

SOCIAL SUPPORT, INFORMATION, EXPECTANCY,
AND ADHERENCE IN OUTPATIENT CANCER
PATIENTS RECEIVING CHEMOTHERAPY

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DEDICATION

To my son, Max Vernon Mettler, the joy of my life. You are still my greatest achievement, and I love you dearly. Your unselfish acceptance of my, seemingly, unquenchable thirst for knowledge has made this quest for a doctorate possible. Thank you from the bottom of my heart.

and

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and

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ABSTRACT

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The investigation focused on the relationships between and among the concepts of social support, information, expectancy, and adherence to a cancer chemotherapy regimen. Additionally, questions examined included participant's perception as to the adequacy of support and information, and, the amount of support and information given by the nurse.

The convenience sample consisted of 46 participants who were undergoing chemotherapy. Between 3 to 6 months later, 24 of the original sample answered the second questionnaire. Two pilot studies were completed prior to use of the researcher-developed instruments in the present study. (Pilot I, \underline{N} = 103; Pilot II, \underline{N} = 60). The Chemotherapy Expectancy Scale, a semantic differential, had a Cronbach's alpha of .93, .91, and .91 respectively, on Pilot I, Pilot II, and the final

study. Exploratory factor analysis extracted five factors in Pilot II and the present study. The second questionnaire consisted of open- and closed-ended questions and was examined for content validity in Pilot II.

Participants reported 100% adherence to the chemotherapy regimen; therefore, the planned inferential statistics could not be computed. Although not significant, a positive relationship was shown between expectancy and support ($r = .15$), and between expectancy and information ($r = .16$) as indicated in the proposed theoretical model for the study. In Pilot II, this relationship was significant at ($r = .35$, $p < .01$). Also in Pilot II there was a positive, significant relationship ($r = .27$, $p < .05$) between expectancy and adherence. No specific predictors of adherence were found among the demographic variables in Pilot II.

Answers to the research questions indicated that the participants perceived the following: (a) nurses provided a large amount of support and information, (b) adequate support and information were received, and (c) doctors had the most influence on participants, precancer expectancy about chemotherapy. Participant comments

to the open-ended questions showed that (a) most people have great fear or apprehension about the chemotherapy treatments, (b) most have moderate to severe side effects to the drugs, (c) hair loss yields a tremendous emotional impact, and (d) many chemotherapy recipients have ambivalent feelings about the value and effects of the treatments.

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CHAPTER I

INTRODUCTION

Over 8 million Americans are alive today who have a history of having had cancer (American Cancer Society [ACS], (1992). At least 4 million of these individuals were diagnosed 5 or more years ago so may be considered "cured" (i.e., have no evidence of the disease), and therefore, have a life expectancy that is the same as a person who has never had cancer (ACS, 1992). Although these statistics are encouraging, there continues to be a steady rise in cancer mortality in the United States with one in every five deaths being attributable to cancer (ACS, 1992). Also, the very word cancer still causes tremendous fear in the American public as documented by studies as late as 1978. A survey of Californians showed that they ranked cancer as being more feared than any other world danger, even crimes and atomic war (Canter, 1978).

As devastating as the diagnosis of cancer may be, the treatments and their side effects can be even more so. Participants in various studies have verbalized

these feelings well. For example, "One learns to vomit so much that when the vomiting stops one misses it and feels there is something wrong;" and, in the same study the following was stated about a relative ". . . only prolonged the [dying] for 6 months (6 months of hell)" (Mettler, 1988). Cancer therapy often becomes a major source of stress, anxiety, and pain. Surgery sometimes cripples and disfigures, side effects of radiation may disable, and chemotherapy can lead to additional cancer or even death. Of these therapies, chemotherapy was selected for the focus of the present study. Patient support, information, and expectancy related to chemotherapy and subsequent adherence to the treatment regimen were explored.

There is some evidence in early Egyptian and Greek civilizations of the unsuccessful use of chemotherapy for treating cancer. However, it was not until the 1940s that an effective and reliable drug therapy was demonstrated (Brown, 1987). The first type of chemical intervention, hormone therapy, was used as treatment for prostate and breast carcinomas. As a result of poisonous gas research during World War II, the potential of nitrogen mustard as a chemotherapeutic agent was found to produce excellent temporary results in chronic

leukemias and lymphomas. Nutrition studies on folic acid led to the discovery of folic acid antagonists in 1948, and since that time there has been rapid development of many chemotherapy agents (Brown, 1987).

When first used, chemotherapy was often considered only when other treatment methods either were not feasible or had been unsuccessful. However, because cancers are invasive at the cellular level, they ultimately must be treated at that level; and chemotherapy is the only systemic treatment available (Koocher, 1986). Widespread use of chemotherapy has been a predominate factor in prolonging the life expectancy of many cancer patients. Today, approximately 40% of those receiving chemotherapy for a diagnosis of cancer remain disease-free for more than 5 years (ACS, 1988).

Unfortunately, even though chemotherapy may be life-saving, it can be one of the most aversive treatments used in medicine and can seriously compromise the quality of a person's life (Burish & Carey, 1986). The costs in personal and financial demands may be so overwhelming that the patient chooses an early death rather than to continue "the hell they have come to know as cancer treatment (Burish & Lyles, 1983, p. 160).

Problem of the Study

The problem for the study was to determine what relationships exist between and among social support, information, expectancy, and adherence to a prescribed chemotherapy regimen. Also examined was the amount of support and information given by nurses, and the patient's perception of the overall adequacy of support and information received throughout the chemotherapy regimen. Participants were adult cancer patients who were recipients of chemotherapy.

Rationale for the Study

The rationale for the study was based on conceptualization of four concepts related to chemotherapy treatment in cancer patients. The four concepts were social support, information, expectancy, and adherence to a prescribed chemotherapy regimen. The rationale is presented in four subsections, one for each of the above concepts.

Social Support

In the 1970s, influential reports began conveying the idea that social support offered beneficial effects

in a wide range of circumstances (Wortman, 1984). Since that time numerous theorists and investigators have endorsed the thesis of a positive relationship between social support and various aspects of psychological and physical health. Even though limited, some researchers have also looked at the negative side of support, including the costs and consequences of a supportive interaction (Wortman, 1984). Wortman (1984) documented the fact that uncertainties and fears of cancer are likely to increase the need for social support, but because of the intense fears and stigma associated with cancer, those who have the disease are likely to face problems in receiving adequate support.

Concurring with the idea of a need for more support in crisis situations, such as adjusting to a major illness or disability, Roberts (1988) added that individuals experiencing a crisis may not feel comfortable in getting support from their usual support system. Roberts (1988) also suggested that the affected person's own network may not feel capable of giving this support and may be in need of support for themselves. Because of this, the nurse is in a position to temporarily offer the needed support to the patient and, as appropriate, to the network members (Roberts, 1988).

After reviewing definitions, types, sources, and measures of social support, Wortman (1984) tendered the following statements for the potential cancer researcher to consider:

1. The importance of measuring support in a way that will permit assessment of distinct types of support (e.g., emotional support, advice) by distinct providers (e.g., spouse, physician, [nurse]) since available evidence suggests that the impact of support is strongly affected by these factors.
2. The importance of considering negative as well as positive support, since there is evidence suggesting that such behaviors may be very prevalent in the interactions between cancer patients and those in their support network [and] that they may have strong influence on subsequent health outcomes.
3. The importance of studying more explicit, specific behaviors that occur between cancer patients and those in their support network, as well as more general judgments regarding whether support is adequate (p. 2356).

Wortman (1984) further stipulated that although social support is a multifaceted concept, researchers will probably find it more practical to limit the scope within a single investigation. Therefore it is important, Wortman (1984) advised, to consider the adaptive tasks of the cancer patient when selecting types of support thought to be most beneficial.

Bullough (1981) noted that nurses are not generally seen as a significant source of support. In a sample

of postmastectomy patients, Bullough found that only 25% of the respondents perceived nurses as a source of support; 32% stated they had received significant amounts of emotional support from their doctors. Bullough (1981) further wrote that some patients apologized for the negative answer by pointing out that "they [the nurses] were so busy" or "they had to do their nursing work" (p. 223).

Information

Information giving and teaching are acknowledged by the nursing profession as an integral part of nursing intervention. The American Nurses Association (ANA) in 1973 specified that the patient and family will be kept informed about health status, health care plan, and will be given the information to make decisions. ANA also identified patient and family teaching as one of the nursing actions designed to promote, maintain, and restore health.

In 1980, the Joint Commission on Accreditation of Hospitals (JCAH) stipulated that patient education and patient-family knowledge of self-care should be given special consideration in the nursing plan, and that it should be consistent with that of the responsible medical

practitioner (Ash, 1984). In 1984, the JCAH added the requirement that nursing policies and procedures should relate to the role of the nursing staff in patient and family education (Ash, 1984). Patients and other health care workers, however, fail to recognize the nurse as a primary source of information. In the research cited earlier, Bullough (1981) found that only 20% of the sample of 139 postmastectomy patients identified the nurse as a significant source for information.

The study surveyed cancer patients to elicit their perceptions of nurses, in terms of the type and amount of support and information provided for patients during the chemotherapy experience. Also examined were relationships between the patient's perceived adequacy of support and information and subsequent adherence or nonadherence to the chemotherapy regimen.

Expectancy

Expectancies can produce effects that range from pain relief to general susceptibility to illness, and may even hasten or delay death itself (Jones, 1977). The effectiveness of a placebo, for example, is directly related to how much the patient thinks it will help (Achterberg, 1985). The relationship between perception

of disease severity and depression was found to be weaker in those with positive expectations about the effects of adhering to the medical treatment than in those with negative expectations (Marks, Richardson, Graham, & Levine, 1986).

Watson and Kendall (1983) suggested that the placebo effect should be taken into consideration in outcome studies, as it can affect the research in two ways:

1. Many patients will exhibit some improvement simply because they expect to get better.

2. In other patients, the increased attention and interpersonal interaction with staff, can produce significant improvements.

Even though the placebo effect is thought to be of short duration, this has not been proven (Watson & Kendall, 1983). The study sought to determine if there is a relationship between expectancy (the underlying stimulus for the placebo effect) and adherence to a prescribed chemotherapy regimen.

Leininger (1985) stated that the nurse, in order to discover truths about human care and health maintenance, must document and understand subjective and intuitive states of human beings. Expectancy is a subjective factor that may influence an individual's

motivation, learning, and response to therapy (Collins & Hyer, 1986; Henshel, 1982; Shapiro, 1959; Tolman, 1967).

Sears (1981) contended that by enhancing expectancy, a person could make better plans for a future event. Also, if the future event is seen to be aversive in nature, the planning could reduce potential frustration. Nursing interventions, such as support and teaching of patients before, during, and after tests, treatments, and other activities, may influence patient expectancy. While this does not ensure freedom from discomfort, or a positive outcome, it may strengthen the patient's resources for adaptation and adherence. No studies were found in the available literature relative to nursing intervention, expectancy, and adherence to a chemotherapy regimen.

Adherence

Many words have been used to identify the situation in which a person chooses to adhere to all aspects of health advice or a prescribed health regimen. Terminology describing these behaviors includes adherence, compliance, cooperative behaviors, staying in treatment, and therapeutic alliance. Compliance is the term selected by most health care personnel; however, to some this

has an unfavorable connotation. For example, Paulen (1981) stated that compliance implies "passivity, submissiveness, and obedience." Paulen argued that therapeutic alliance--which infers a reciprocal and participatory activity--should be the goal of health care providers in working with patients and their families. Sackett (1976), on the other hand, declared that it was too cumbersome to use the concept of therapeutic alliance. Adherence is the term most often used in place of compliance. Turk, Salovey, and Litt (1986) suggested that adherence connotes collaboration, active participation, and self-control. Adherence was selected as the concept for the study.

