer patient as the disease progresses. It has also failed to describe the total situation confronted by the cancer patient. Some research has more directly reported observations of the behavior of cancer patients as they cope with the disease and its treatment. These studies have particular relevance to the data presented in the present study.

Survey of Literature Related to the Experience of Cancer

In contrast to research that investigated a relationship between psychological variables and the etiology of cancer, other studies have focused upon the cancer patient's experience of their illness. Several authors have studied the impact of surgical interventions

upon cancer patients. The initial stages of cancer treatment usually include referral to a surgeon who may perform a biopsy or exploratory surgery to assist in the diagnostic process. When indicated, the surgery might involve a radical removal of tissue in an attempt to arrest the disease. Although radical surgery in some cases may be curative, it often poses serious problems for the patient who must live with a radically altered body.

Sutherland, Orback, Dyx and Bard (1952) observed 57 patients who had surgically constructed colostomies for colon cancer. These authors found that:

Serious changes in body form and function cause stress that is determined by the specific conscious and unconscious meaning of an organ and its functioning either real or symbolic. When such stress threatens adaptation, it is reflected not only in affective experience but also in major changes in function in the areas of work, sex, or social relations [p. 859].

The colostomy patients studied by the above authors exhibited a consistent pattern of life changes and emotional reactions to their surgery. All patients reported feelings of shame, depression and degradation because of their inability to control expulsion of gas from their colostomies. Also, they all reported fear of spillage of feces. In order to avoid public exposure of this lack of bowel control, the colostomy patients reduced their contact with other people. These self-imposed restrictions included withdrawal from employment, sexual activity, and social participation.

Shands, Miles and Cobb (1951) described the emotional response of a 41 year old married woman to a radical mastectomy for breast cancer. This patient's premorbid adjustment had appeared normal, but following surgery, her tendency toward suspiciousness and idealization of authority figures became exaggerated. She became preoccupied with the idea of being injured, spoiled and dirty. As the disease progressed, the patient withdrew from her family and in the terminal stages of her illness, became isolated and detached, referring to herself as "that woman in the bed."

Abrams (1966) described the changing pattern of communication that accompanies the advancing stages of cancer. In her work with cancer patients, Abrams noticed that the terminal phase of the illness is often associated with a withdrawal of interest in the environment. She considered this withdrawal an adaptive response to the fact that all ties with the world would soon be broken by death. Although the level of detachment attained by the patient described by Shands, et al., (1951) is more extreme than the patients whose behavior Abrams (1966) described, a similarity exists.

Nahum and Golden (1963) described some of the psychological problems of laryngectomy patients. They studied 25 patients who had their larynx removed because of cancer. These patients reported feeling mutilated and

expressed a fear that they would be socially rejected because of their reduced ability to speak.

The articles cited above consistently failed to consider the subjects' behavior in the complex framework in which it occurred. Thus, fears, withdrawal and psychological detachment were viewed as maladaptive behavior when they may have represented a constructive and realistic adaptation to a total set of circumstances that would permit few other responses.

Body changes that result from radical surgery may conflict with or alter the patients' internalized self-image and stimulate psychological problems. However, the body changes also may alter the patients' stimulus value to other people and draw strong reactions from people who become highly threatened by signs of disfigurement. Thus, laryngectomy patients described by Nahum and Golden (1963) may have expressed realistic fears when they anticipated rejection by others because of their reduced ability to speak. Although these reactions may have represented psychological "problems," when viewed in an interpersonal setting, the fears may have been realistic and justified by the responses of other people.

Cancer patients do not live in social isolation and at least part of their reactions to their illness may be stimulated by the reactions of other people. Much of the

descriptive literature has failed to place cancer patients' reactions to their illness in a realistic context. It seems possible that attempts to present data in a clear and unambiguous manner have simplified the picture until it falsely appears that cancer patients' reactions to their illness is primarily in response to their own psychological makeup. This point of view obscures the natural complexity of the human experience.

Some authors have attempted to give a more comprehensive picture of cancer patients and their reactions to the disease and its treatment. Although much of this literature is anecdotal in nature, reflecting the experience of psychologists who have worked with cancer patients, it does attempt to reflect the complexity of cancer patients' reactions to their illness.

Drawing upon his long experience in doing psychotherapy with cancer patients (1958), Leshan provided a phenomenological description of the experience of patients with intractable pain (1964). This was an important contribution to the literature as it exposed the fears and vulnerabilities of his patients as well as their great sensitivity to the important human aspects of their environment.

Abrams and Finesinger (1953) described the guilt feelings expressed by cancer patients. Many patients viewed cancer as a form of retribution for past sins. In addition

to their guilt over past behavior, these patients expressed guilt over their inability to function in their families as they had prior to the illness.

Sutherland (1966) emphasized that the defensive mechanisms that are developed by cancer patients before their illness may become exaggerated during treatment to the point of seeming maladaptive. However, he observed that severe depression or psychoses seem to occur when the disease or its treatment interrupts some activity or function that is part of the patient's defense against anxiety. For example, a neurotic conflict over the wish to soil and fear of punishment for this behavior may be contained by an obsessive concern for cleanliness. If a person with this kind of conflict and defense were operated on for colon cancer and given a colostomy, heightened anxiety, depression and/or psychoses might occur.

Bahnsen (1975) reported some of the behavior patterns he has observed among cancer patients. He noticed that patients are often very submissive and dependent upon authority figures in the hospital setting. However, these same patients often displaced their anger and frustration and took it out on less important figures in their environment such as nursing personnel, or physicians who were no longer involved in their treatment.

Luce and Dawson (1975) observed that the major fears of cancer patients center around the issues of pain, fear of

dependency and fear of abandonment. Cancer patients also expressed the fear that their disease is either infectious or hereditary.

Cancer among Other Threats to Survival

Articles that have focused upon the patients' reaction to the disease and its treatment have offered valuable insights into the psychological impact of cancer. However, these studies have not addressed the unique attributes of cancer treatment or investigated the commonality between the experience of cancer patients and the experience of patients with other life threatening diseases. For example, cancer treatment may pose a unique stress for the cancer patient because the course of the disease lies between that of a chronic and that of an acute disease.

A chronic disease is a potential threat to survival but, with proper treatment, long term survival is possible. Therefore, the patient with a chronic disease must anticipate long and extensive treatment but at the same time may expect survival as a reward. In contrast, an acute, life threatening illness requires intensive treatment that will either succeed or fail in an attempt to preserve life. In treatment of acute, life threatening illnesses, physicians may sacrifice the quality of the patient's life in order to preserve life itself. The patient may be subjected to intensive, uncomfortable treatments but may reasonably

expect that if life is preserved, he may again regain a high quality, comfortable existence.

The experience of the cancer patient is intermediate between the chronic and the acute because the disease is life threatening and therefore, extreme treatment seems justified, while survival is relatively long term. Thus, the cancer patient may have to endure uncomfortable treatment over a long period of time with no guarantee of survival. It is difficult to conceive of a group of patients who experience a similar set of circumstances. Perhaps that is why the studies of cancer patients have so often been done without the use of a control group. Studies of cancer patients which provide basic descriptive data may allow future researchers to develop realistic control groups to which cancer patients may be compared.

Lefebvre (1977) made a valuable contribution to the literature when he described how individuals with cancer experienced the illness and its treatment. He studied 15 cancer patients and their spouses and found that cancer and its treatment had a serious impact upon the quality of life experienced by the patient and spouse. His patients reported important changes in basic areas of life such as eating, sleeping, sexual activity as well as changes in employment status, family role, friendships, recreational activities and participation in community activities.

Lefebvre's patients also described their experience of uncomfortable side effects from their chemotherapy treatments. Their complaints ranged from objectively observable physical symptoms such as vomiting, diarrhea and blistered mouths, to more subjective complaints of nausea, tiredness, soreness and treatment anxiety.

The present research represents an extension of Lefebvre's work in that it uses similar methods and descriptive data but focuses upon a possible relationship between the patient's experiences of changes in their life to the experience of drug side effects.

CHAPTER III

METHODS AND PROCEDURES

Subjects

The subjects of the present study were all inpatients on the University of Tennessee Memorial Research Hospital oncology unit. Each patient had been told that they had cancer before their admission to the hospital. This was usually done by the family physician or surgeon who had been consulted after the first symptom of cancer had been noticed. Following some initial treatment by a family physician, surgeon or radiologist, the patients had been referred to the University Hospital Hematology and Oncology Service to begin chemotherapy treatments.

Before hospitalization for chemotherapy treatments, each patient had been seen in the outpatient Oncology Clinic and hospitalization had been recommended by one of four doctors who worked at the clinic. New patients were seen at the outpatient Oncology Clinic on Monday and Wednesday mornings and all subjects in this study were admitted to the inpatient unit from the clinic on Monday or Wednesday afternoon.

Although a formal system of random selection of subjects was not applied, the subjects were contacted in the order of their admission to the hospital over a period of

time extending from January to August of 1977. Due to changes in the schedule of the interviewer, there were occasional weeks where the admission list was not checked. However, the patients were contacted in an approximately consecutive manner and no patient was included in this study on the recommendation of any staff person, or other special basis.

Each subject was initially contacted by the interviewer on the afternoon of admission to the hospital. During that contact, the purpose of the research was described. The interviewer introduced herself as a psychologist who was part of the oncology treatment team. She told the patients that one of the functions of the unit was research and that she and the Chief Oncologist were presently engaged in a study of factors that might influence the patient's experience of the chemotherapy treatments. Following this brief introduction, the patient was given a copy of a permission form that described the research and informed the patient of the potential risks involved in the study. This form also assured patients of their right to withdraw from participation in the research at any time. When a patient agreed to participate in the study, she/he was asked to sign a form that indicated understanding of the above explanation.

(See Appendix A for a copy of the permission form.*)

Each subject was initially contacted and interviewed during the interval of time between admission to the hospital and the start of chemotherapy. During this time, a medical workup was completed by hospital personnel. The diagnostic tests were done to confirm the diagnosis and also to provide a baseline from which treatment could be measured. Because the x-rays and other diagnostic tests required that the patients leave the unit for long periods of time, interviews were scheduled between tests or in the evening after visiting hours when patients were free to talk.

A total of 32 patients were contacted. Of those patients, 28 agreed to participate in the study. Two of the patients refused because the results of the study would be of no immediate benefit to themselves since results would not be obtained or utilized during their treatment. Of the 28 patients who agreed to participate, four died before data collection was completed, two patients did not receive chemotherapy and two tape recordings were inaudible. Complete data was collected on 20 subjects and partial data were collected in the case of the four subjects who died.

*The permission form indicates that subjects will be asked to fill out an Adjective Check List. These data were obtained but did not produce any findings that were useful in this study.

After each subject had received at least 3 cycles of chemotherapy, they were contacted again. This was approximately 3 months after the initial interview. During the second contact, they were asked to rate their experience of side effects from the chemotherapy. These subjective ratings were used to group the subjects. Group A was composed of 11 subjects who were made very uncomfortable by their chemotherapy treatments and Group B was composed of the 9 subjects who were comfortable throughout their chemotherapy treatments. (See Table 1 for the age and sex composition of each group.)

Table 1

Age and Sex of Subjects in Group A (High Side Effect)
and Group B (Low Side Effect)

Group	Age Range	Median Age	Male	Female	Number
A	30-62	57.5	7	4	11
B	22-87	60.8	4	5	9
Total			11	9	20

Each subject group included individuals with cancer diagnoses of differing cell type and organ involvement. (See Table 2 for cancer diagnoses and organ involvement for each subject group.) The number of cases in each subject group that had signs of cancer that were externally visible

Table 2
Cancer Diagnoses for Each Subject Group
by Organ Involvement

Organ	Group A	Group B	Number of Cases
Skin	2	1	3
Blood	2	2	4
Genito-urinary	1	-	1
Colon	3	1	4
Larynx	1	-	1
Lung	1	1	2
Pancreas	-	2	2
Breast	1	1	2
Stomach	-	1	1
Total	11	9	20

to the patient is described in Table 3 as well as the numbers of cases which involved a metastatic spread to other organs from the primary lesion.

Table 3
Cases in Each Group with External* Signs of the
Disease or Metastatic Spread of the Cancer

Group	External Signs	Metastasis
A (N = 11)	6	2
B (N = 9)	3	2
Total	9	4

*Visible to patient, not to others.

Instruments

Before the first chemotherapy treatment, subjects were interviewed utilizing a structured interview. Interviews were conducted by the present writer.

The interview inquired about the circumstances under which the subjects first found out about their cancers. It also asked about subjects' emotional reaction to that information. Subjects were asked to describe changes in their family life, employment status and social participation that had occurred since the cancer diagnosis. They were also asked to describe their knowledge of chemotherapy, expectations about treatment outcome and potential experience of side effects from the chemotherapy. (See Appendix B for a copy of the interview check list.)

After three cycles of chemotherapy had been completed, each subject was again interviewed to find out about their experience with the chemotherapy. (See Appendix C for a copy of the post-chemotherapy interview.) This interview inquired about the number of treatments received, the interval between treatments and where the treatments had been given. It also asked subjects to describe any changes in their reaction to the chemotherapy and what side effects they had experienced. Subjects were asked to describe changes in their employment status, church and community activities, family life and friendships that had occurred

because of the side effects from the chemotherapy. They were also asked to describe how long after chemotherapy they were able to resume normal activity levels. Finally, subjects were asked to rate the severity of any side effects they had experienced. Because of the exploratory nature of the present study, all data are reported including those with nonsignificant findings.

All subjects who received chemotherapy were evaluated by a physician who rated the apparent severity of the side effects. The physician utilized the grading system of the Southeastern Cancer Study Group. In that rating system, side effects are rated as absent (Grade 0), mild (Grade 1), moderate (Grade 2) or severe (Grade 3). Grades 2 and 3 are ratings that reflect sufficient organic disturbance to require medication. However, Grade 2 reactions are responsive to treatment while Grade 3 reactions are more intractable. The location of the side effect symptom was identified by the organ system that was involved in the reaction. (See Appendix D for a copy of the physician's rating form for side effects.)

The structured interview provided information about subjects prior to their first chemotherapy treatment. These data reflected the psychological set that subjects carried into the chemotherapy setting.

It was decided to obtain both a patient and a physician's rating of the severity of side effects because

of the frequently observed apparent discrepancy between the two sources of evaluation. Patients on the cancer unit were often suprisingly tolerant of their physical condition while the physicians felt that they had serious medical problems that were caused by chemotherapy. Other patients were extremely critical of their state of health while the physicians were satisfied with their tolerance of the chemotherapy treatments. Thus, it seemed likely that the patients' judgments of side effects might be different from the evaluation of side effects made by a physician.

Data Collection

The pre-chemotherapy interviews were each begun with a question about how the subject first learned about having cancer. The order of the rest of the interview varied from subject to subject. Pilot interviews indicated that rigid adherence to the structure of an interview prevented the subjects from freely telling a story that was enormously important to them. To allow the subjects freedom to express themselves, the interviewer adopted a technique of allowing the interview to flow freely while checking off content areas on a list as the areas of inquiry were satisfied. When pertinent information was spontaneously mentioned by the subjects, probing questions were asked until all of the structured interview data had been elicited by questions or spontaneously offered. At the end of the interview, any

areas that had not been covered were directly asked about until all the desired information had been obtained. The topical areas covered in the interview structure functioned as a stimulus to the subjects, who all provided much more data than the interview directly required.

Interviews ranged in length from 45 minutes to 1-1/2 hours. Because interviews were usually conducted in the subject's hospital room, after visiting hours, there were few interruptions. Occasionally, a nurse or an aide entered the room to check on the patient, but these intrusions were kept to a minimum since the interviewer always let the nurse in charge know who was being interviewed. If family members were present at the beginning of the interview, they were asked to leave the room. If the subject shared a room with another patient, the interview was conducted in a sitting room on a wing adjacent to the inpatient unit. In this way, privacy was provided and subjects were thus encouraged to speak candidly.

All interviews were tape recorded on 120 minute cassettes, utilizing a Sharp tape player-recorder. The tape recorder was openly displayed at all times.

The post chemotherapy interview was developed in the form of a questionnaire that was mailed to all subjects when they had completed at least 3 cycles of chemotherapy, approximately three months after the initial interview.

Only three out of twenty subjects filled out the questionnaire and returned it by mail in the addressed, stamped envelope that had been included. Ten subjects were interviewed in the hospital during their subsequent chemotherapy treatments and seven subjects were interviewed over the telephone. The subjects who were interviewed in person or over the telephone indicated that they had wanted to send back the questionnaire but had felt frustrated by the structure of the questionnaire which had attempted to elicit brief responses to questions about complex life experiences. Therefore, the three subjects who had returned the questionnaire by mail were contacted to give them the opportunity to discuss their responses. All three subjects expanded upon their written responses but gave no new information.

After subjects had received three chemotherapy treatments, a physician was asked to rate the severity of side effects using a rating form that listed the organ systems that might be affected by the chemotherapy drugs. The physician used medical records, laboratory findings and clinical data to grade the severity of side effects according to the grading system of the Southeastern Cancer Study Group.

Data Analysis

At the end of the data collection, twenty subjects had been interviewed before and after their chemotherapy treatments, they had rated the severity of their side effects and the side effects had also been rated by a physician. An initial attempt was made to analyze the data by grouping together all statements that referred to categories of the structured interview. This method of data organization was abandoned because subjects frequently talked about subjects that were not part of the structured interview categories and subjects frequently repeated themselves, making it difficult to compare categories on the basis of relative frequency of statements in each category. For example, a single interview category might have been mentioned several times by a few subjects, and only once by the other subjects. The total frequency of comments might not reflect the importance of that item for a group of subjects because of the false inflation of frequency caused by the repetition.

Because of these problems, another method of analysis was adopted. All pre-chemotherapy interviews had been transcribed by a technician who worked with charts and records in the Oncology research office. Three of the hand written transcriptions that were especially neat and easy to read were selected for an intensive analysis. To insure

that each transcription was complete and accurate, it was read while the taped interview was playing and any necessary corrections were made. The transcriptions were then organized like a play with statements by the patient labeled "P" and statements by the investigator labeled "D."

A content analysis by topic of each of the three transcripts was accomplished by writing a sentence that described what the subject was talking about in each section of the transcript that was labeled "P." When this had been accomplished for each transcript, a list of the descriptive sentences was made and evaluated. There were many areas of overlap, i.e., subjects on all three tapes talked about the same things. However, there were also topics that were not mentioned in all three transcriptions. By a process of combining the three lists, 22 different subject areas were identified that had been mentioned in at least one of the three transcripts. Appendix E has a list of the interview categories that were obtained from the analysis of the three transcriptions and that were used in the data analysis.