Nonadherence to medical regimens continues to be a major problem for the health professions. Numerous studies have addressed adherence in a variety of situations or conditions (e.g., health regimens in elderly women) [Chang, Uman, Linn, Ware, & Kane, 1985], myocardial infarction [Miller, Wikoff, McMahon, Garrett, & Ringel, 1985], and hemodialysis regimens [O'Brien, 1980]]. In a 1979 review of health compliance studies, Haynes, Taylor, and Sackett identified over 200 factors that might contribute to nonadherence behaviors. Haynes et al. (1979) found a wide range in the rate of adherence

behaviors. For example, only 10% of a sample of 30,000 kept their appointment for a Tay-Sachs screening test; while 94% of 2,322 men surveyed for hypertension remained on therapy at the end of 1 year (Haynes et al, 1979). Whatever the rate or cause, nonadherence frequently compromises the effectiveness of the treatment regimen and possibly, in the long run, the quality or extent of the patient's life. In spite of the vast amount of literature about nonadherence to medical regimens, there is a dearth of studies that address this problem in cancer patients. Findings in two studies related to cancer patients revealed an 11% nonadherence rate for clinic appointments, and just over 21% nonadherence to chemotherapy regimens (Garrett, Ashford, & Savage, 1986; Itano, Tanabe, Lum, Lamkin, Rizzo, Wieland, & Sato, 1983).

Although investigators have explored the relationship of social support and information with adherence, no studies were found relating nursing intervention, social support, information, and expectancy with adherence to a chemotherapy regimen. Further rationale is offered under the section entitled "Merging of Concepts".

Theoretical Framework

The framework for the study was derived from the expectancy theory proposed by Sears (1981). Sears postulated that "a person's adequacy of adaptation to . . . changes depends on the precision and realistic quality of his or her expectancies about them" (p. 407). Sears (1981) further suggested that information and social support can strengthen expectancies related to specific outcomes; therefore, both of these concepts were addressed in the study's framework. Finally, the concept of adherence represents the outcome concept that was explored in the present investigation.

Social Support

Numerous definitions relative to the concept of social support appear in the literature; however, at the present time, there is little consensus toward one that offers an appropriate focus for health care research. DiMatteo and Hays (1981) contended that social support is not a single concept and that it can be interpreted in several ways.

Caplan (1974), from extensive work in community mental health and building on Cassel's epidemiologic

and ethological studies, described support systems as continuing or intermittent social aggregates. Caplan (1974) asserted that these aggregates provide support by helping the individual in three ways:

1. They help mobilize psychological resources and master emotional burdens.
2. They share in the tasks.
3. They provide material support such as money, tools, and cognitive guidance.

In this approach to social support, Caplan (1974) emphasized the need for professionals to enhance and work with these natural sources of support but not to force professional viewpoints and methods on them.

According to Cobb (1979) there are four kinds of support:

1. Social support, consisting of three components, is the most important and is entirely informational. It conveys to the individual a feeling of being: (a) cared for and loved, (b) esteemed and valued, and (c) part of a mutual obligation network.
2. Instrumental support or counseling that helps the person to cope better and to be more autonomous.
3. Active support or mothering that can lead to dependency when used inappropriately.

4. Material support or services that are similar to what Kahn called aid.

Cobb (1979) pointed out that the last three types of support--instrumental, active, material--may involve or imply social support to the receiver.

Social support in the study was based on Kahn's (1979) conceptualization which described social support as an interpersonal transaction that included one or more of the following:

1. The expression of positive affect of one person toward another.
2. The affirmation or endorsement of another person's behaviors, perceptions, or expressed views.
3. The giving of symbolic or material aid to another (p. 85).

Affective transactions may involve expressions of love, admiration, or respect, while an affirmation transaction refers to expressions of agreement or acknowledgment of appropriateness of an act or statement of another person (Kahn, 1979). Although Kahn believed the aid transaction too extensive, it was recognized as a form of social support that encompassed the giving of material things, money, time, information, and entitlements.

In Kahn's (1979) support model, convoy was similar to the mutual obligation network used by Cobb. Convoy represents the sets of people (social networks) on whom the individual can rely for support and conversely who rely on the individual for support. These relationships often overlap with one both giving and receiving support; however, Kahn (1979) stated that not all relationships are necessarily symmetrical. Kahn and Antonucci (1981) maintained that the person's convoy is shaped by an interaction of situational factors as well as enduring properties (i.e., personality, age, and other demographic characteristics). According to Kahn and Antonucci (1981) the convoy, at least partially, determines one's well-being and ability to perform various life roles successfully. Convoys are dynamic in that they are constantly changing as the individual moves through life and assumes various roles.

The type and source of support needed by cancer patients varies throughout the experience. The period of diagnosis and initial treatment is considered a crisis situation. During this time, research has shown that specific support needs of the patient include: (a) information about the disease, treatment, and expected outcome, (b) reassurance that they are loved, (c) someone

to spend time with them and listen to their fears and other feelings, and (d) acceptance of their fears and feelings (Wortman, 1984).

In the present study, the researcher suggested that when an individual assumes the role of a cancer patient who is receiving chemotherapy, the nurse becomes a temporary but important member of that person's convoy. At this point in the cancer patient's life, nursing interventions can contribute significant amounts of support in each of the areas identified by Kahn.

Information

Various studies have attempted to show the part that information plays in an individual's health or well-being in times of stress. For example, Cohen and Lazarus (1979), included information-seeking as one of five main coping mechanisms that the individual may use to help decrease stress levels. Caplan (1981) supported this premise and further stated that the demands that contribute to stress are, in part, "the loss or threatened loss of appropriate levels and quality of essential information and energy" (p. 414). In nursing, various investigators have attempted to measure information needs and information-seeking behaviors to determine how

nursing interventions can help the patient meet those needs (Derdiarian, 1987, 1989; Dodd & Ahmed, 1987; Dodd & Mood, 1981; Hopkins, 1986). However, many aspects about the concept of information remain elusive to health care workers.

The researcher postulated that information (a) is supportive in nature, (b) enlarges a person's knowledge base, and therefore (c) is positively associated with expectancy, adaptation to chemotherapy, and adherence to the chemotherapy regimen.

The most frequently used model for explaining the use of information is a cybernetics model in which the organism is compared to a computer (Hirt & Genshaft, 1980). Within this conceptualization the following occur:

1. During the input stage, information or stimuli from the environment enter the system and is coded in memory.

2. The information is categorized, stored, and organized to facilitate retrieval.

3. An examination of categories determines the relevance and suitability of available information.

4. Information is selected to make the appropriate response.

Reasons for failure of this system include: (a) receiving incomplete, incorrect, or irrelevant information, (b) information lost in the system due to memory deficits or interference, and (c) selection of incorrect responses due to high-order processing or integration deficit (Hirt & Genshaft, 1980).

Unfortunately, the recently diagnosed cancer patient who undergoes chemotherapy may fail to correctly process information for any of the above reasons. Numerous studies support the assumption that patients receive inadequate information relative to the disease, diagnosis, treatments, and expected outcomes (Karani & Wiltshaw, 1986; Messerli, Garamendi, & Romano, 1980; Reynolds, Sachs, Davis, & Hall, 1981). Memory deficits or interference, and diminished high-order processing may result from the distress associated with the crisis situation. Also, one study suggested that chemotherapy is associated with cognitive (higher cerebral function) impairment (Silberfarb, Philibert, & Levine, 1980). Reinforcement, repetition, and encouraging questions are nursing interventions that may enhance patient information processing. Identifying types of information the patient wants or does not want may assist the nurse

in information giving. The present study looked at information wanted and not wanted, as well as perceived adequacy of the information received.

Expectancy

Sears (1981) defined expectancy as an intervening variable that directs action or thought toward specific goals and provides the force or instigation for the action. Sears asserted that expectancy results from a learning experience and

the exact nature of the expectancy, its strength, the extent to which it is conscious and verbalized, and the kinds of actions attached to it as responses will be determined by the general laws of learning operating in a specific context, both intrapersonal and environmental (p. 409).

Because the learning process is related to specific conditions, expectancies are unique for the individual.

According to Sears (1981), expectancy plays a role in both cognitive and motivation theory; it may be viewed as foresight or foreknowledge, which can foster a better understanding of behaviors. Sears cited past research (Hull, 1930, 1931; Lewin, 1935; Tolman, 1932 [which has been reprinted in 1967 in The Century Psychology Series]) in describing the following four functions of expectancy:

1. Once learned, expectancy acts as a cue stimulus that directs thought and action toward the goal represented in the expectancy.

2. Expectancy acts as a facilitative agent to increase the strength of instigation to the actions, whether initiated by the expectancy or some other stimulus.

3. Because of increased motivation, there may be increased frustration if the goal is not achieved.

4. When the expectation is of an aversive outcome, the cue stimulus may lead to adaptive avoidance or evasive action.

Expectancy offers a better opportunity for adaptation if a person: (a) knows the timing and conditions within which the adaptive response must occur, (B) can make some choice about the occurrence of the event, and (c) has time enough for planning and rehearsal of the adaptive responses (Sears, 1981). Sears further submitted that relevant information can be useful for making expectations more precise.

Based on the above functions of expectancy, the researcher speculated that expectancy of a positive experience with chemotherapy can enhance adaptation and adherence to the treatment regimen. Conversely,

expectancy of a negative or aversive experience with chemotherapy can contribute to adaptive avoidance or nonadherence.

Adherence

Adherence is generally defined as behaviors in which the patient carries out specific recommendations of a health prescription. A multitude of social-psychological factors have been identified as possible determinants for adherence to a prescribed health regimen. For practical reasons each study is usually limited to considering one or two of these factors (Caplan, Robinson, French, Caldwell, & Shinn, 1976). Included in this list are social support and completeness of information, two variables examined in the present study.

A variety of models have been applied to the nonadherence problem. Stone (1979) cited numerous authors in summarizing the following approaches: (a) personality trait theories, (b) psychodynamic theories, (c) sociocultural theories, (d) learning theories, (e) cognitive theories, and (f) transaction theory.

The personality trait approach included psychological traits and demographic factors which usually amounted to "blaming the victim" (Stone, 1979). Only about 25%

of the studies, according to Stone, entertained the consideration that the physician might be at fault.

Various aspects of the treatment situation are identified as the reason for nonadherence, according to the psychodynamic approach (Stone, 1979). Most frequently the problem is due to an authoritarian physician, a completely dependent patient, or a combination of the two. Improving the patient-physician relationship, in this case, is the responsibility of the physician.

In sociocultural models the patient's behavior can be affected by a variety of social norms. For example, any of the following might affect adherence behavior--cultural or subcultural roles, beliefs, practices, and taboos related health and health behavior (Stone, 1979).

When learning theories are applied to adherence, rewards and punishment become the primary influence (Stone, 1979). Taking a medicine that brings prompt relief might be considered a reward; therefore, adherence is more likely to occur. Likewise, if a medicine has unpleasant side effects or no immediate discernible benefit, then adherence may not follow.

Cognitive theories of adherence incorporate such variables as attitudes, beliefs, values, and intentions

(Stone, 1979). These theories focus on the conceptualization that people are self-conscious decision makers. The health belief model is a cognitive learning model that has been widely used in adherence studies. However, the model has so many independent variables that it becomes difficult to determine how each influences the outcome (Stone, 1979). Another drawback to this model, according to Stone (1979), is the lack of an objective analysis of the expert-patient relationship.

The health transactions model presumes that adherence arises from a transaction between two people. The model is comprised of three phases, one prior to and one following the actual patient-expert transaction. Characteristics of the patient, the health professional, and their interaction draw equal attention when this model is used for the study or explanation of adherence (Stone, 1979).

Dracup and Meleis (1982) proposed an interactionist approach based on role theory for explaining adherence. In this model adherence is defined as "the extent to which an individual chooses behaviors that coincide with a clinical prescription" (p. 31). According to the model, a person is an actor who reacts selectively to the environment and to significant others within the

environment. For the individual to adhere to a health regimen he must "identify himself with a [adherence] role, have access to cues and behaviors of the proposed role, receive cues from others to enact such a role, and evaluate himself and others vis-a-vis that role" (Dracup & Meleis, 1982, p. 33).

Merging of Concepts

As a result of the patient's previous experience with chemotherapy, either directly or indirectly, the patient develops beliefs and attitudes relative to this experience. These beliefs, attitudes, and experiences contribute to the patient's foreknowledge of chemotherapy. When the patient learns of the necessity to receive chemotherapy, this foreknowledge triggers an expectancy of the upcoming event. Depending on whether this expectancy is of a positive or negative nature, the patient is influenced toward or against adaptation and adherence to the chemotherapy regimen.

Between the prescription for chemotherapy and the actual therapy, nursing intervention, in the form of information, can influence the patient's expectancy. With accurate, pertinent information that is adequate to meet the patient's needs, the expectancy should become

more positive. Additionally, adequate and appropriate social support can enhance the patient's ability to adapt. Both interventions could positively influence the patient's behaviors toward adherence with the chemotherapy regimen.

Conversely, if either social support or information are inadequate or inappropriate, expectancy may move toward the negative side, adaptation can be impeded, and nonadherence becomes more likely. These interactions and behaviors are not absolute but occur on a continuum between extremes.

Formalization of the Theory

Walker and Avant (1983) defined theory derivation as the "process of using analogy to obtain explanations or predictions about a phenomenon in one field from the explanations or predictions in another field" (p. 163). Theory derivation is especially useful where there is no available data, or if new insights about a phenomenon might enhance needed research and testing. Theory derivation can promote rapid theory development for building the needed knowledge base in nursing (Walker & Avant, 1983). The theory for the present study was derived from the concepts of: (a) social support

(Kahn, 1979), (b) information (Dodd & White, 1980), (c) expectancy (Sears, 1981), and (d) adherence (Dracup & Meleis, 1982).

According to Fawcett and Downs (1986), theory formalization results in a "concise and polished version of the theory that sets forth its components clearly, concisely, pictorially, and if desired, symbolically" (p. 15). The theory for the study was formalized based on the definition proposed by Gibbs (1972). A theory, Gibbs suggested, is a "set of interrelated statements in the form of empirical assertions about properties of infinite classes of events or things" (p. 5).

Gibbs (1972) identified two major divisions of a theory (intrinsic and extrinsic) which can be represented pictographically or with descriptive statements. The extrinsic part of a theory defines substantive terms (constructs, concepts, and referentials) and makes the intrinsic statements understandable. It is the extrinsic portion that determines the testability and predictive accuracy of theory (Gibbs, 1972). Intrinsic statements (i.e., axioms, postulates, propositions, transformational statements, and theorems) make assertions about empirical relations and are distinguished as to type, position, and constituent terms (Gibbs, 1972). The schematic

representation of the relationships of social support, information, expectancy, and adherence to chemotherapy are depicted in Figure 1. The theory consists of three axioms, three postulates, two propositions, three transformational statements, and is referred to as a 3-3-2-3 structure.

Extrinsic Theory Components

In the expectancy model the constructs are: (a) convoy, (b) life experiences, and (c) beliefs and attitudes. A construct, according to Gibbs (1972) is a term that is neither completely defined nor empirically applicable. Definitions for the constructs are:

Convoy: The dynamic social networks on whom the individual can call for support (Kahn, 1979).

Life experiences: Events that contribute to one's learning and subsequent formation of beliefs and attitudes.

Beliefs: Organized perceptions or cognitions that one maintains about specific objects or events.

Attitudes: "Learned predisposition to respond to an object or class of objects in a consistently favorable or unfavorable way" (Fishbein, 1967, p. 477).

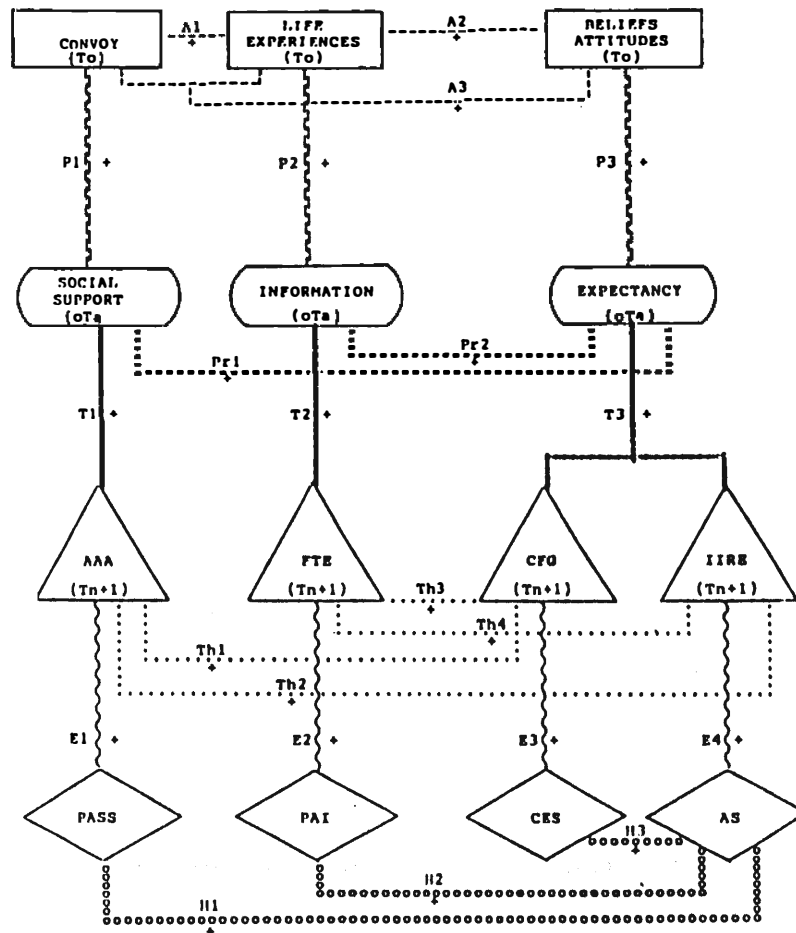


Figure 1. Expectancy-Adherence Model

Legend:

To	Time when chemotherapy prescription received	PASS	Perceived adequacy of social support
oTa	Intervening time between prescription and therapy	PAI	Perceived adequacy of information
Tn+1	Time interval when treatments are received	CES	Chemotherapy expectancy scale
AAA	Support (i.e., affect, affirmation, & aid)	AS	Adherence score
FTE	Factual, theoretical, and experiential information	A	Axiom
CFG	Cue stimulus, facilitative agent, goal related behavior	P	Postulate
IIRE	Intention to adhere, identify self in role, adherence role enactment	Pr	Proposition
		Th	Theorem
		E	Epistemic statement
		H	Hypothesis

A concept according to Gibbs (1972) is a "substantive term defined by the theorist in such a way that he regards the definition as complete but not empirically applicable" (p. 128). Social support, information, and expectancy are concepts in the model and are defined as follows:

Social support: An interpersonal transaction that includes one or more of the following: (a) affect, (b) affirmation, and (c) aid (Kahn, 1979).

Information: Factual, theoretical, or experiential knowledge relevant to an object or situation (Dodd & White, 1980).

Expectancy: Foresight or foreknowledge that provides the image of future events either positive or aversive (Sears, 1981).

Referentials are intrinsic terms that appear as capitalized acronyms and represent a formula in the extrinsic portion of the theory (Gibbs, 1972). The values that are derived from the referentials are designated as referents. The referentials and referents in the model are:

1. AAA (index of social support) may include any combination of affect, affirmation, and aid. The referent is the score on the Perceived Adequacy of Social Support Scale (PASS).

2. FTE (index of drug information) includes factual, theoretical, and experiential knowledge which are components of information. The referent PAI is the score on the Perceived Adequacy of Information Scale.

3. CFG (index of expectancy) includes the functions of expectancy which are cue stimulus, facilitative agent, and growth related behaviors. The referent CES is the score on the Chemotherapy Expectancy Scale.

4. IIRE (index of adherence) includes decision making or the intention to adhere, identification of self in adherence role, and adherence role enactment. The referent AS designates the score on the Adherence Questions.

The unit term in a theory represents a class of events or things (Gibbs, 1972). For the expectancy-adherence model the unit term is adult cancer chemotherapy patient. This refers to any person 18 years of age or older who has a diagnosis of cancer and a prescribed chemotherapy regimen.

According to Gibbs (1972) the designation of a substantive term is incomplete without a temporal quantifier to designate either an interval or point in time. Time units in the model are T_0 , oT_a , and T_{n+1} . The point in time when the cancer patient receives the

prescription for chemotherapy is represented by T_0 . The symbol ΔT_a refers to the intervening time interval between the prescription and the first chemotherapy treatment. The time period during which the treatment is actually given is designated as T_{n+1} .

Intrinsic Theory Components

An axiom is a "direct intrinsic statement in which the substantive terms are constructs" (Gibbs, 1972, p. 167). The axioms (A) in the theory are:

Axiom 1. Among adult cancer chemotherapy patients the greater the conviction at T_0 , the greater the life experiences at T_0 .

Axiom 2. Among adult cancer chemotherapy patients the greater the life experiences at T_0 , the stronger the beliefs and attitudes at T_0 .

Axiom 3. Among adult cancer chemotherapy patients the greater the conviction and life experiences at T_0 , the stronger the beliefs and attitudes at T_0 .

Postulates differ from axioms in that they always include a concept as one of the substantive terms. The three postulates (p) in the model are:

Postulate 1. Among adult cancer chemotherapy patients the greater the life experiences at To, the greater the information at oTa.

Postulate 2. Among adult cancer chemotherapy patients the greater the life experiences at To, the greater the information at oTa.

Postulate 3. Among adult cancer chemotherapy patients the stronger the beliefs and attitudes at To, the greater the expectancy at oTa.

Propositions are direct intrinsic statements that include only concepts. The two propositions (Pr) in the model are:

Proposition 1. Among adult cancer chemotherapy patients the greater the social support at oTa, the greater the expectancy at oTa.

Proposition 2. Among adult cancer chemotherapy patients the greater the information at oTa, the greater the expectancy at oTa.

Transformational statements include a concept and a referential. A theory cannot be tested without transformational statements. Three transformational statements (T) are included in the model.

Transformational statement 1. Among adult cancer chemotherapy patients the greater the social support at oTa , the higher the AAA at $Tn+1$.

Transformational statement 2. Among adult cancer chemotherapy patients the greater the information at oTa , the higher the FTE at $Tn+1$.

Transformational statement 3. Among adult cancer chemotherapy patients the greater the expectancy at oTa , the higher the CFG and IIRE at $Tn+1$.

Referentials are the constituent substantive terms that are linked by theorems. Theorems are derived statements and designate the final step in theory construction. The four theorems (Th) in the model are:

Theorem 1. Among adult cancer chemotherapy patients the greater the AAA at $Tn+1$, the greater the CFG at $Tn+1$.

Theorem 2. Among adult cancer chemotherapy patients the greater the AAA at $Tn+1$, the greater the IIRE at $Tn+1$.

Theorem 3. Among adult cancer chemotherapy patients the greater the FTE at $Tn+1$, the greater the CFG at $Tn+1$.

Theorem 4. Among adult cancer chemotherapy patients the greater the FTE at $Tn+1$, the greater the IIRE at $Tn+1$.

Epistemic statements link referentials with referents. They are not a part of the theory and are not directly testable. In the model there are four epistemic (E) statements.

Epistemic statement 1. Among adult cancer chemotherapy patients the greater the AAA at T_{n+1} , the higher the score on the PASS at T_{n+1} .

Epistemic statement 2. Among adult cancer chemotherapy patients the greater the FTE at T_{n+1} , the higher the score on the PAI at T_{n+1} .

Epistemic statement 3. Among adult cancer chemotherapy patients the greater the CFG at T_{n+1} , the higher the score on the CES at T_{n+1} .

Epistemic statement 4. Among adult cancer chemotherapy patients the greater the IIRE at T_{n+1} , the higher the score on the AS at T_{n+1} .

The expectancy-adherence model is a situation-relating model with some predictive quality. According to Dickoff, James, and Wiedenbach (1968) this type of theory makes a statement of relationship (i.e., situation A happens, so then situation B occurs). This model offers directions for nursing intervention; therefore, it also would be considered a practice-oriented model.