The tape recordings of all subjects were listened to and as each subject mentioned a topic that was included in the list of interview categories, a check was made. A separate list was made for each subject to avoid repetitive counting of a topic once it had been mentioned. For example, if a subject mentioned feeling angry toward his/her

physician several times in one interview, this content was counted only once, the first time it was mentioned; this was a measure of incidence. After that, the category would have been checked off for that subject. When all the tapes had been heard (including the three tapes which had been the basis for the original list of categories), each subject was coded for the severity of side effects. The post chemotherapy interviews and the physicians' evaluation of side effects were used to group the subjects into high or low side effect groups.

Each subject was coded as doctor high side effect or doctor low side effect and as patient high side effect or patient low side effect according to the information obtained in the post-chemotherapy interview and in the physician's rating of the side effects. The data was thus organized in a table with coding of side effects at the top of each subject column and the interview categories at the left of the table. (See Appendix F for example of the way data was organized.) It was then possible to total the frequency of statements for a given interview category for each subject group and compare the relative frequency of items for the high or low side effect subject groups.

Reliability Check

To check for the reliability of the observations, an undergraduate student in the Psychology Honors Program was

asked to listen to the tape recordings and indicate when she heard statements that corresponded with each interview category. The percentage of agreement between the second observer and the investigator was calculated for each category and for each subject.

In addition to the above comparison, the ratings of the two observers were analyzed to determine how frequently they both agreed on an observation and how often one observer made an observation that was not heard by the other observer. These frequencies were compared, using a tetrachoric correlation in order to obtain another measure of the relationship between the two sets of observations.

These data represent a tabulation of the observations made by the investigator and not those of the second observer who reviewed the tapes. A sum of frequencies in each interview category was computed for each subject group. These totals were compared, utilizing the Fishers Exact Test (Hays, 1973). This test is a non-parametric statistical test that makes no assumptions about the distribution of the data. It is a rigorous test, applicable to low cell frequencies and yields a probability that observed arrangement of frequencies occurs by chance.

Survival Analysis: Reported Death

Five months after the last subject interview (in January 1978), a hospital staff member mentioned to the

investigator that a few of the subjects had recently died of their cancer. This information stimulated a search of the hospital records to determine which subjects had died over the 5 months since the initial data collection had been completed.

It is important to note that the hospital does not keep careful records of patient survival or non-survival. Patients leave treatment for a variety of reasons and the hospital staff do not follow up to determine why a patient fails to continue treatment. Therefore, information about patient non-survival includes casual reports by family or friends or chance notice of an obituary by a staff member. The potentially harmful impact of a phone call to ask about a subject who may have died several months earlier was too great to justify a complete inquiry into the survival rates by this means. Nor could a systematic search of obituary columns or city records be undertaken.

In addition to the above weaknesses in the information about survival of non-survival, it should also be noted that subjects were interviewed across a period of eight months and survival was defined in terms of subjects' survival at one point in time. Therefore, survival time would vary from a maximum of one year for some subjects to as little as 5 months for some other subjects. Because no systematic bias had been introduced in the original selection of subjects or

in the order of their interview, it was decided to compare surviving and non-surviving subjects in spite of the inadequacies of the data described above.

Further justification for use of the hospital records of survival, non-survival for a further grouping of subjects was provided by an analysis of the relationship between survival and the time of the first interview. Subjects had been numbered consecutively according to the order in which they had been interviewed. Therefore, the first ten subjects could be compared with the second ten subjects in their rate of survival in January 1978. This comparison showed that fewer of the first ten subjects were dead in January 1978 than were the second ten subjects. Thus, survival in this group was not associated in any obvious way with length of the illness. Table 4 shows a significant relationship between time of interview and reported death.

Table 4

The Relationship between Time of Interview
and Survival in January 1978*

Interview	Survival	Non-Survival	Total
1-10	8	2	10
11-20	4	6	10
Total	12	8	20

* $p = .08$

Subjects were arranged into a group of reportedly living subjects who were compared with subjects reported dead. The original interview data and interview categories were tabulated for each item and frequencies were compared to see if subjects reported dead within the interval since their interview were different from the presumed surviving subjects. The frequencies were tested for significance using the Fishers Exact test.

CHAPTER IV

RESULTS

Reliability

The investigator and an undergraduate Psychology Honors Program student each listened to the tape recordings of subject interviews. The percentage of agreement between the two observers ranged from 50% to 100%. (See Table 5 for the percentages of agreement between the two observers.)

Table 5

Percentage of Agreement between the Two Observers

% Agreement	Number of Items
50	2
55	1
60	3
65	3
70	6
75	3
80	4
100	1
Total	23

The three items for which there was the lowest percentage of agreement (50 and 55%) required that the rater evaluate the emotional state of the subjects as they described their experience with cancer. The two items that

yielded 50% agreement evaluated whether the subjects were upset by their illness and/or were angry toward one or more of their physicians. The item that yielded 55% agreement required that the raters evaluate whether or not the subjects expressed calm acceptance of their illness. An analysis of the observations on which the raters disagreed about the emotion expressed by the subjects indicated that the second rater observed the emotion of anger and a state of calmness more frequently than did the investigator. However, the investigator observed that patients seemed upset more frequently than did the second observer. (See Table 6 for frequencies of observations by the two raters.)

The raters shared highest agreement (80-100%) when they rated the subjects' assertions that they had discussed their illness with family members, actively questioned their physicians about their illness, used a religious philosophy to help themselves cope with their illness, were employed at the time of the interview, and continued to attend social activities after the cancer diagnosis had been made. (See Table 7 for the items of high agreement and the percentage of agreement.)

A tabulation was made of the total number of agreements and disagreements in which the investigator made an observation when the second observer did not or when the second observer made an observation when the investigator did not.

Table 6
Observations by Two Raters where There
Was 50% and 55% Agreement

	2nd Observer	
	Observed	Not Observed
Item: Anger toward Physician (50% Agreement)		
Investigator		
Observed	5	0
Not Observed	10	5
Item: Calm Acceptance of Illness (55% Agreement)		
Investigator		
Observed	8	1
Not Observed	8	3
Item: Upset by Illness (50% Agreement)		
Investigator		
Observed	5	7
Not Observed	3	5

Table 7

The Items with High Inter-Rater Agreement

Items	% Agreement
Active Questioning of Doctors	80
Use of Religious Philosophy	80
Employed at Time of Interview	80
Attending Social Activities	80
Talk with Family about Illness	100

These Frequencies were analyzed using a Tetrachoric correlation. A correlation between the two sets of observations was found of .54. (See Table 8 for an analysis of the relationship between the raters' observations.)

Table 8

Correlation between the Observations
of the Two Raters*

	Second Observer		Total
	Observed	Not Observed	
Investigator			
Observed	119	54	173
Not Observed	86	179	265
Total	205	233	438

$$*r_{tet} = .54$$

Patient Identified High or Low
Side Effect Groups

The subjects who evaluated their experiences of side effects as uncomfortable (high side effect) were compared with subjects who rated their experience of side effects as comfortable (low side effect). There were significant differences between these groups in the frequency with which they reported several items. The most significant difference appeared in the frequency with which the high side-effect group of subjects reported that they had received the wrong treatment for their cancers at some point in their illness. This difference was significant at the .003 level of significance. The subjects with high side effects were also less likely to have continued to attend church ($p = .02$) and did not express the expectation that they would get well as often as did the low side effect subjects ($p = .03$). The high side effect subjects were less likely to discuss their illness with anyone who asked about it ($p = .07$) or with friends ($p = .08$). Table 9 compares the high side-effect subjects with low side effect subjects on items with p values between .003 and .08.

The high side effect subjects complained more frequently that information had been withheld by their physicians ($p = .11$). They also reported that they had been told that a surgical cure of their cancer had been accomplished ($p = .14$). High side effect subjects complained of

Table 9

Items Which Yielded p Values between .003 and .08
in Comparison of Patient Identified
High and Low Side Effect Groups

Item	High	Low	p Value
	Side Effect N = 11	Side Effect N = 9	
Wrong Treatment	7	1	.003
Continued to Attend Church	4	8	.02
Expect to Get Well	0	4	.03
Discuss Illness with Anyone	0	3	.08
Discuss Illness with Friends	4	7	.08

receiving confusing information from different physicians ($p = .16$) and were having more difficulty in doing their routine household tasks ($p = .11$). High side effect subjects were also less likely to report a use of a religious philosophy in helping themselves to accept their illness ($p = .12$). (See Table 10 for a comparison of high and low side effect groups on items which yielded a p value between .11 and .16).

The items that failed to suggest a difference between the high and low side effect groups included the frequency with which they tended to express anger toward one or more of their physicians ($p = .21$), or were upset ($p = .20$) or depressed ($p = .26$). The two subject groups were also not significantly different in number of employed individuals ($p = .21$) or calm individuals ($p = .33$). There was no significant difference in the frequency with which subjects

Table 10

Items That Yielded p Values between .11 and .16 When
Patient Identified High and Low Side Effect
Subjects Were Compared

Item	High	Low	p Value
	Side Effect N = 11	Side Effect N = 9	
Trouble Doing Household Tasks	5	1	.11
Information Withheld by Doctor	5	1	.11
Use of Religious Philosophy	6	8	.12
Claim of Surgical Cure	3	0	.14
Confusing Information	6	2	.16

in each group described methods that they used to divert their attention away from thoughts of the cancer ($p = .22$).