Assumptions

The assumptions for the study were:

1. Expectancy and information can be positive or negative (Cohen & Lazarus, 1979; Sears, 1981).
2. Individuals have expectancies about chemotherapy.
3. Nonadherence to a prescribed chemotherapy regimen is a significant problem for cancer patients.
4. Cancer patients have some type of social support.

Hypotheses

The following hypotheses were tested:

1. Among adult cancer patients the greater the perceived adequacy of support the greater the adherence to a prescribed chemotherapy regimen.
2. Among adult cancer patients the greater the perceived adequacy of information the greater the adherence to a prescribed chemotherapy regimen.
3. Among adult cancer patients the greater the expectancy of a positive outcome the greater the adherence to a prescribed chemotherapy regimen.

Research Questions

In addition to the hypotheses, patient responses to the following research questions were evaluated:

1. From the cancer patient's perception, how much support is given by the nurse during the chemotherapy regimen?
2. From the cancer patient's perception, how adequate is the overall support received during the chemotherapy regimen?
3. From the cancer patient's perception, how much information relative to the chemotherapy regimen is given by the nurse?
4. From the cancer patient's perception, how adequate is the overall information received regarding the chemotherapy regimen?
5. What personal characteristics are related to the patient's adherence to the chemotherapy regimen?

Definition of Terms

Terms in the study are defined in the next two subsections. Conceptual definitions are given first followed by the operational definitions.

Conceptual Definitions

Expectancy: Foresight or foreknowledge that provides the image of future events, either positive or aversive (Sears, 1981).

Chemotherapy: Any form of chemical agent that is used for treatment or control of disease.

Chemotherapy regimen: A planned program for taking prescribed medications and carrying out associated required activities.

Adult cancer patient: An individual 18 years of age or older who has a diagnosis of cancer.

Outpatient: An individual seen in a clinic-like setting for diagnosis or treatment of an illness, who then returns home.

Social support: An interpersonal transaction that involves the provision for one or more of the following: (a) expression of positive affect, (b) affirmation, or (c) giving aid (Kahn, 1979).

Information: Factual, theoretical, and experiential knowledge relevant to an object or situation (Dodd & White, 1980).

Adherence: The extent to which the person chooses behaviors that coincide with the clinical prescription (Dracup & Meleis, 1982).

Operational Definitions

Expectancy: Feelings, beliefs, or images an individual has about chemotherapy, as measured by the researcher-developed Chemotherapy Expectancy Scale (CES).

Chemotherapy: Self report on the Chemotherapy Follow-up Questionnaire (CFQ) of intravenous drugs received specifically for the treatment or control of cancer.

Adult cancer patient: An individual with a self-reported age of 18 years or older who consents to participate in the study, has a confirmed diagnosis of cancer, is scheduled to receive chemotherapy, and is not confined to the hospital except for the purpose of receiving chemotherapy.

Social support: Self report of: (a) support activity, (b) patient's perception of the amount of support provided by the nurse as measured by a single item on the CFQ on which the patient rates this support as large amount, some, little, or none, and (c) adequacy

of support as perceived by patient and measured on a scale of 1 to 7 on the CFQ.

Information: Self report of: (a) information received prior to first chemotherapy treatment, (b) patient's perception of the amount of information supplied by the nurse as measured by a single item on the CFQ on which the patient rates this information as large amount, some, little, or none, and (c) adequacy of information received, as perceived by patient and measured on a scale of 1 to 7 on the CGQ.

Adherence: Self report on the CFQ of completion, partial completion, or no completion of any of the three phases of a chemotherapy regimen including: (a) keeping scheduled appointments, (b) having blood work and required tests, and (c) receiving chemotherapy treatments at the scheduled time.

Limitations

The study was limited in the following ways:

1. Participants were recruited from two geographical locations.
2. Participants were selected by convenience sampling.

3. The sample was limited to adults scheduled to receive chemotherapy during a specified period of time.

Delimitation

The delimitations were as follows:

1. Participants were adults 18 years of age or older.
2. Participants received parenteral chemotherapy on an outpatient basis.

Summary

Adherence with cancer chemotherapy represents an underresearched but important issue (Taylor, Lichtman, & Wood, 1984). In Chapter I, the researcher presented an overview of the study. The problem for the study included the testing of relationships that exist among social support, information, expectancy, selected demographic variables, and adherence to a chemotherapy regimen. The rationale cited the lack of studies relating cancer chemotherapy to the identified concepts, and a documented need for the study.

The framework for the study was based on Sear's expectancy theory in combination with the concepts of social support, information, and adherence. Assumptions,

definitions, limitations, and delimitations were presented. Three hypotheses and five research questions emerged as the focus of the study.

CHAPTER II

REVIEW OF LITERATURE

The vast majority of persons who develop cancer, today and in the future, will have chemotherapy as a part of their treatment regimen. Because of the aggressiveness of cancer chemotherapy protocols, and the multitude of side and toxic effects that accompany the therapy, adherence to the regimen can be a problem. Many studies were found that addressed the subject of adherence or nonadherence to various types of health regimens; however, only a few related to cancer chemotherapy adherence. No studies were discovered that explored the influence of expectancy on adherence, which is a major focus of the present investigation. This chapter presents a review of the literature divided into the following sections: (a) social support, (b) information, (c) expectancy, and (d) adherence.

Social Support

Gardner and Wheeler (1987) postulated that patients who feel supported by health workers probably experience

greater satisfaction with health care. O'Conner, Wicker, and Germino (1990) identified social support as an important factor in the newly diagnosed cancer patient's personal search for meaning, and they suggested that the nurse "can facilitate the process by which patients may explore what the cancer means for their lives" (p. 174). DiMatteo and DiNicola (1982) cited literature reviews (Becker & Maiman, 1980; Haynes, Taylor, & Sackett, 1979) that referred to growing evidence of the influence of social support on adherence behavior. The review of social support includes those studies deemed to be relevant to the study.

In a literature review that focused on social support and help seeking, Roberts (1988) determined that the complexity of this phenomenon--social support--suggested the need for a typology that guides planned nursing interventions. To this end Roberts presented six categories as reasons for patients seeking the support of nurses. The categories are:

- (a) lack of support for a needed change in health-related behavior, (b) acute lack of support related to a normal developmental crisis that involves a change in the network, (c) acute lack of support related to a crisis that temporarily changes the need for support, (d) acute lack of support related to a crisis that involves a loss of support, (e) chronic

lack of support that is adequate except in a crisis, and (f) chronic lack of support that is inadequate (p. 7).

The cancer chemotherapy patient could conceivably be in need of nursing intervention in any of the above categories. Even with a normally adequate support network the emotional impact of cancer diagnosis and treatment as a crisis situation, a recurring event, or a chronic illness may tax the limits of the patient's network. Nurses can play a paramount role: (a) in offering continuing support throughout the cancer experience and (b) by conducting research to explore and validate appropriate interventions in each of the categories.

Using telephone interviews and both open- and closed-ended questions, Dunkel-Schetter (1984) investigated social support among cancer patients. The purposes for the research were to study behaviors that cancer patients perceive as supportive or nonsupportive, to evaluate perceived adequacy of support, and to determine if and how the support was associated with adjustment. The sample consisted of 79 cancer patients who had been diagnosed (during the year just prior to the study) with either breast or colon-rectal cancer. The age range of participants was 30 to 70 years; most were women (86%),

white (91%), married (62%), employed at time of diagnosis (73%), with a mean income of \$33,975.

Results supported the hypothesis that "medical workers" provide a substantial amount of support during the cancer experience. The "most helpful" sources of support were family members--usually spouse, children, or siblings--(34%), medical staff-physicians and nurses, not listed separately--(30%), and friends (16%). In the area of supportive behaviors 81% of the participants mentioned emotional support, 41% identified informational support as most helpful, 6% mentioned appraisal (approval) support, and 6% enumerated instrumental aid or assistance. The emotional support specified most frequently (46%) was love and concern and included presence, companionship, listening, as well as more direct expressions of caring. Other types of emotional support that rated high were understanding (29%) and reassurance or encouragement (26%). Forty-four percent of the respondents reported one or more nonsupportive behaviors by family, friends, physicians (and other medical workers), co-workers, or strangers. Nonsupportive behaviors were not itemized but the following examples were given: (a) medical care provided without apparent emotional support, and (b) "insensitive, hurtful, and thoughtless comments of

friends" (Dunkel-Schetter, 1984, p. 85). Some respondents also considered information and advice provided by family and friends to be nonsupportive.

Support was found to be significantly associated with adjustment for the overall sample (Dunkel-Schetter, 1984). However, when the group was divided into "better" versus "poorer" prognosis there were some differences. For those with a poorer prognosis the relationship between support and the psychological measures was not significant. Also, support was inversely related to functioning and symptoms in those with poorer prognosis. The researcher suggested that prognosis was an important variable to control in future studies.

Gardner and Wheeler (1987) conducted a study to identify nursing activities that patients perceived as being supportive, and to examine the reliability and validity of a newly-developed Supportive Nursing Behavior Checklist (SNBC). A total of 128 patients participated in the study, with 110 answering the structured interview questions and 119 completing the SNBC. During the interview, which was completed first, patients were asked to respond to four statements regarding (a) nursing care that had met their needs, (b) an incident in which they had received nursing support, (c) an incident when they

did not receive support from the nurse, and (d) what they thought kept nurses from giving support.

From the interviews, 11 support categories were extracted. The first five categories were (a) being available, (b) promoting comfort, (c) giving information, (d) assisting in expression of feelings, and (e) performing specific nursing tasks. Being available, promoting comfort, and giving information accounted for 85% of the behaviors, with over 50% falling in the being available category. From 40 incidents describing nonsupportive behaviors, those most frequently given related to: (a) lack of availability, (b) lack of comfort, (c) lack of treatment or nursing tasks, (d) lack of information, and (e) aggressive and rejective attitudes.

Following the interview the 67 items on the SNBC were rated on a 7-point scale. Nine of the first 12 items, identified by the results of this questionnaire, corresponded with the categories identified from the interviews. Even though the overall list of behaviors tended to be similar, psychiatric patients and medical-surgical patients prioritized supportive behaviors differently (Gardner & Wheeler, 1987). Psychiatric patients placed the highest value on honesty, medical

patients on a friendly nurse, and surgical patients on confidence that they were receiving adequate care. The investigators concluded that in spite of a small nonrandom sample, validity and reliability tests indicated that the SNBC could prove useful for studying patients' perceptions of supportive nursing behaviors.

In a more recent study Dakof and Taylor (1990) interviewed 55 cancer patients to determine the specific actions that they considered as helpful or unhelpful from various support providers. The sample consisted of 30 females and 25 males, with an age range of 30 to 66 years. Most (83%) were married, 84% had children. All participants had been diagnosed with or had a recurrence of cancer within 6 years of the study. The potential support providers were spouse, other family members, friend, acquaintance, other cancer patients, physician, and nurse. Using a structured interview, the same four open-ended questions were asked about each of the potential support providers. Ninety-eight percent of married participants reported receiving helpful support from their spouse. The percentage of respondents identifying at least one helpful action from each of the other support providers was (a) family (96%), (b)

friend (94%), (c) acquaintance (62%), (d) cancer patient (86%), (e) physician (94%), and (f) nurse (87%).

Cochran Q tests were computed for differences across each of the potential support providers. The types of support were "collapsed into the common social support taxonomy of (a) esteem/emotional support, (b) informational support, and (c) tangible support" (p. 82). Not all participants indicated that they received support from each of the possible support categories. Overall, participants indicated that esteem/emotional support was the most helpful support action received from spouse (74%), other family (74%), friends (72%), acquaintances (40%), and nurses (53%). The most helpful support action of other cancer patients (48%) and physicians (58%) was informational. With one exception, the least helpful support actions were in the same categories (as helpful actions) across all providers. From physicians the least supportive activity fell under the esteem/emotional category rather than informational.