An approximately equal proportion of both subject groups reported changes in their family life that they attributed to the cancer ($p = .46$). Active questioning of their physicians to obtain information about their cancer was reported by an approximately equal proportion of subjects in each group ($p = .57$) as were their expressions of faith in their current physicians ($p = .69$). (See Table 11 for a comparison of subject groups on items that yielded a p value between .20 and .69).

The results in Table 11 suggest that patients who judged their side effects as uncomfortable had more grievances about the quality of the care they had received and were more upset by their illness. They tended to judge themselves as more impaired and were less active than were

Table 11

Items Which Yielded a p Value between .20 and .61
in Comparison of Patient Identified
High and Low Side Effect Groups

Item	Side Effect		p Value
	High N = 11	Low N = 9	
Upset	8	4	.20
Employed	3	5	.21
Anger toward Doctors	4	1	.21
Attention Diversion	2	4	.22
Depressed	5	2	.26
Calm	4	5	.33
Changes in Family Life	5	3	.46
Active Questioning of Doctor	3	3	.57
Faith in Doctors	4	3	.69

the low side effect subjects. The high side effect subjects were also less optimistic about the outcome of their illness, tended to talk about it less and used fewer coping mechanisms to help themselves deal with the illness.

Physician Evaluation of Side Effects

Although the subjects' perceptions of the severity of side effects provides important data, these perceptions may reflect a low pain tolerance or other subject variables that tend to exaggerate the severity of the side effects. Therefore, a physician was asked to rate the side effects on the basis of laboratory findings and other medical studies that are utilized to diagnose and evaluate side effects from chemotherapy. Subjects were grouped into a high side effect group and a low side effect group on the basis of the physician's evaluation. These ratings were compared with the subjects' evaluation of side effects and the two sets of side effect evaluations were not found to be significantly different ($p = .33$). Table 12 compares the physician's evaluation of side effects with the patient evaluations of side effects.

The data were examined for a relationship between patient perceptions of the severity of side effects and short term survival. The relationship between these two variables was $p = .16$. (See Table 13 for a comparison of

Table 12

Physician Ratings of the Severity of Side Effects
Compared with Subject Ratings of Side Effects*

	Physician High	Physician Low	Total
Patient High	7	4	11
Patient Low	3	6	9
Total	10	10	20

* $p = .33$

Table 13

Comparison of Groups Defined by Patient Perceptions
of Side Effects and Short Term Survival*

	Alive	Dead	Total
High Side Effects	5	6	11
Low Side Effects	7	2	9
Total	12	8	20

* $p = .156$

patient defined side effect groups and the groups defined by short term survival.)

There was no significant relationship between the high or low side effect groups that were defined by the physician's evaluation of side effects and the group of subjects defined by short term survival ($p = .32$). Table 14 illustrates the relationship between the physician's side effect group and survival rates.

Table 14

Relationship between Groups Defined by Physician's
Evaluation of Side Effects and
by Short Term Survival*

	Survivors	Non-Survivors	Total
High Side Effects	5	5	10
Low Side Effects	7	3	10

* $p = .32$

Subjects who experienced high or low side effects according to the physician's evaluation of the side effects were rated on the same items as were the patient defined side effect groups. The ratings were tabulated and compared. There were some significant differences between the physician identified high and low side effect groups.

Subjects in the high side effect group were more likely to complain that information had been withheld by their physicians ($p = .07$). They also were more likely to report that they had been confused by information they received from their physicians ($p = .08$). The high side effect subjects were less likely to have continued to attend social activities ($p = .09$). However, the low side effect subjects reported changes in family life that were caused by the cancer ($p = .08$) more frequently than did the high side effect subjects. (See Table 15 for a comparison of

Table 15

Items That Yielded a p Value between .07 and .09
in Comparison of Physician Identified
High and Low Side Effect Groups

Item	Side Effect		p Value
	High N = 10	Low N = 10	
Confused	6	2	.08
Information Withheld	5	1	.07
Changes in Family Life	2	6	.08
Continued Social Activity	4	8	.09

physician identified high and low side effect groups on items that yielded a p value between .07 and .09).

The physician's high side effect subjects reported that they had been told that surgery had cured their cancer more often than low side effect subjects ($p = .11$) and were more frequently angry toward their physicians ($p = .15$) and depressed ($p = .17$). The low side effect subjects more often described themselves as calm ($p = .18$) and were more likely to discuss their illness with friends ($p = .17$). (See Table 16 for items with p values between .11 and .18 when physician identified high and low side effect subjects were compared.)

Several of the items failed to differentiate between subject groups. Subjects in each group were equally likely to express the expectation that they would recover from their illness ($p = .29$). Both groups reported that they had

Table 16

Items with p Values between .11 and .18
in Comparison of Physician Identified
Side Effect Groups

Item	Side Effect		p Value
	High N = 10	Low N = 10	
Surgical Cure	3	0	.11
Angry with Physician	4	1	.15
Depressed	5	2	.17
Talk with Friends	4	7	.17
Calm	3	6	.18

actively questioned their physicians to find out about their illness ($p = .31$) and believed that they had received the wrong treatment for their illness ($p = .33$). Subjects in both groups reported that their treatment had been delayed ($p = .33$) and stated that they had used a religious philosophy to help themselves cope with their illness ($p = .31$). (See Table 17 for a comparison of high and low side effect groups on items which yielded a p value between .29 and .33.)

An approximately equal proportion of subjects in each group stated that they were willing to discuss their illness with anyone who asked about it ($p = .50$). An equal proportion of subjects in each group also reported that they were upset by their illness ($p = .50$). Church attendance ($p = .67$), employment ($p = .67$), use of attention diversions

Table 17

Items Which Yielded p Values between .29 and .33
in Comparison of Physician Identified
High and Low Side Effect Groups

Item	Side Effect		p Value
	High N = 10	Low N = 10	
Expect To Get Well	1	3	.29
Religious Philosophy	6	8	.31
Active Questioning	4	2	.31
Treatment Delay	5	3	.33
Wrong Treatment	5	3	.33

($p = .63$), early diagnosis ($p = .67$) and trouble doing household tasks ($p = .69$) also failed to differentiate between these subject groups. Table 18 illustrates which items yielded p values between .50 and .69.

Table 18

Items with a p Value between .50 and .69
When Physician Identified Side Effect
Groups Were Compared

Item	Side Effect		p Value
	High N = 10	Low N = 10	
Discuss with Anyone	1	2	.50
Upset	7	5	.50
Church Attendance	6	6	.67
Employment	4	4	.67
Attention Diversion	3	3	.63
Early Diagnosis	4	4	.67
Trouble Doing Household Tasks	3	3	.69

The high side effect subjects as defined by the physician's evaluation of side effects described themselves as depressed, angry and upset and they were less likely than low side effect subjects to discuss their illness with other people. The high side effect subjects also reported the belief that they had been badly treated by their physicians more often than did low side effect subjects. The high side effect group was less active and described their functioning as impaired.

Survivors versus Non-Survivors

As mentioned earlier, in January of 1978, hospital records were examined to determine which of the subjects were still living and which subjects had died from their cancers. Of the twenty subjects, twelve were still alive and 8 had died. The group of surviving subjects were compared with non-survivors on the frequency of their responses in each interview category.

The surviving subjects were found to be more likely to have continued attending social activities ($p = .08$), and were more often employed ($p = .05$) and were less likely to report that they were having trouble doing their household tasks ($p = .02$). Also, the living subjects more frequently reported that they expected to get well ($p = .10$). (See Table 19 for the comparison of surviving with non-surviving subjects on items with a p value between .02 and .10.)

Table 19

Items with p Value between .02 and .10 in Comparison
of Surviving Subjects with Non-Survivors

Item	Survivors N = 12	Non-Survivors N = 8	p Value
Trouble Doing Household Activities	1	5	.02
Employed	7	1	.05
Attend Social Activities	10	2	.08
Expect To Get Well	4	0	.10

Survivors reported more frequently than non-survivors that they continued to attend church ($p = .13$), were calm ($p = .16$) and used attention diversions to get their minds off of thoughts of the cancer ($p = .19$). The subjects who died more frequently reported that their treatment had been delayed ($p = .12$). (See Table 20 for items with p values between .12 and .19 when surviving and non-surviving subjects were compared.)

Table 20

Items with p Values between .12 and .19
When Surviving and Non-Surviving
Subjects Were Compared

Item	Survivors N = 12	Non-Survivors N = 8	p Value
Treatment Delay	3	5	.12
Attend Church	9	3	.13
Calm	7	2	.16
Attention Diversions	5	1	.19

More of the survivors reported that their cancers had been diagnosed after their first contact with a physician ($p = .26$). However, being upset ($p = .41$), active questioning of the physicians ($p = .54$), being confused by information received from physicians ($p = .43$) or willingness to discuss the illness with friends ($p = .54$) did not differentiate between the two groups. Table 21 gives items with p values between .26 and .54 when surviving subjects were compared with non-survivors.