The 30 participants who reported receiving esteem/emotional support from nurses, identified the following specific nursing behaviors: (a) expression of concern and affection (24%), (b) being pleasant and kind (18%), and (c) being optimistic about the patient's

prognosis or ability to successfully live with the cancer (11%). Only 16% of the participants said that nurses gave useful information. As for unhelpful nursing behaviors 20% of the respondents stated they were "annoyed by nurses who provided technically incompetent nursing care? (p. 85). Other unhelpful nursing behaviors included minimization of cancer impact (14%), showed little concern or affection (11%), and were rude or inappropriate (9%).

Kesselring, Lindsey, Dodd, and Lovejoy (1986) compared Swiss cancer patients' perception of social support and its components with results of similar studies with Taiwanese and Egyptian cancer patients. In this replication study the Norbeck Social Support Questionnaire (NSSQ) was translated into German and given to a group of 42 participants. The results indicated that the Swiss-German group had fewer people (9.3 as compared to 10.25 for Taiwanese and 14.8 for Egyptian) in their total support networks. Spouses, family members, and other relatives comprised 66.2% of the support networks listed. Further results indicated that when compared to the Taiwanese and Egyptians, the number of support functions was less for the Swiss group. Those participants with the highest number of people in their support networks expressed the most accepting attitudes toward their

illness. The investigators concluded that the results corroborated previous research findings relative to the cushioning effects of social support. They suggested that the NSSQ could be translated into other languages to obtain general information about social networks from many different cultural groups. They cautioned, however, that in order for the information gleaned by this instrument to have meaning for cross-culture nursing, it should be evaluated by knowledgeable interpreters.

Three areas that have received minimal attention in social support studies are: (a) cost and conflict of social support, (b) the timing of types of support, and (c) sexual differences in perceived social support. Tilden and Galyen (1987) addressed the "darker side" of support and pointed out that most support instruments include only positive subdivisions. Tilden and Galyen argued that future research must include both sides of the supportive relationship. Even though types and timing of social support have been studied separately, Jacobson (1986) suggested that integrating the two dimensions would enhance learning about social support-what it is and how it works. Some studies (e.g., Gardner & Wheeler, 1987) found that significant differences exist between a person's gender and the supportive activities

that are thought to be most important. However, this is not always incorporated into planned research or nursing interventions.

Summary of Social Support Literature

Selected studies of social support from 1984 to the present indicate family as a primary source of support. Patients from a variety of cultures perceived the following as components of support: presence, companionship, listening, understanding, reassurance, encouragement, availability, promoting comfort, giving information, expressing feelings, honesty, friendliness, and receiving adequate care. Some researchers believe there are negative aspects of social support and that more research in this area is necessary.

Information

Even in today's information-oriented society lack of information and misinformation about cancer and cancer therapy still abound. Ash (1990) claimed that all too frequently individuals are unaware of the resources such as the Cancer Information Service, American Cancer Society, and cancer centers that are available for their use. Ash extended the notion that as long as this

information is not disseminated to all that need it, cancer will continue to be a leading cause of death in the United States and other parts of the world.

Research linking information to adherence has shown conflicting results, but it is evident that a person cannot follow a therapeutic regimen without the necessary information for doing so. Numerous investigators (e.g., Baer, 1986; Becker & Maiman, 1980; Kolton & Piccolo, 1988) include information giving as one strategy for improving adherence behavior. Traditional functions of nursing include giving health and illness information to individuals and groups; therefore, nurses can make a significant contribution to this aspect of adherence (Baer, 1986).

Other research findings have demonstrated that certain types of information reduce the anxiety and stress that accompany aversive procedures (Hartfield, Cason, & Cason, 1982; Johnson, 1973; Johnson & Leventhal, 1974). Also, information can help to meet the personal control needs of adult cancer patients (Brockopp, Hayko, Davenport, & Winscott, 1989; Dennis, 1990). Although not all persons want or need huge volumes of information, nurses should identify each individual's information

needs and plan information interventions accordingly. This section reviews research concerning information.

While patient education is an acknowledged nursing intervention, studies indicate that nurses may not take advantage of all teaching opportunities (Close, 1988). For example, using a survey approach, Clarke and Sandler (1989) sought to determine the frequency at which breast self-examination (BSE) was taught by staff nurses in a tertiary care hospital. Three hundred questionnaires were distributed with a return rate of 35% ($N = 105$). Of the 100 female and 5 male nurses, 99 responded to the questions in regards to teaching BSE. In spite of the fact that 82% purported to practice BSE only 40% included the procedure "sometimes" to "always" in their patient teaching. Of those that did teach BSE it was usually by discussion of the procedure. Only a few also demonstrated the technique. A chi-square analysis failed to reveal that age, own BSE habits, or their breast cancer risk scores had any influence on teaching behavior. The researchers concluded that the nurses demonstrated ambivalence by practicing but not teaching the BSE procedure. They speculated that general attitudes toward cancer might contribute to this behavior. The researchers suggested one way to improve the attitudes might be to

ensure that the nurses had updated and valid information (Clarke & Sandler, 1989).

In a 1980 exploratory study, Messerli, Garamendi, and Romano demonstrated that 86.2% of a sample of 58 breast cancer patients had unanswered questions about their treatment. Reasons given for not asking questions about their concerns included not knowing what questions to ask (46.6%) and being too emotionally upset to ask questions (27.6%).

In this same study, 77 surgeons, plus the breast cancer patients, were asked to rank-order the importance of nine potentially available information resources. Patients identified written information, such as information about breast cancer, treatments, information agencies, and questions to ask, as the number one priority. This potential resource was ranked second by the surgeons. The least important potential resource according to patients was "a more complete informed consent form explaining the treatment" (given as #5 by surgeons). For surgeons, two potential resources tied as least important (i.e., discussion with other mastectomy patients before surgery and family counseling). These were #3 and #7 respectively for patients. Individual counseling by other health workers (e.g., nurses and

social workers) ranked 4th for patients and 6th for surgeons. Although both patients and surgeons ranked written information sources high, 77.9% of the surgeons reported not having this available for patients. The investigators suggested that the presently preferred two-step approach for breast cancer surgery should allow up to 2 weeks between biopsy and mastectomy for health professionals to provide appropriate information and support services as a crisis intervention.

Based on a survey of 2,500 calls to a Cancer Information Service Office, Morra (1985) identified information most frequently requested by cancer patients and their families. Soon after the diagnosis, the patient was most interested in learning about the symptoms and diagnostic tests. Patients also wanted to know about treatment, coping methods, referrals, site of the cancer, and symptoms. Thirty-four percent of the questions asked by family members related to the treatment. Also, the family requested information about coping, referrals, site information, and day-to-day living (Morra, 1985).

Using the survey results and a review of the literature, Morra (1985) drew the following conclusions about the information needs of cancer patients and their families:

1. Patients have unanswered questions and don't ask them.
2. Both patients and family members want more information than they are currently receiving.
3. Patients seek information from diagnosis through the treatment process.
4. Family members are more concerned with treatment and care issues and need to be included in the decision-making.
5. Patients who want more information and are more actively involved are more hopeful and have a more positive attitude towards the present and the future (Morra, 1985, p. 57).

Dodd and Mood (1981) conducted two studies to evaluate the knowledge that cancer patients have about drugs they are receiving in chemotherapy and the role of the nurse in imparting information. The first study elicited recall of information given during the informed consent session with a physician. In the second study a nurse reviewed the consent information with the patient; then recall accuracy was evaluated 3-4 weeks later.

Results of the first study indicated that information given during the informed consent procedure was not

well-retained (Dodd & Mood, 1981). There were 30 participants in the first study, all of whom were receiving chemotherapy that had been started within the previous 12 months. Of this number 70% were unable to recognize the names of any drug(s) they were receiving. Fewer than one-third of the possible side-effects were correctly identified. Only 10 of the participants included infection and no one identified bleeding, both of which are potentially lethal side effects. When asked the reason for receiving chemotherapy, 80% (4 of 5) of the adjuvant cases correctly answered "to cure the disease". However, 72% (17 of 25) with advanced cancer, responded in the same way, which was an incorrect answer for them. Most of the patients (86%) were aware that chemotherapy would shrink the tumor, but only 50% realized the potential for pain relief (Dodd & Mood, 1981).

Twenty-four patients participated in the second study and were randomly assigned to either the control or research group. Selection criteria for participants was similar to that used for the first study, except that all patients had been assigned their chemotherapy protocol within the previous 2-3 days. All participants were given the standard informed consent protocol and all were visited by the nurse investigator within

48-72 hours. During the 20-minute visit, the control group received disease-related information. Patients in the experimental group were reviewed on the content of the informed consent session.

The most pronounced difference in findings for the second study was the ability of participants to recognize the potentially lethal side effects (i.e., infection and bleeding). Seventy-one percent of the experimental group correctly responded to this question. The experimental group in the second study also demonstrated the following: (a) a significantly greater ($p < .05$) recall of names for drugs they were receiving, (b) a significantly greater ($p < .01$) number of possible side effects, and (c) a significantly greater ($p < .05$) knowledge of the reasons for receiving chemotherapy than those in the control group.

Dodd and Mood (1981) concluded, from the two studies, that information intervention did not decrease the number of incorrect responses. However, the number of correct responses pertaining to critical aspects of therapy did increase for patients who received information from the nurse (in addition to that given by the physician).

Using a nonexperimental, ex post facto design, Hopkins (1986) developed and tested an instrument

(Information Preference Questionnaire [IPQ]) with women receiving chemotherapy for breast cancer. The primary purpose for the study was to determine the relationship between information-seeking and adaptational outcomes (i.e., mood states and level of functioning) and to test Lazarus' theory of stress and coping. Thirty-eight women (mean age = 55), participated in the pilot to determine the reliability and validity of the IPQ. Clarity and face validity were established by a nurse educator, oncologist, and three patients who were receiving chemotherapy. Chronbach's alpha was .88 ($N = 38$), and the test-retest reliability was .92 ($n = 30$). An attempt to establish criterion-related validity of the IPQ by administering the Chemotherapy Knowledge Questionnaire (CKQ) showed virtually no relationship between the scores (Hopkins, 1986).

Fifty-eight women (mean age = 54.7) were selected by convenience sampling to participate in the second phase of the study (Hopkins, 1986). All participants had breast cancer and were receiving chemotherapy. Data were collected during a single session and included a semi-structured interview, a medical record review, and administration of three standardized instruments (i.e., the IPQ, SIP, and POMS). No significant relationships

were found between information-seeking and the adaptational outcome measures of mood states and level of functioning. The findings indicated that older women and persons having a more advanced disease condition demonstrated less information-seeking activity than younger women and individuals with limited disease. There was a significant positive relationship between information-seeking and years of education. Hopkins (1986) believed the Lazarus theory of stress and coping assisted in explaining the stressful sequence of events associated with cancer chemotherapy and the coping responses. The theory was not helpful in predicting specific adaptive outcomes. The frequency with which nurses were identified as a significant source of information, according to Hopkins, supports the belief that nurses administering chemotherapy can meet many of the learning needs of these patients.

Hartfield, Cason, and Cason (1982) explored the effects of information about a threatening procedure on expectations and emotional distress. Using a quasi-experimental approach, 13 females and seven males were alternately assigned to procedural information and sensation information groups. The mean age was 40.9 years for the sensation group and 40.5 years for the

procedure group, with the overall age range being 24 to 61 years. Mean education level was 12.4 years and 11.8 years for the sensation and procedure group, respectively. Participants, all scheduled for barium enema, had a variety of gastrointestinal diagnoses, such as irritable colon and colitis. Each individual completed the State-Trait Anxiety Inventory (STAI) and a preinformation sensation inventory before listening to a taped message about either procedural or sensation information. Subsequently the sensation inventory was completed after listening to the information tapes and again immediately after having the barium enema. The STAI was also completed immediately after having the procedure. Results suggested that receiving sensation information enhanced congruence between expected and experienced sensations. The results also suggested that increased congruency between expected and experienced sensations decreased the anxiety level during the actual procedure (i.e., barium enema). Hartfield et al. (1982) concluded that the results supported the coping theory offered by Lazarus and his colleagues in that: "Receiving information about commonly experienced sensations allows the individual to appraise a threatening situation (modify

faulty expectations) and use available coping mechanisms to deal more effectively with the situation."