Table 21

Items Which Yielded a p Value between .26 and .54
When Living and Dead Subjects Were Compared

Item	Living N = 12	Dead N = 8	p Values
Diagnosis After 1st Work-Up	6	2	.26
Upset	6	6	.41
Changes in Family Life	5	3	.46
Confusion	4	4	.43
Active Questioning of Physicians	4	2	.54
Discuss Illness with Friends	7	4	.54

Other items failed to differentiate between surviving and non-surviving subjects. The two groups were equally likely to report that they were depressed ($p = .63$), or angry ($p = .70$), or to express faith in their current physicians ($p = .63$). They were also equally likely to

express the belief that they had received the wrong treatment for their disease ($p = .64$), that information had been withheld from them by their doctors ($p = .61$) or that a surgeon had claimed to cure their cancer ($p = .65$). Approximately equal proportions of each group expressed willingness to discuss their illness with anyone who was interested ($p = .65$). (See Table 22 for items with p values between .61 and .70 in comparison of surviving and non-surviving subjects.)

Table 22

Items That Yielded a p Value between .61 and .70
When Surviving and Non-Surviving Subjects
Were Compared

Item	Surviving	Non-Surviving	p Value
Information Withheld	3	3	.61
Depressed	4	3	.63
Surgical Cure Claimed	2	1	.65
Wrong Treatment	5	3	.64
Anger toward Doctors	3	2	.70
Faith in Doctors	4	3	.63
Discuss Illness With Anyone	2	1	.65

Summarizing the preceding data, the living subjects expressed less resentment toward their physicians, were more active, viewed themselves as less impaired and were more optimistic than were subjects who died.

In order to determine whether there was an age or a sex factor that might be associated with short term survival, these variables were examined. Subjects who survived were somewhat younger than non-survivors and there was no significant relationship between sex and survival. Table 23 shows the age-sex comparison of surviving and non-surviving subjects.

Table 23
Age and Sex Comparison of Surviving
and Non-Surviving Subjects*

	Survivors	Non-Survivors
Median Age	52.8	64.5
Mean Age	47.5	53.1
Male	7	4
Female	5	4
Total	12	8

* $p = .33$

"Cluster" Analysis

The pattern of results suggested that there might be several clusters of items that were related to the experience of adverse side effects from chemotherapy as well as to death from the cancer. The item clusters were labeled as follows: Activity cluster, Resentment cluster, Impairment cluster, Coping mechanism cluster, Pleased with treatment

cluster, and Optimism cluster. Table 24 presents items that were included in each cluster.

The six item clusters included all of the interview items that were individually used to evaluate group differences. The grouping of items reflected the investigator's judgment of a relationship among the items. For example, continued employment, social attendance and church attendance were all items that reflected an ability to continue routine activities. In contrast, the Impairment cluster implied that, because of the illness, subjects were no longer living in their typical way. They felt depressed, upset, unable to continue doing household tasks as usual and had either a higher or a lower level of communication with their families. Although a higher level of communication might imply an improvement in family relationships, it was also typically accompanied by a heightened anxiety level, greater risk taking and a sense of acute need to say and do things that might never be possible again. For that reason, it was associated with some other negative results of the disease.

Item clusters were tabulated by counting the frequency with which subjects in each group made statements that corresponded with one or more of the cluster items. Thus, any one subject might contribute to up to three or as few as none of the total number of items that were counted for a cluster such as the three item activity cluster.

Table 24
Item Clusters

Activity:	Employed at the time of the interview Social activity continued up to time of interview Church attendance continued up to time of interview
Resentment:	Treatment delay Received the wrong treatment Information withheld by doctors Confusing information from doctors Anger expressed toward doctors Surgical cure of cancer claimed
Impairment:	Depression Upset by illness Changes in family life No longer able to do household tasks
Coping Mechanisms:	Active questioning of doctors Use of a Religious Philosophy Attention Diversion Talk with friends about illness Talk with anyone about illness
Pleased with treatment:	Diagnosis after initial work-up Express faith in doctors
Optimism:	Expect to get well Calm

Activity

The activity cluster included items that reflected continued involvement in routine activity patterns. When patient defined high and low side effect subjects were compared, a Chi square value of 12.97 was obtained with a p value of .01. The activity cluster was also highly significant when surviving and non-surviving subjects were compared ($\chi^2 = 24.739$, $p = .01$). This cluster of items failed to differentiate between physician identified high and low side effect groups. (See Table 25 for results of activity cluster across all groups of subjects.)

Resentment

The cluster of items called "Resentment" included items that revealed various complaints that had been expressed about the quality of the cancer treatment. These complaints included the feeling that treatment had been delayed too long because of misdiagnosis or improper diagnostic procedures, that physicians had withheld information about the illness from the patient or that information that had been conveyed had been confusing. The subjects also complained that they had received wrong treatments for symptoms that later turned out to be from the cancer, and that surgeons had falsely claimed that they had cured cancers that later reoccurred. This item cluster also included expressions of anger toward former physicians.

Table 25

Activity Cluster

One or more of the

following items: continued church activity,
continued social activity,
employment

	Item Present	Item Absent	Total
Patient defined:			
High side effect	13	20	33
Low side effect	<u>23</u>	<u>4</u>	<u>27</u>
Total	<u>36</u>	<u>24</u>	<u>60</u>
$x^2 = 12.97$ $p = .01$			
Physician defined:			
High side effect	14	16	30
Low side effect	<u>18</u>	<u>12</u>	<u>30</u>
Total	<u>32</u>	<u>28</u>	<u>60</u>
$x^2 = 1.07$ $p = .30$			
Survivors	27	7	34
Non-Survivors	<u>6</u>	<u>20</u>	<u>26</u>
Total	<u>33</u>	<u>27</u>	<u>60</u>
$x^2 = 24.74$ $p = .01$			

When the patient identified high side-effect group was compared with the low side-effect group, a χ^2 value of 16.83 ($p = < .01$) was obtained for the resentment cluster. The physician identified high side-effect subjects were compared with low side-effect subjects and the χ^2 value of 11.628 ($p = < .01$) was obtained. The resentment cluster did not significantly differentiate between living and dead subjects ($\chi^2 = .368$, $p = .50$). (See Table 26 for analysis of the resentment cluster.)

Impairment

Subjects' descriptions of themselves as depressed, upset, unable to perform usual household tasks, and the expression of the feeling that the cancer had changed family life, were all grouped under the heading of "Impairment." This category of items was able to significantly differentiate between patient identified high and low side effect groups ($\chi^2:17.21$, $p = < .01$). In contrast, the physician identified high and low side effect subjects and the living and dead subjects were not significantly different in their rate of description of themselves as impaired. Table 27 presents the Impairment Cluster.

"Coping"

Items that suggested methods of coping with the illness were grouped in a cluster entitled "coping mechanisms."

Table 26

Resentment Cluster

One or more of the following items: received the wrong treatment, information withheld by physicians, confusing information received from physicians, anger toward physicians, false claim of surgical cure of cancer, treatment delay

	Item Present	Item Absent	Total
Patient defined:			
High side effect	31	34	65
Low side effect	<u>7</u>	<u>48</u>	<u>55</u>
Total	38	82	120
$x^2 = 16.831$ $p = .01$			
Physician defined:			
High side effect	28	33	61
Low side effect	<u>10</u>	<u>49</u>	<u>59</u>
Total	38	82	120
$x^2 = 11.628$ $p = .01$			
Survivors	20	48	68
Non-Survivors	<u>18</u>	<u>34</u>	<u>52</u>
Total	38	82	120
$x^2 = .368$ $p = .50$			

Table 27

Impairment Cluster

One or more of
the following items: depression, upset by illness,
changes in family life, no longer
able to do household tasks

	Item Present	Item Absent	Total
Patient defined:			
High side effect	27	17	44
Low side effect	9	27	36
Total	36	44	80
$x^2 = 17.21$ $p = .01$			
Physician defined:			
High side effect	17	22	39
Low side effect	16	25	41
Total	33	47	80
$x^2 = .17$ $p = .70$			
Survivors	16	26	42
Non-Survivors	20	18	38
Total	36	44	80
$x^2 = 1.703$ $p = .26$			

These items included active questioning of physicians to find out about their illness, use of a religious philosophy to help in accepting the illness, use of attention diversions to get attention away from thoughts of the cancer, and talking with friends or with any person who expressed interest about the illness. Table 28 presents the analysis of the Coping Mechanism cluster of items.

The patient identified side effect groups and the surviving or non-surviving subjects were different in their use of the coping mechanisms. The comparison of these two groups yielded χ^2 values of 7.305 ($p = .01$) for the patient identified side effect subjects and 8.744 ($p = .01$) for the alive-dead comparison. Physician identified side effect groups were not significantly different in their use of coping mechanisms.

Optimism

Calm feelings about the illness as well as an expression of the expectation of getting well were two items that were grouped in the "optimism" cluster. In all three group comparisons, these items yielded at least one expected frequency tabulation that was less than 5. Therefore, the Fisher's Exact Test was used to compare results.

The patient identified high side effect group was significantly different from the low side effect group in the frequency of their optimistic statements or feelings

Table 28

Coping Mechanism Cluster

One or more of
the following items: active questioning of physician,
attention diversions, talking with
friends about illness, talking with
anyone who asks about illness

	Items Present	Items Absent	Total
Patient defined:			
High side effect	15	39	54
Low side effect	<u>25</u>	<u>21</u>	<u>46</u>
Total	40	60	100

$$x^2 = 7.305$$

$$p = .01$$

Physician defined:			
High side effect	18	33	51
Low side effect	<u>22</u>	<u>27</u>	<u>49</u>
Total	40	60	100

$$x^2 = .958$$

$$p = .30$$

Survivors	29	27	56
Non-Survivors	<u>10</u>	<u>34</u>	<u>44</u>
Total	39	61	100

$$x^2 = 8.744$$

$$p = .01$$

($p = .04$). The physician identified high and low side effect groups yielded differences that were significant at $p = .09$ while the surviving or non-surviving subjects were different at a p value of .10. (See Table 29 for analysis of the optimism clusters.)

Pleased with Treatment

Diagnosis after initial work-up and expression of faith in the current physicians were grouped into an item cluster entitled "Pleased with treatment." These items failed to differentiate any of the subject groups. (See Table 30 for analysis of Pleased with Treatment cluster of items.)

Table 29
Optimism Cluster

One or more of
the following items: calm, expect to get well

	Items Present	Items Absent	Total
Patient defined:			
High side effect	4	19	23
Low side effect	9	8	17
Total	13	27	40

$$p = .037$$

Physician defined:			
High side effect	4	16	20
Low side effect	9	11	20
Total	13	27	40

$$p = .086$$

Survivors	11	11	22
Non-Survivors	2	16	18
Total	13	27	40

$$p = .098$$

Table 30
Pleased with Treatment Cluster

	Items Present	Items Absent	Total
Patient defined:			
High side effect	7	14	21
Low side effect	<u>8</u>	<u>11</u>	<u>19</u>
Total	<u>15</u>	<u>25</u>	<u>40</u>
$\chi^2 = .326$ $p = .70$			
Physician defined:			
High side effect	9	11	20
Low side effect	<u>6</u>	<u>14</u>	<u>20</u>
Total	<u>15</u>	<u>25</u>	<u>40</u>
$\chi^2 = .96$ $p = .30$			
Survivors	10	12	22
Non-Survivors	<u>5</u>	<u>13</u>	<u>18</u>
Total	<u>15</u>	<u>25</u>	<u>40</u>
$\chi^2 = .234$ $p = .82$			

CHAPTER V

DISCUSSION

The data presented in this paper are intended to identify items or clusters of items that may predict cancer patients' tolerance or intolerance for chemotherapy treatments. Since this is an exploratory study, it is important to evaluate the quality of the data.

There are three areas in which the present results are open to criticism: (1) the reliability of the data, (2) the correlation between subject groups, and (3) the small frequencies which were compared.

Reliability and Validity of the Data

The correlation between the observations made by the investigator and those of the second observer was only .54. This is a moderately low correlation that only explains .25 of the variability in the observations of the two raters. However, it should be noted that this low correlation reflects the relatively low inter-rater agreement for items where the emotional tone of the interviews was evaluated.

In rating the emotional state of the subjects, the second observer noted that subjects seemed calm more often than was observed by the investigator. The second observer also noted that subjects were angry toward their physicians

more often than was observed by the investigator. In contrast, the investigator found the subjects to be upset more frequently than did the second observer.

These discrepancies might be explained by differences in the clinical background of the two observers. The investigator is a 4th year graduate student in clinical psychology while the second observer is an undergraduate psychology student. Given this difference in training, it is likely that the investigator might have been more aware of signs of emotional arousal in the subjects and, therefore, more likely to evaluate the subjects as upset and not calm. Similarly, because of her greater awareness of the potential for displacement of affect, the investigator was more conservative in her observations of anger. Therefore, the investigator only noted the expression of anger when the patient directly stated that he or she felt angry toward a physician or described past angry feelings. In contrast, the second observer stated that many of her notations of anger occurred when she felt that anger was justified by the content.

Thus, the investigator noted that subjects seemed upset but didn't necessarily attribute this emotional arousal to anger toward the physician. The second observer felt that subjects were calm but also indicated that they were more angry. The conclusions derived from the investigator's

observations have face validity and seem to reflect the greater caution that comes from additional training.

The validity of the results is further strengthened by the fact that even in cases where the two observers did not agree at a high rate, the trend of the observations by the second rater are in the same direction as those made by the investigator.

Since the only acceptable test of the reliability and validity of an exploratory study lies in replication, the present data will remain questionable until it is tested by replication with a new and larger subject group. The methodology used in the present study as well as the pattern of strong consistency in the results, justify acceptance of the results as reliable to the point where repetition and extension of the investigation using this and other appropriate methods seems demanded.

Correlation between Subject Groups

The present study has used 20 subjects who were into three different groups: (1) high and low side-effect groups as defined by subjects' judgments of the severity of side effects, (2) high and low side-effect groups as defined by physician's evaluation of the severity of side effects, and (3) subjects reported alive or who had died by January 1978 when hospital records were examined.

Thus, the three subject groups yield data that are highly correlated. It is impossible to calculate exactly how the correlated samples have affected the results because the statistics used were non-parametric and therefore not suitable for the usual adjustments for correlated samples. However, it seems likely that the degree of significance observed in the present results might be inflated by the correlation between subject groups. When the same items are observed on the same subjects who have been rearranged to form three different groups, it seems that, by chance, some highly significant relationships might be found. In another study with independent subject groups and a larger total number of subjects, the results may be less highly significant but may be expected to trend in the direction of the present results. The present data point the direction for further research with a larger population of subjects in which statistical problems related to correlated samples may be coped with.

Use of Small Frequencies in Data Analysis

Another criticism which might be made of the present results is that, even in cases where a highly significant p value was obtained, the actual number of responses that was compared was small. For example, when patient identified high and low side effect subjects were compared, only 4 of the 9 low side effect subjects and none of the 11 high

side-effect subjects indicated that they expected to get well. This difference yielded a p value of .03, which suggests that that item might be an important predictor of side effects. When it is considered that only four out of 20 subjects indicated that they expected to get well, and slightly over half of the low side effect subjects did not make that statement, it becomes obvious that an individual item such as "expect to get well" cannot be considered seriously as a predictor of side effects, but must be considered an important entry for later research.

This study, then, is exploratory and only small numbers of subjects could be observed. The subjects were limited in diversity and reflected East Tennessee middle-class society. For those reasons, some caution is maintained when evaluating the predictive value of the results.

Subject Comparisons

In the present results, patient identified high and low side effect groups were not significantly related to physician identified side effect groups. Thus, the physiologic changes that were observed by the physician were not significantly related to the degree of discomfort that the subjects experienced. However, the subjects' judgments of the severity of side effects were more closely related to survival than was the physician's evaluation of side effects.

It therefore appears that the subjects were better able to rate their health than was the physician.

The association between subject ratings of side effects and subject survival emphasizes the importance of items that differentiated the high and low side effect groups. It is these items that may allow future workers to predict not only which subjects may tolerate chemotherapy with comfort but also which subjects will benefit from their treatments. The present data suggest that subjects tolerate their chemotherapy and are able to survive their illness not because of an inevitable response to the drugs but because of their willingness to allow the drug to help.

Because of the erratic pattern of significance for individual items, as well as the small number of responses that were used to test for significance, it would be premature to consider developing an interview that would aim to predict drug tolerance or patient survival at the time of intake. However, the present findings suggest that such an interview may yield positive results in the future research efforts to develop.

Even more suggestive than the results obtained in the analysis of individual items were the results of the analysis of item clusters. The pattern of results from the cluster analysis was able to suggest some important subject characteristics that may help us to understand why certain

cancer patients tolerate their drugs better and survive longer than other patients. They suggest, too, which of possible additional items might be fruitfully included in the interview.

The item clusters strongly suggest that survival and tolerance of chemotherapy, but not necessarily absence of serious physiological changes from the chemotherapy, are associated with certain psychological sets that the patients carried into the chemotherapy setting. The low side effect subjects had better coping skills that appeared to help them tolerate the stress of cancer treatment. They appeared to have a drive to survive and maintain a good quality of life that may promote survival from cancer. The low side effect subjects as defined by subject evaluation of side effects were more likely to use attention diversion to avoid ruminative thoughts of the cancer, they appeared to be more religious and utilized their religious philosophy to help themselves accept their illness and they actively sought information to help themselves understand what was being done to their bodies. The low side effect subjects were also more likely to talk about their illness to friends, family and to anyone else who was interested and supportive.

It is interesting to note that the above coping mechanisms were significantly related to drug tolerance and survival but not to absence of side effects as defined by a

physician. Thus, subjects with good coping skills were able to experience the physical symptoms that were rated as serious side effects by a physician while continuing to report themselves physically comfortable. They also continued to live longer in spite of their physical conditions.

Closely related to the coping skills described above was the pattern of items that comprised the activity cluster. These items reflected continued employment, church attendance and social activity. Patient defined low side effect subjects and surviving subjects were both more likely than high side-effect subjects or non-survivors to maintain a normal activity level. It can be conjectured that the continued activity level may have been made possible by the good coping skills and enhanced stress tolerance suggested by the Coping Mechanism cluster. As with the coping mechanism cluster, the activity cluster did not significantly differentiate the high and low side effect subjects that were grouped on the basis of the physician's ratings. Thus, continued activity occurred both in the presence and in the absence of physiological changes caused by the drugs and was associated with the subject's coping skill as well as their own perception of the side effects.