Sime and Libera (1985) randomly assigned participants ($N = 113$) into four information groups to determine the effects of information interventions on adjustment during stressful or threatening situation. In this study, the stressful event was dental surgery. Age of participants ranged from 22 to 71 years. Based on results of a preintervention State-Trait Anxiety Inventory (STAI) and scores on the dental trait anxiety scale, participants were blocked according to presurgery anxiety (i.e., high or low). The four interventions were: (a) sensation information (i.e., description of what patient could expect to feel, see, taste, and smell during surgery), (B) self-instruction information (i.e., information on how to instruct self in relaxation, controlled-breathing, or to focus on pleasant thought during the surgery), (c) combined sensation and self-instruction information, and (d) control information (i.e., information routinely provided all patients). All interventions were by audio tape, made by the same female in a nonthreatening manner. Seven dependent variables, representing adjustment during surgery, were measured four ways using: (a) the Profile of Mood States, (b) a 10-point Likert-type distress scale,

(c) a self-statement inventory, or (d) a rating of patient adjustment made by the dental student who did the surgery.

Results of the study demonstrated an interaction between the anxiety state and information intervention. When compared with the control group, high anxiety participants reported less tension and distress ($p < .05$) after receiving sensation information, less tension ($p < .005$) after self-instruction information, and increased positive self-statements ($p < .05$) with combined information. Conversely, low anxiety participants showed negative treatment effects by reporting fewer positive self-statements both for sensation information alone ($p < .001$) and when combined with self-instruction ($p < .01$). Differentiation in treatment effect was not apparent when participants were classified by trait anxiety. These findings suggest another dimension (level of anxiety) should be considered when an information intervention is used for individuals about to undergo a stressful or threatening situation.

Summary of Information Literature

Recent literature in regards to giving information to cancer patients confirmed low acquisition, retention, and use of knowledge in patients, whether information

was delivered by physician or nurses. Review of information given seemed to increase the knowledge base in patients. Sensation information has been shown to change expectancies and decrease anxiety in aversive diagnostic tests and some treatment situations. These results could have implications for information giving relative to cancer therapy.

Expectancy

Jones (1977) postulated that until about 100 years ago most medications and procedures were basically placebos. However, Jones continued, it has only been within the past three decades that modern medicine has begun to take seriously the view that psychological factors play important roles in both health and disease. "Only with the development of specifically effective medications, vaccines, and procedures could interest in placebo effects per se emerge without posing too much of a threat to medical practitioners" (Jones, 1977, p. 205). Before that time, Jones asserted, medicine would have been totally destroyed if the placebo effects were highly publicized.

The placebo effect is thought of as one form of self-fulfilling prophecy. Placebo effect, self-fulfilling

prophecy, expectations, and imagery are terms that have been used in the same context as expectancy. Expectancy or expectations appear to be the underlying stimulus for the outcome of placebos and self-fulfilling prophecies. Studies (Beecher, 1966; Shapiro, 1971; Wolf, 1959, cited in Smale, 1977) have revealed that placebos can be more powerful than and can reverse the action of potent active drugs. Further they found that negative attitudes of nurses toward a placebo injection can reduce the effects from 70% to 25%. Smale (1977) continued that more than likely the results of insulin coma therapy were due to the prestige of the treatment and the attention the patients received during and after the treatment rather than the effects of the drug itself.

Jones (1977) posited that interpersonal expectancies affect either the behavior of the one having the expectancy or the behavior of the person about whom the expectancy is held. According to Jones expectancy allows the individual to extract meaning from past experiences, or by making social comparisons, and provides some control over life events. It is the basis for making choices. Expectancy occurs in degrees, is similar to hope, and affects the probability of achieving a goal. After reviewing many studies that examined the key variables

affecting performance, Jones speculated that the greater one's expectancy of success, the more one is likely to do whatever is required to achieve success.

The idea of expectancy affecting outcomes has been applied in many disciplines other than the health care field. For example, labeling theorists purported that the social group creates deviance by developing rules which when broken cause a person to be treated as a deviant. Once labeled as such, this sets in motion the self-fulfilling prophecy and the expected behavior continues (Becker, 1963). In 1952, Becker asserted that teachers hold different expectations for upper, middle, and lower class students. Becker (1952) further contended that the teacher's approach to the student differed in each of these classifications and that students tended to achieve at about the level of the teacher's expectations. Finally, market fluctuations, inflation and depression spirals, and occupational stereotypes have each been explained on the basis of the expectancy concept (Henshel, 1982).

Wilkins (1973) reviewed numerous studies that demonstrated expectancy to be an explanatory construct for treatment gains from psychotherapy. For example, Krause, Fitzsimmons, and Wolf (1969) reported significant

differences in improvement and motivation between subjects who participated in group sessions that first focused on their expectations of therapy and those in groups where the discussion was not included. Marcia, Rubin, and Efran (1969) illustrated that expectancy instructions made a significant effect on therapeutic gains for patients receiving "T-scope" therapy. Wilkins (1973) identified eight studies that found no significant relationship between expectancy and psychotherapy.

One study (Johnson, 1973) investigated the effects of accurate expectation about sensations on the sensory and distress components of pain. Participants were given information relative to the physical sensations they could expect from the painful stimuli. A second study (Johnson & Leventhal, 1974) explored the effects of accurate expectations and behavioral instructions on reactions during a noxious (endoscopic) medical examination. In both studies the findings supported the premise that accurate expectations relative to an aversive situation do influence patient coping responses. Less emotional distress was experienced by participants with the accurate expectations. Furthermore, results of the second research suggested that providing information that promotes formation of accurate

expectations better prepared a person for the noxious experience than did behavioral instruction.

Concerned about the effects of expectancies on functional impairment from chronic low back pain, Council, Adhern, Follick, and Kline (1988) examined the following hypotheses:

1. Perceived self-efficacy will have a direct relationship to actual performance.
2. Response expectancies for pain will be inversely related to performance.
3. Response expectancies will have a stronger relationship to avoidance behaviors than self-efficacy expectancies.
4. Expectancy ratings will have significant correlations with global measure of pain and functional impairment in everyday life.

Participants included 20 males and 20 females who were being evaluated for chronic low back pain (duration > 6 months) with no indication of organic pathology. Ages ranged from 20 to 69 years. After completing the Movement and Pain Prediction Scale (MAPPS), participants were videotaped performing the 10 movements for which expectancy ratings had been made. Although participants

gave written consent for the taping, they did not know beforehand that the identified movements would be evaluated.

To measure self-efficacy, patients rated their ability to perform movements. Response expectancies were the patients' rating of the amount of pain they expected to accompany the movements. The Sickness Impact Profile (SIP) and a Daily Activity Diary were used as global measures of pain and functional impairment.

Findings showed significant ($p < .0001$) relationships between self-efficacy and response expectancy for all 10 movements, with correlations ranging from $-.49$ to $-.75$. Additionally, for many of the movements there was a consistent and significant ($p < .05$ or $p < .01$) relationship with self-efficacy, response expectancy, and the specific motor behaviors. Multiple regression analysis indicated that self-efficacy for movements was the strongest predictor of both movement ratings and pain behavior. The study, according to Council et al., suggested that "patient expectancies of physical impairment and pain bear a substantial relationship to actual performance" (p. 330). Council et al. further suggested that although clinicians probably try to instill positive expectancies in their patients, research on

expectancy modification procedures in chronic pain should be encouraged.

Summary of Expectancy Literature

In general, literature on expectancy and related concepts supported the idea that expectations affect outcomes. Specifically, expectancy was linked with hope, control, body movement, and choice.

Adherence

Adherence is a dynamic and complex concept that has been studied in a variety of situations. The fact that many patients adhere completely to part of a prescribed health regimen and ignore other aspects further complicates the problem. Because of this multidimensionality, operational definitions of adherence vary greatly, and research relating to adherence has provided many conflicting results. De-Nour (1986) suggested that the etiology for nonadherence should be diagnosed on an individual basis so that "rational interventions" are developed based on that patient's needs. At the very least, studies are needed that identify commonalities for specific treatment regimens in various conditions and situations. Most cancer

adherence studies relate to prevention and screening behavior. Little attention has been focused on adherence behavior of cancer patients receiving chemotherapy or other treatment modalities.

Nehemkis and Gerber (1986) observed that in their experience with cancer patients at Long Beach Veterans' Administration Medical Center [LBVAMC], nonadherence to therapy regimens is practically nonexistent. While reasons for this "extraordinary" adherence is no doubt multifaceted and complex, Nehemkis and Gerber outlined three experiential aspects that possibly contribute to the psychological motivation for this behavior. Included were:

1. Pressure of time (i.e., cancer patients probably feel the pressure of limited time and perceive it as passing very swiftly).

2. Good versus evil (i.e., cancer [unlike other chronic life-threatening illnesses that are due to malfunction or wearing out] is often characterized as a foreign evil growing within the body). Adherence to treatment offers the only "hope of exorcism".

3. A chance for beating the odds (i.e., by having the treatment, the patient has a certain chance for

prolongation of life). Wanting to beat the odds is a common human trait.

In spite of the fact that acute lymphocytic leukemia (ALL) in children has been shown to be curable in a significant number of patients, relapse continues to be a major problem in about one-half of all cases (Klopovich & Trueworthy, 1985). There is little information as to why therapy fails but one possibility is nonadherence to the medical regimen. Until recently, it was assumed that the diagnosis of cancer would assure adherence to medication taking; however, this has proven to be a false assumption. Klopovich and Trueworthy (1985) cited numerous studies that identified factors related to nonadherence in children with cancer. The authors also examined interventions that might improve this behavior. Perceived severity of illness, complexity and duration of therapy, severity of current symptoms, and age appear to influence the degree of adherence. Adolescents are especially prone to nonadherence. Parental characteristics must be considered when looking at nonadherence in children. These characteristics seem to be associated more with boys' adherence to therapy than with girls. Parental behaviors (i.e., hostility, obsessive-compulsiveness, anxiety) usually considered

maladaptive are associated with higher adherence in boys. Girls seem to be less of a worry and concern for their parents and presumably have the responsibility for their own medication taking.

A nursing intervention that might prove life-saving is the early detection of potentially nonadherent patients, followed by appropriate planning and attempts at preventing the behavior. Education, frequent patient contact, behavior modification, and health care contracts with use of positive reinforcers are the most successful interventions that have been identified. For the most part, education has been less successful than the behavior approaches (Klopovich & Trueworthy, 1985).

Basch, Gold, McDermott, and Richardson (1983) completed a review of literature for studies that focused on cancer patient adherence to therapy and required follow-up activities. Because minimal research existed on this topic, patient adherence in other areas were used in an attempt to determine the optimum approach for studying adherence of cancer patients. Providerpatient relationship, the therapeutic regimen, psychosocial, and demographic characteristics of the cancer patient were identified as important factors to be considered. The patient's perception of disease

severity and efficacy of treatment were other possible variables. Basch et al. proposed that appointment keeping could be the measure of adherence if a treatment was administered at the time of the appointment. They further suggested qualitative follow-up on those patients not keeping appointments as a method for defining high-risk groups for nonadherence.

Rimer, Davis, Engstrom, Meyers, and Rosan (1988) investigated reasons for adherence and nonadherence to a breast screening program offered by the Health Maintenance Organization of Pennsylvania and New Jersey (HMO). Only 31% of eligible women (age 40 years or older) returned a completed Risk Assessment Form (RAF) sent by this organization. Included in the mailed packet were "health education materials on breast cancer, breast self-examination and mammography" (p. 105). The goal of the HMO was to increase the use of regular mammograms. Cost for the mammography would be covered by the HMO. A random sample of adherers ($n = 241$) and nonadherers ($n = 261$) was selected from those returning the RAF. Structured interviews were conducted with this sample. Five percent of the women contacted refused to be interviewed, and 4% of the interviews were incomplete. Age range of respondents was 40 to 70 years, with the

majority ($n = 251$) in the 40- to 49-year-age group. Forty-one percent of adherers and 14% of nonadherers had less than 11 years of education, while 38% of adherers and 36% of nonadherers had more than 12 years.