The low side effect subjects, as defined by both the subjects and the physician as well as the surviving subjects

were optimistic about the outcome of treatment. They also were more calm and more frequently expressed the expectation that they would ultimately get well.

In contrast to the good tolerance for the stress of cancer treatment that was exhibited by the low side effect subjects, is the difficulty experienced by the high side effect subjects. The high side effect subjects can best be characterized as resentful. They had multiple complaints about the quality of their medical treatment, felt mistreated by their doctors and often suspected malpractice. Thus, both the subject-reported intolerance for chemotherapy and the medical side effects evaluated by the physician on the basis of physiological reaction to the drugs were associated with dissatisfaction about earlier treatment. Feelings of resentment were not significantly related to survival.

In addition to their expression of resentment over previous treatment, the subjects who reported high side effects were more likely to see themselves as impaired. The impairment cluster did not differentiate between physician identified side effect groups and surviving or non-surviving subjects. Also, satisfaction with the present treatment did not differentiate between any of the subject groupings.

The pattern of results from the analysis of item clusters strongly suggests that the habits and viewpoints

that subjects brought into the chemotherapy setting had a strong impact upon what happened during treatment. It also implies that the quality of care given by the current group of physicians is not sufficient to overcome the discouragement and resentment accumulated by subjects during earlier parts of their treatment. The chemotherapy phase of cancer treatment often begins after a long interval of treatment by other physicians. The quality of the earlier treatment appears to have a significant impact upon the patients' ability to maintain a high quality of life during treatment and perhaps upon their ability to benefit from chemotherapy.

The present findings seem related to earlier research in that they suggest alternative ways of interpreting the behavior of cancer patients. Several authors have described the interpersonal withdrawal exhibited by cancer patients during advanced phases of their illness (Sutherland, Orback, Dyx, 1952; Shands, Miles & Cobb, 1951; Abrams, 1966). This withdrawal was variously interpreted as evidence of disease stimulated psychopathology, preparation for death, and shame or guilt.

In the present study, social withdrawal as evidenced by reduced social participation or unemployment is related to resentment toward medical personnel, fewer methods of coping with the stress produced by cancer and its treatment and a perception of self as impaired. If the withdrawal subjects

in the cited literature had been administered the structured interview used in the present study, it is possible that their responses might have been similar to those given by the high side-effect subjects who exhibited social withdrawal.

Bahnson (1975) suggested that the anger expressed by cancer patients toward their former physicians might represent a displacement of angry affect upon people who were no longer directly involved in patient care. The present results imply that the resentment or anger of the subjects is directly related to specific grievances about the quality of former treatment. Cancer patients who are angry with their former caretakers should be questioned carefully about the causes of their anger. The present findings suggest that the anger may well be justified and represent a realistic response to the circumstances that have surrounded treatment.

It is tempting to try to explain the present findings by relating them to already existing theories of human behavior. As was already noted, several of the articles cited in this study have explained the behavior of cancer patients in terms of traditional theories of psychopathology. However, the present results have offered an alternative way of understanding the behaviour shared by the present subjects and those observed in earlier studies.

The fact that the present findings may shed additional light on the meaning of the behavior of cancer patients raises an important philosophical issue that is relevant to the atheoretical nature of this research. Behavior is complex and it is the task of researchers to tease apart the natural complexity until a phenomena can expose its own meaning. As Kuhn (1970) has suggested, knowledge typically advances slowly when scientists direct their research in terms of what is already known. However, true advances in knowledge have occurred when scientists have attempted to remain as naive as possible in order to try to understand a phenomena on its own terms.

For the present research, this is an important issue as the real question being asked is what sorts of things about a subject might be associated with side effects from chemotherapy. With that question in mind, the subjects were examined. The interview was structured but the subjects were allowed to restructure the interview by telling the interviewer what was important to them. The present findings are an analysis of what the subjects said, not of what they were asked. This approach was fertile. It yielded results that point in a direction of further investigation. It would be premature to attempt to structure the potential unfolding of the meaning of these results by arranging them to fit a theory. Ultimately, the findings

may lead to an understanding of behavior that does support some theory, but for the moment, an attempt to make them conform would tend to abort the process of finding out what the phenomena are like and what the subjects have to tell us.

CHAPTER VI

SUMMARY, CONCLUSIONS AND IMPLICATIONS

Summary

The present study has investigated the relationship between the experience of side effects from chemotherapy treatments and subjects' reactions to the cancer and the impact of the illness upon their lives.

Twenty subjects were administered a structured interview before their first chemotherapy treatment. After approximately 3 months of chemotherapy treatments, subjects were asked to rate the severity of their side effects. Using laboratory findings and clinical data, a physician also rated the severity of side effects. Five months after the last interview, hospital records were examined to determine which subjects were still living and which had died.

The side effect evaluations by both the physician and subjects as well as the 5 month survival data were each used to group subjects. High side effect subjects were compared with low side effect subjects and survivors were compared with non-survivors in the frequency with which they made statements that corresponded with items that were obtained from an analysis of three interview tape recordings.

The results indicated that high side-effect subjects are more resentful of the poor quality of their earlier medical treatment, less active than low side-effect subjects while the low side-effect subjects reported more coping mechanisms for dealing with the stress of their illness, and were more optimistic about the outcome of treatment and less likely to describe themselves as impaired in functioning.

Conclusions

The results indicated that cancer patients' response to chemotherapy are related to their previous experience as patients. If their perception of earlier treatment was negative, they were also likely to perceive their current treatment as uncomfortable. There was also a relationship between an absence of negative statements about earlier treatment and survival. This suggests that more satisfied subjects tended to live longer than dissatisfied subjects.

There are several variables that seem to interact in the present findings to influence drug response. Subjects were apparently different in their ability to help themselves tolerate the stress of cancer treatment. It is possible that resentment expressed by high side-effect subjects may have resulted from their relatively smaller ability to act in ways that reduced the stress of treatment. Perhaps helpless feelings may have contributed to the frequency with which high side-effect subjects described

themselves as victims of insensitive treatment by medical personnel.

On the other hand, insensitive treatment by earlier medical personnel may have reduced the coping ability of the high side effect subjects. Their ultimate dissatisfaction with all treatment may be justified by the destructive impact of their early treatment.

Implications

The results point the direction for further study. The study should be replicated with subjects who are representative of a larger population. Also, the coping ability of subjects should be compared both early in cancer treatment and prior to chemotherapy to determine whether the poor medical treatment reduces the ability to cope or increases the possibility of expression of resentment.

The quality of medical treatment is possibly indicted by the present results. Further work should be done to determine whether or not insensitive medical treatment increases the chance of drug intolerance or if subjects are intolerant of treatment because of their poor ability to cope with stress.

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APPENDIXES

APPENDIX A

PERMISSION FORM



1924 ALCOA HIGHWAY
KNOXVILLE, TENNESSEE 37920

THE UNIVERSITY OF TENNESSEE
MEMORIAL RESEARCH CENTER

The University of Tennessee Memorial Research Center and Hospital is constantly involved in research that is designed to improve patient care. We are requesting your participation in a research project that is designed to help cancer patients who are receiving chemotherapy.

Medical personnel and clinical psychologists on the University of Tennessee medical oncology service have often noticed that patient's tolerance of chemotherapy seem related to their feelings about their life, attitudes about cancer and expectations about treatment. We hope to identify which feelings and attitudes seem related to the best response to chemotherapy treatment as well as which attitudes and feelings seem to be associated with poor drug response. Once these attitudes and feeling patterns have been identified, we plan to develop a program that will attempt to change the psychological states that are associated with poor drug reactions.

Your participation in this research will involve the following:

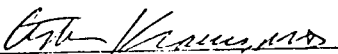
1. An interview which will be conducted by a graduate student in clinical psychology. The interview will be conducted before you receive your first chemotherapy treatment.

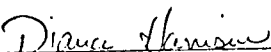
2. You will be asked to fill out a check list that includes a series of adjectives that describe how you view yourself.

3. After your first chemotherapy treatment, you will be asked to evaluate your experience with the drugs.

You are free to withdraw from participation in this project at any time and can do so by telling any of the staff or the interviewer that you no longer wish to participate. Your withdrawal from this research project will in no way jeopardize your treatment program. Also, we will be available to discuss your responses with you during the research process or after your participation has ended.

Thank you very much.


Stephen Krauss, M.D.
Principal Investigator


Diana Harrison, M.A.
Licensed Psychological Examiner

UNIVERSITY OF TENNESSEE CENTER FOR THE HEALTH SCIENCES, KNOXVILLE

I authorize the performance upon _____
(myself/name of patient)

the following: An interview conducted by a graduate student in clinical psychology, filling out a check list and evaluation of my experience with chemotherapy after my first treatment.

The nature and purpose of the experimental procedure, the risks involved, possible side effects, and the possibilities of complications have been explained to me. I understand that the procedure is part of a research project; that it may not result in a treatment for my disorder nor directly benefit me; that the specific procedures to be performed on me are primarily for gathering information related to my disease and treatment thereof.

Further, I consent to the publication of any information learned from this experimental procedure.

I have been informed that I may, at any time, withdraw from continued participation if I so desire.