Chi-square and Kruskal-Wallis tests identified major factors related to adherence or nonadherence. Characteristics associated with adherers and nonadherers were found by use of discriminant analysis. Results showed that more adherers than nonadherers knew what a mammogram was (99% to 87%), had previous mammograms (54% to 37%), and were likely to get the free mammogram (74% to 51%). Nonadherers were more likely than adherers to be worried about cancer (39% to 31%) and at higher risk for getting cancer (21% to 13%). The materials were read and considered useful, interesting, and calming by significantly more ($p = .0001$) adherers than nonadherers. In this study, more was learned concerning adherers to the program than about those who did not adhere. The strongest influence on adherence status was reading the materials. Those who were less likely to get cancer and people in the older age group were also more likely to be in the adherence group.

Using Becker's Health Belief Model for a conceptual framework, Itano et al. examined the relationships of

six independent variables (health locus of control, self-esteem, anxiety, patient's understanding of illness, patient's perception of severity of symptoms, and patient's perception of nurse's care and concern) to adherence with an established chemotherapy regimen. Adherence, in this study, included three areas: (a) keeping all appointments, (b) completing ordered laboratory work, and (c) receiving all prescribed medications. The data were treated as dichotomous. To be considered adherent, a patient had to have 100% completion in all three areas for a 3-month period. Data were collected on a convenience sample of 66 adult outpatients. Questionnaires were used to gather data for the six independent variables. A review of records provided information for the dependent variable, adherence. Findings of this study indicated that the individual most likely to be adherent was female, with higher external locus of control scores, higher state anxiety scores, and a perception of having less severe symptoms. Patients generally perceived nurses as being very caring and concerned; however, there was no significant correlation between this factor and adherence. There was no significant correlation between understanding

of illness and adherence, The nonadherence rate for this sample was 21.2%.

In a study conducted to explore the extent and reasons for nonadherence with intravenously-administered chemotherapy the results disclosed a high rate (92%) of adherence (Taylor, Lichtman, & Wood, 1984). Participants (N = 78) were recruited through three private practice oncologists on the west coast. All participants were female breast cancer patients with an age range of 29-78 years. Data were collected by an interview asking predominantly open-ended questions. However, some factors were rated by the participants including: (a) unpleasantness of the side effects and (b) the effectiveness of counteractions taken to relieve these symptoms (Taylor et al., 1984).

In addition to the patient interviews, 62 significant others (usually the spouse) were asked questions that paralleled the topics presented to patients. The interviewers and physicians rated the patient's psychological adjustment to illness with the Global Adjustment to Illness Scale (GAIS). Chart materials (assembled by physicians' nurses) provided information relative to each patient's other illnesses, delay in seeking treatment, stage of cancer, additional treatments

for the cancer (e.g., surgery), resistance to the therapy, and other pertinent facts.

Results of this investigation disclosed that: (a) two patients refused chemotherapy, (b) six patients initially resisted the therapy, and (c) two patients received chemotherapy intermittently. Binge drinking (just prior to chemotherapy) by a chronic alcohol user can depress the white count sufficiently to contraindicate the therapy (Taylor et al., 1984). Both patients apparently made use of this knowledge to avoid receiving chemotherapy when they felt they could not tolerate the side effects of the treatment.

Taylor et al. (1984) attributed the high rate of adherence to chemotherapy to the "centrality of chemotherapy for survival, the medical trappings associated with the procedure, the high level of monitoring that occurs by medical personnel, and the use of successful coping techniques" (p. 559). These researchers identified two potential trouble spots relative to chemotherapy: (a) chemotherapy's bad image with the public and (b) the alcoholic patient.

Weddington (1982) proffered four case studies to illustrate the possibility of pretreatment nausea and vomiting leading to nonadherence with long-term

chemotherapy. All patients, three males (ages 17, 22, and 24) with Hodgkins and one 38-year-old female with lung cancer, either received treatments sporadically or discontinued them altogether. The reason given by each patient was that he or she could no longer tolerate pretreatment symptoms (i.e., nausea and vomiting). However, in each case there appeared to be underlying resistances and ambivalences toward their cancer. Weddington (1982) stated that patients can usually be assisted to overcome or tolerate these symptoms (i.e., nausea and vomiting). He cautioned that further investigation is needed when this is the reason given for dropping out of treatment.

A prospective evaluation of oncology clinic attendance over a 12-month period at Harlem Hospital Center in New York City disclosed an overall attendance rate of 89% (Garrett, Ashford, & Savage, 1986). During this study 100 patients were scheduled for a total of 657 appointments. The sample consisted of 59 women and 41 men with an average age of 60 years. All but three of the participants were black. Appointments were for a variety of reasons including chemotherapy, diagnostic work-ups, and follow-up care. Findings revealed that 53% of the patients kept all appointments and 69% of

the clients attended at least 80% or more of all scheduled appointments. No significant difference in percentage attendance occurred for: (a) patients younger than 50 years when compared with those over 50, (b) male versus female patients, (c) tumor type, or (d) mode of therapy. Bad weather, transportation difficulty, personal business, and forgetting were reasons given for 23 missed appointments. No reason was given for the remaining 51 absences. Only one patient stated an unwillingness to continue chemotherapy. Analysis of compliance for the subgroups failed to show significant differences in attendance behavior from that of the total population.

Summary of Adherence Literature

Recent studies on adherence confirm studies of earlier years in that adherence appears to be comprised of numerous variables and thus continues to be an elusive phenomenon. The ambiguities and inconsistencies which surround the adherence concept call for further research using new approaches.

Summary

The literature review for the study included social support, information, expectancy, and adherence with cancer chemotherapy. Numerous studies have addressed the problem of adherence to health care protocols but only a few have related specifically to cancer chemotherapy. No studies were discovered that explored the influence of the variables support, information, and expectancy on adherence.

The literature reviewed suggested that both health workers and the general public continue to have negative attitudes about cancer and cancer therapy. This pessimism influences the care and support that cancer patients receive (Corner, 1988; Holleb, 1986; Sontag, 1978). Even though most cancer patients reported the family as the primary source of support (Dunkel-Schetter, 1984; Wortman, 1984) they also identified supportive measures that health workers provide. Roberts (1988) identified six reasons why patients seek support from nurses. Gardner and Wheeler (1987) concluded that patients who feel supported by health workers probably experience greater satisfaction with health care.

Recent studies indicate that cancer patients have unanswered questions and poor retention of information received (Morra, 1985). Dodd and Mood (1981) found that reinforcing information the patient received during the informed consent enhanced retention of information. However, not all patients seek out information. Hopkins (1986) found that older women and those with more severe disease demonstrate less information-seeking activity.

Research relating expectancy to health outcomes has been most prevalent in counseling and psychotherapy. Conflicting results have been obtained in these studies (Wilkins, 1973). Johnson (1973) studied the effects of accurate expectations on sensory and distress components of pain. Johnson and Leventhal (1974) investigated the effects of accurate expectations on reactions during a noxious examination. Both studies supported the premise that if individuals have accurate expectations about aversive situations they will show less emotional distress when it occurs.

As stated before, the review of literature revealed a dearth of studies related to adherence with chemotherapy treatments, and the few that were found reported inconsistent findings. Studies have shown that many children and adolescents are nonadherent to medical

regimens for cancer (Klopovich & Trueworthy, 1985). Likewise, Itano et al. (1983) found a 21.2% nonadherence rate in adult cancer chemotherapy patients; however, in a study conducted by Taylor et al. (1984) the adherence rate for chemotherapy participants was 92%. Nehemkis and Gerber (1986) claimed that nonadherence to chemotherapy regimens was practically nonexistent at the LBVAMC.

The review of literature revealed conflicting results in the studies for each of the concepts used in the present study. The need for continuing systematic inquiry on the concepts support, information, expectancy, and adherence seems evident.

CHAPTER III

PROCEDURES FOR COLLECTION AND TREATMENT OF DATA

A descriptive correlational design was used to investigate the relationships among social support, information, expectancy, and adherence to a prescribed cancer chemotherapy regimen. A component of the study sought to describe the characteristics of the variables as they related to the chemotherapy regimen and nursing intervention. The descriptive correlational design allows the researcher to examine the variables and relationships among the variables in a situation that has occurred in the past, or in a situation that is in progress (Burns & Grove, 1987). Variables must be clearly defined and no attempt made to control or manipulate the situation (Burns & Grove, 1987). This chapter describes the setting, population, sample, and protection of human subjects. Included is a discussion of the researcher-developed instruments and the two pilot studies that evaluated the psychometric properties of the instruments. Finally, information concerning the collection and treatment of data for the study is delineated.

Setting

Data for the study were collected in six settings including a southern metroplex, a smaller southern city, and two western cities. The metroplex, with a population of over 2 million persons, had a multitude of physicians and health care agencies. One medical center and two oncologists' offices were selected in the metroplex. A medical center and an oncologist's office in a southern city, with a population of approximately 100,000, provided two settings. With the exception of one individual, the remainder of the participants were obtained in one of the western cities (population over 200,000) from patients of a group of five oncologists practicing within the same office complex. All participants had been diagnosed as having some form of cancer and had recently started or would be starting chemotherapy treatments.

Population and Sample

The study population consisted of any adult cancer patient, 18 years of age or older, who was scheduled to begin a chemotherapy regimen in an oncologist's office; or who was admitted to a hospital unit, on an outpatient basis, for the purpose of receiving the treatment.

Participants were selected by nonprobability convenience sampling over a timespan of 23 months. The convenience sample includes whatever elements meet the study criteria and happen to be available at the time of data collection.

There is no way to estimate that members of the population have the same chance of being in the sample (Brink & Wood, 1988). Findings cannot be generalized but are used for description and to facilitate understanding.

The projected sample size of 60 participants was selected to allow for factor analysis of items on the CES used to measure the expectancy variable. Tatsuo (1971) suggested that the sample size for factor analysis should be a 3:1 ratio with no less than a 2:1 ratio of observations to variables. Hair, Anderson, and Tatham (1987) wrote that generally factor analysis would not be used for fewer than 50 observations and preferably the sample size should be 100 or larger. To factor analyze, it is best to have four to five times as many observations as the number of variables; however, the nature of the study population may force the investigator to work with a ratio as small as 2:1 (Hair et al., 1987).

Protection of Human Subjects

The questionnaires used in the study qualify as Category I according to the Department of Health and Human Services Federal Guidelines and the Policies of the Human Subjects Review Committee of Texas Woman's University. A Category I study is exempt from review by the Human Subjects Review Committee (see Appendix A). Written permission was obtained from the University Graduate School prior to initiation of the study (see Appendix B).

To protect confidentiality, participants were requested not to put their name on any of the instruments. Forms were coded in order to keep the two questionnaires for each participant together. Completion and return of questionnaires indicated consent to participate in the study. Each questionnaire included a statement to this effect. Participants were given verbal and written explanations of the study. They were assured that participation was voluntary and that they could withdraw at any time without penalty.

Instruments

Two researcher-developed instruments and a background information sheet were used for data collection. Data for expectancy were collected using the Chemotherapy Expectancy Scale (CES) (see Appendix C). A background information sheet was attached to the CES and included participant's age, ethnicity, family income, cancer type and stage, treatments received, health status, and original (before cancer and chemotherapy) sources for chemotherapy information. The Chemotherapy Follow-up Questionnaire (CFQ) provided the data related to social support, information, and adherence (see Appendix D).

Chemotherapy Expectancy Scale (CES)

The CES, a semantic differential, was developed to measure the expectancy (about chemotherapy) that the cancer patient had before the actual treatments were started. Items for the scale were derived from a review of the literature, from the researcher's clinical experience with cancer patients, and personal experience of having had chemotherapy. Beginning reliability and validity were established by a pilot study during the spring of 1988. A second pilot to examine the

psychometric properties of the instrument was completed in March, 1990. All participants in Pilot II had a diagnosis of cancer. Most of the sample had actually received chemotherapy.