Date: _____ Signature: _____

Date: _____ Witness: _____

APPENDIX B

STRUCTURED INTERVIEW

1. Knowledge about cancer
 1. How did you first discover that you had cancer?
 2. Did you expect the diagnosis to be cancer?
 3. How did you react to the news?
 4. Since that first reaction, have your feelings changed? How?
2. Sharing of information about cancer with others
 1. Do you talk about your cancer (Ask questions, read about, actively seek information)
 2. Who have you talked with?
 3. Have you and your family discussed your illness? Who was there?
 4. Are there members of your family that you have deliberately not told about your illness?
 5. Have you discussed your illness with your neighbors? husband/wife? children?
3. Knowledge of chemotherapy
 1. What have you been told about chemotherapy (sources)?
 2. Describe what you expect to happen when you have chemotherapy.
 3. What do you hope that chemotherapy will accomplish?
4. Mood, anxiety level
 1. When you think about your total situation, what causes you the greatest amount of worry?
 2. What is your typical mood like? How has this affected your family?
5. Important changes in family relationships
 1. Since you found out that you have cancer, has your life with your family changed?
 2. What changes have you noticed?
 3. Are there changes in what you do for your family?
 4. Does your family ask for your help as much as usual?
 5. Does your husband/wife now do things for that he/she didn't usually do?

6. Social contact

1. Have your social activities changed since you've been ill?
2. Do you belong to any clubs, churches or organizations?
3. How much time do you spend away from home, attending meetings of these groups?
4. Is this different from the amount of time you spent away from home before you became ill?
5. Before you became ill, how did you usually contact your friends? Now what do you do?

7. Employment—How important is work, how does this person use free time, will loss of work constitute a serious emotional deprivation?

1. Are you employed at the present time? What kind of work?
2. Has your work been affected by your illness?
3. Has your ability to hold down a job been threatened by your illness?
4. When not working, how do you spend your days?

APPENDIX C

CHEMOTHERAPY QUESTIONNAIRE

Subject# _____

How many chemotherapy treatments have you received? _____

How often do you receive treatment? _____

After the first cycle of treatment, did you receive treatment at the clinic office or as an inpatient? _____

Has your response to chemotherapy changed since the first treatment? yes _____ no _____ If there has been a change, please describe what happened. _____

What side effects have you experienced? _____

As treatment series have progressed, have you noticed changes in your experience of side effects? Please describe what has happened. _____

Please describe how chemotherapy has influenced each of the following activities:

Employment: _____

Church: _____

Community activities: _____

Family life: _____

Did you work outside of your home before chemotherapy treatments were started? Full-time or part-time? _____

At the present time, do you work outside of your home? Full-time or part-time? _____

If you work, please describe any changes in what you do on your job that are caused by chemotherapy. _____

Did you attend church before chemotherapy treatments started? yes____ no____ If yes, how often did you attend church each week?_____

At the present time, do you attend church? yes____ no____

How often do you now attend church each week?_____

Please list the community groups of which you were an active member before chemotherapy treatments began:_____

In a typical week before chemotherapy treatments began, how many hours were devoted to those activities?_____

At the present time, which community activities do you participate in regularly?_____

How many hours/week do you now devote to community activities?_____

Are you as active as ever with your family?_____

What changes have you noticed in your activity with your family?_____

Please describe how chemotherapy treatments have influenced your friendships: Have you noticed any difference in your relationships with friends? _____

Are you able to carry on normal activity during the days that you are receiving chemotherapy? yes _____ no _____

24 hours after chemotherapy ends? yes _____ no _____

48 hours after chemotherapy ends? yes _____ no _____

1 week after chemotherapy ends? yes _____ no _____

2 weeks after chemotherapy ends? yes _____ no _____

Chemotherapy prevents me from maintaining normal activity.
yes _____ no _____

Have chemotherapy side effects been:

A. About as expected _____

B. More severe than expected _____

C. Less severe than expected _____

When coming to the hospital for treatment, do you:

A. Look forward to coming _____

B. Dislike coming _____

C. Feel indifferent _____

What about the chemotherapy treatments has been the most difficult for you to tolerate? _____

APPENDIX D

PHYSICIAN'S SIDE EFFECT RATING FORM

Patient _____

Drugs _____

Please indicate side effects experienced by this patient and grade side effects using the system outlined by the South-eastern group.

Side effect	Grade
B.M. apasia	_____
Leucopenia	_____
Thrombocytopenia	_____
Granulocytopenia	_____
Lymphocytopenia	_____
Nausea-vomiting	_____
Mucosal lesions	_____
Diarrhea	_____
Paralytic ileus	_____
Fibrosis of Lung	_____
Allergic reactions	_____
Hyperceratosis	_____
Skin necrosis	_____
Hyperpigmentation	_____
Folliculitis	_____
Alopecia	_____
Paresthesia	_____
Polyneuritis syndrome	_____
Deafness	_____
Somnolence	_____
Psychic changes	_____
Cerebellar ataxia	_____
Orthostatic hypotens	_____
Liver	_____
Pancreas	_____
Kidney	_____
Bladder	_____
Heart	_____
Hemorrhagic syndrome	_____
Immunocompetent cells	_____

Immunocompetent cells _____
Cushing's syndrome _____
Hypoglycemia _____
Hyponatremia _____
Fever _____

APPENDIX E

INTERVIEW CATEGORIES

1. Received the wrong treatment
2. Continued church attendance
3. Expect to get well
4. Upset by the illness
5. Willing to discuss the illness with anyone who asks
6. Willing to discuss the illness with friends
7. Use of a Religious Philosophy to help accept the illness
8. Unable to do usual household tasks
9. Information withheld by physicians
10. Surgeon claimed to have removed all of the cancer
11. Received confusing information from doctors
12. Employed at the time of the interview
13. Used diversions to keep attention away from thoughts of the cancer
14. Angry toward physicians
15. Depressed
16. Calm
17. Changes in family life since diagnosis of cancer
18. Active questioning of doctors to find out about illness
19. Faith in present physicians
20. Continued social activities
21. Treatment was delayed
22. Diagnosis was done after first contact with doctor

APPENDIX F

DATA ORGANIZATION

Table A-1

Example of Method of Data Organization
and Tabulation

	Subject Identification No.			
	1	2	3	4
Patient evaluation of side effects	H	L	L	H
Physician evaluation of side effects	H	L	H	L
Items:				
Treatment delay		1		1
Continued social activity	1		1	

APPENDIX G

ANALYSIS OF THE FREQUENCY OF SIGNIFICANT FINDINGS

In the present study, the Fishers Exact test has been repeatedly used to compare the frequency with which various items were mentioned by subject groups. The p values obtained are part of a normally distributed population of values and, therefore, it might be expected that at least some of the obtained values would, by chance, be significant. To find out if the found frequency of significant values exceeded chance, the number of p values falling within the range of significance from .01 to .20 was compared with p values that were .21 or above. A χ^2 value of 12.45 ($p = < .01$) was obtained when found p values between .01 and .10 were compared with expected frequencies. The same χ^2 value was obtained for p values between .11 and .20. The obtained frequency of p values between .20 and 1.0 were significantly less than expected, yielding a χ^2 value of 6.22 ($p = < .01$). These findings indicate that the frequency of obtained significant p values far exceeded a chance distribution. The analysis of the obtained frequency of p values is demonstrated in Table A-2.

Table A-2
Frequency of Significant Results Compared
with Non-Significant Results

<u>p</u> Values	Obtained Frequency	Expected Frequency	χ^2 Values
.01-.10	16	6.8	$\chi^2 = 12.45$ $p = < .01$
.11-.20	16	6.8	$\chi^2 = 12.45$ $p = < .01$
.21-1.0	<u>36</u>	54.4	$\chi^2 = 6.22$ $p = < .01$
Total	68		

VITA

Diana Scott Harrison was born in Poughkeepsie, New York, on August 2, 1942. She attended elementary and high school in Millbrook, New York, and did her undergraduate work at Syracuse University in Syracuse, New York, where she majored in nursing. Mrs. Harrison was awarded the Bachelor of Science degree in nursing from Syracuse in 1962 and subsequently worked as a staff nurse, head nurse, Public Health nurse and clinical nursing instructor over the next several years.

In 1972, Mrs. Harrison began working on a Masters degree in clinical psychology at Meharry Medical College and Fisk University in Nashville, Tennessee, and completed the Master of Arts degree in May of 1974. In the fall of 1974, she began study toward the Doctor of Philosophy degree with a major in psychology at the University of Tennessee. After completing all the University requirements for the Ph.D. in psychology in May of 1978, Mrs. Harrison moved to Los Angeles, California, where she completed a Clinical Psychology Internship at Sepulveda Veterans Administration Hospital in October of 1979.

Mrs. Harrison has worked in a variety of settings where she has done supervised clinical work. Her experience includes work in a University Psychological Clinic,

hospital oncology unit, community mental health center and inpatient psychiatric unit where she worked as a part-time psychiatric nurse while completing her graduate training at the University of Tennessee.

In addition to the present work, Mrs. Harrison has research experience as a participant observer in an Anthropological study of store front churches and evaluation of impact upon selected audiences of the Nashville Panel of American Women. She also completed a Masters thesis that reported her follow-up investigation of an intervention program on infants that had been done at Peabody College in Nashville, Tennessee. During the summer of 1978, Mrs. Harrison was research assistant for a federal project that studied the life styles of aged Black Americans in the southeastern United States.

Mrs. Harrison is the mother of three children, aged 13, 10 and 8 years.