The origin of the semantic differential began with research on synesthesia or the role of form in visual responses to music (Osgood & Suci, 1969). These investigators found that polar opposites, for example high-low, loud-soft, and hot-cold, described and gave meaning to visual response to musical stimulus. A semantic differential is a series of scales (with five to nine steps) anchored on the extremes by bipolar adjectives (Waltz, Strickland, & Lenz, 1984). According to Nunnally (1970), adjectives are a plausible method for measuring various facets of meaning because they are the major means by which characteristics of real things are described. Nunnally (1970) stated that Osgood and associates had identified the three major factors--evaluation, potency, and activity--that are most frequently found with factor analysis of semantic differential scales. The evaluative factor is the strongest and often very little common variance remains for defining other factors. Nunnally (1970) cautioned that the meaning of scales frequently depends on the

concept being rated. Of the three overlapping facets of meaning (i.e., denotation, connotation, and association) the semantic differential measures mainly connotation (Nunnally, 1970).

Scoring a semantic differential is accomplished by giving the most negative response a rating of one. Each step (usually seven) is increased by 1 to the most positive response, which is rated as 7 (Burns & Grove, 1987). The scales are then summed to give a total score for each individual. Osgood, Susi, and Tannenbaum (1967) demonstrated mathematically that the semantic differential is an interval measurement scale.

The researcher-developed semantic differential was named the Cancer Chemotherapy Scale (CCS) (see Appendix E) and was composed of 37 bipolar word scales. These words were selected from a list of terms frequently associated with cancer chemotherapy. A six-step scale was employed in order to force participants to select an answer that gives an opinion (not neutral). Some authorities believe a neutral answer indicates no opinion at all and therefore should not be an option (Burns & Grove, 1987; Nunnally, 1970). Others contend that forced choices can sometimes lead to frustration and even anger to the extent that respondents refuse to complete the

scale (Burns & Grove, 1987; Kerlinger, 1973). Based on comments of participants in Pilot I and those of the expert validators, the six-step scale was changed to a seven-step scale for both Pilot II and the final study. A complete description of Pilot I is found beginning on page 94.

Chemotherapy Follow-up Questionnaire (CFQ)

A second researcher-developed instrument, the CFQ, was used to elicit findings about support, information, and adherence to the chemotherapy regimen. Although existing instruments were available for measuring each of these variables, the investigator believed that return of questionnaires would be enhanced if participants had only one form to complete. Therefore, the researcher opted to develop questions specific to the study. The CFQ contains open- and closed-ended questions. The closed-ended questions included both fixed alternative and scaled responses. The information questions sought to determine the kind of information received prior to treatments, the information giver, the amount of information given by the nurse, and overall adequacy of information as perceived by the patient. The same type of questions were asked relative to social support.

Adequacy of information and adequacy of social support were each measured on a scale of 1 to 7. For the purpose of measuring adherence, three factors were included: (a) keeping scheduled appointments, (b) having blood work and other tests, and (c) receiving the scheduled chemotherapy treatments. Answer choices for each subdivision of adherence were: (a) all of them, (b) part of them, and (c) none of them.

Comments were solicited by including a comment space with many of the questions. If appointments, tests, or treatments were missed the participant was asked to give a reason. The last question on the CFQ asked for narrative input relative to the individual's experience with the chemotherapy regimen.

Three doctoral nursing students evaluated the CFQ for content and clarity of questions. Based on comments of the panel, recommended changes were made prior to use of the instrument in Pilot II. Two fixed alternative questions were changed to open-ended questions and several wording changes were again made before the final study.

Collection of Data

The protocol used for the collection of data was:

1. After receiving the signed agency permit form (see Appendix F), a personal or telephone appointment was made with a nurse in the setting where data were collected.

2. The project and data collection were explained to individuals (data collectors) who would assist in collecting the data.

3. Two hundred research packets, printed patient criteria, verbal explanation sheets (see Appendix G), and stamped, pre-addressed envelopes for returning completed forms were mailed or hand delivered to participating agencies.

4. Research packets consisted of a cover letter (see Appendix H), the CES and demographic record with written instructions, participant address sheet (see Appendix I), and two stamped pre-addressed envelopes.

5. Packets were distributed to patients on or before the day of their first chemotherapy treatment by data collectors.

6. Participants completed the CES and demographic sheet, sealed them in one of the two envelopes, and returned them to a data collector, or mailed them directly to a major investigator.

7. Address sheets were returned separately in the second envelope given to the participants.

8. Collection of completed forms continued for 23 months. Forty-six completed CES forms were obtained during this time.

9. Three to six months after each CES was completed, the CFQ, with cover letter (see Appendix J) and a stamped self-addressed envelope was mailed to participants who returned the address sheet or had placed a return address on the first envelope. Twenty-four of the original 46 participants also returned the CFQ.

Pilot Studies

Pilot I

The first pilot was conducted to determine the reliability and validity of the researcher-developed instrument for measuring expectancy. Four groups participated in Pilot I including: (a) 23 junior-level nursing students enrolled in a southern university, (b) 35 women of a Methodist church group in Colorado, (c) 16 members of a cancer support group in Colorado, and (d) 29 employees of a regional hospital in central Texas. A total of 104 individuals completed the CCS. One form

was discarded because fewer than half of the scales were checked. On the remaining forms an occasional scale, in no discernible pattern, was left blank. For the purpose of computing the reliability and factor analysis, a score of 3 was used for the blanks.

In addition to the expectancy scale the CCS also contained a demographic section and several questions related to support during chemotherapy treatments. Participants were asked whether or not they had ever had cancer chemotherapy and if so, who was their greatest source of support. For those that had not had chemotherapy, they were asked to identify who had given the most support to a family member or friend who had received cancer chemotherapy. All participants were asked to describe, in their own words, their feelings about chemotherapy.

The investigator explained, distributed, and collected the CCS in the student group. Questionnaires for the remaining participants were distributed and collected by two master's prepared professional nurses. Verbal instructions (see Appendix K) were read to the participants and a cover letter (see Appendix L) was included with each questionnaire. The instructions explained the purpose of the study and guaranteed

confidentiality for the participants. In order to utilize test-retest as one means for establishing reliability, the questionnaires were coded. This was also explained verbally and in the letter. Three to four weeks after completion of the CCS, 58 of the original participants completed the scale a second time.

Of 103 participants who completed the CCS one time, 84 were female, ages ranged from 20 to 72, 15 had been diagnosed as having some form of cancer, nine had received chemotherapy. In the group ($n = 58$) that repeated the CCS, 54 were female with the same age range, 20 to 72 years. The most frequently listed support person for those who had received chemotherapy was their spouse; one stated the doctor. For those who answered the question on the basis of their experience with a family member or friend, the support person(s) mentioned most frequently was family. Other support persons listed included specific family members, friends, church, or clergy. Doctors were noted as giving support by five participants and nurses by three participants.

To help determine information sources that had influenced the participant's expectancy about cancer chemotherapy, individuals were asked to rate as first, second, and third the sources that had most influenced

their feelings about chemotherapy. Only 85 of these responses were tabulated. The wording was apparently confusing; therefore, the remaining 18 forms were either marked wrong or not marked at all. The wording was changed for the second pilot. Of the 85 participants answering this question on Pilot I, 47 (55.3%) indicated that their current feelings had been most influenced by a family member or friend who had received chemotherapy. Word-of-mouth and television were the most frequently identified second and third sources of information. Table 1 depicts the information sources identified as first most important, second most important, and third most important by number and percent of respondents answering the question.

When describing cancer chemotherapy in their own words, both positive and negative comments were made. Many of the words used for the CCS were found in the comments written by participants. See Appendix M for comments of participants.

Before a new instrument can be used in an actual study, the reliability and validity must be established for the instrument. Reliability concerns the extent to which the instrument yields consistent results with

Table 1

Three Most Important Information Sources, before Diagnosis of Cancer, that Influenced Participant's Expectancy about Chemotherapy by Number and Percent of Participants in Pilot I

<u>Source of information</u>	<u>First source</u>		<u>Second source</u>		<u>Third source</u>	
	Number of participants	Percent of participants	Number of participants	Percent of participants	Number of participants	Percent of participants
Family member had chemotherapy	47	55.3	6	7.1	5	5.9
Word-of-mouth	8	9.4	14	16.5	13	15.3
Television	7	8.2	7	8.2	16	18.8
Have had chemotherapy	7	8.2	1	1.2	0	0.0
Other sources	6	7.1	1	1.2	6	7.1
Professional books/journals	4	4.7	15	17.6	9	10.6
Doctors	3	3.5	13	15.3	12	14.1
Newspapers and magazines	2	2.4	13	15.3	13	15.3
Nurses	1	1.2	9	10.6	7	8.2
Radio	0	0.0	2	2.4	0	0.0

n = 85

repeated measurement of the same phenomenon (Carmines & Zeller, 1979).

Wilson (1985) described the following methods for establishing reliability of a research instrument: (a) test-retest or administering the instrument to the same individuals on two or more occasions, (b) parallel-forms or alternate forms, (i.e., when equivalent forms of an instrument are administered), and (c) determination of internal consistency. Polit and Hungler (1985) specified the internal consistency approach for reliability testing as the most widely used, and recommended Kuder-Richardson-20 or Cronbach's alpha coefficient as the methods of choice. Carmines and Zeller (1979) recommended that as a general rule alpha should not be below .80; however, they pointed out that this number may vary depending on the situation. Burns and Grove (1987) contended that an alpha between .80 and .90 reflects an instrument with better discrimination in levels of the construct than an alpha that is greater than .90.

The Pearson product-moment correlation coefficient was used to determine the test-retest reliability for the CCS. Pearson r for the test-retest was .72. Cronbach's alpha coefficient for the total scores on the CCS was .93.

Burns and Grove (1987) stated that validity determines if an instrument actually measures the concept it purports to measure. As with reliability, one validates an instrument for the situation in which it is being used. Burns and Grove (1987) described three primary types of validity: (a) content validity, (b) predictive validity, and (c) construct validity.

A panel of four experts from various areas in the United States reviewed the CCS for content validity. Three validators were doctorally prepared. The remaining panel member had a master's degree. All were experienced in clinical practice and/or research with cancer patients. Each expert received a written overview and model of the conceptual framework for the study. Using a researcher-developed form (see Appendix N), panel members rated each word pair as (a) very relevant, (b) quite relevant, (c) slightly relevant, or (d) not relevant to expectancy as related to chemotherapy. One panel member also had a psychiatric clinical nurse specialist peruse the instrument relative to psychosocial overtones. Participants in Pilot I provided input on clarity and ease in using the instrument.

One method used for organizing items into clusters on a measurement tool is factor analysis. Factor analysis

groups items together that have a high correlation with other items in the group and is one method for establishing construct validity for the instrument (Munro, Visintainer, & Page, 1986). In fact, according to Munro et al. (1986) factor analysis is the "most important statistical tool for validating the structure of our instruments" (p. 268).

Burns and Grove (1987) stated that factor analysis is especially useful during the process of developing a new instrument that measures attitudes, beliefs, opinions, or other psychological variables. Exploratory factor analysis which is similar to stepwise regression, partials out the variance for the first factor prior to analysis of the second factor, then for the second factor before the third factor, and so on until all factors are identified. Factor analysis tends to be sample specific and is not absolute in the organization of items (Burns, 1984). Burns (1984) further stated there are usually several different mathematically correct item organizations so researcher judgement is required at various points in the development of factors. However, greater consistency in the number of factors and items appearing on the factors is indicative of a more powerful instrument (Burns, 1984).

A principal component factor analysis with varimax rotation was performed to examine relationships among the individual items of the CCS. From the 37 scales, eight factors were identified that accounted for 66% of the total variance. Thirteen items loaded (at .56 or above) on Factor 1, and accounted for 32% of the variance. Factor 2, with 10 items (loading at .4 or higher), accounted for an additional 11% of the variance. Each of the remaining six factors contained one to four items. Several items loaded (at .4 or higher) on more than one factor. Table 2 shows the amount of variance accounted for by the factors on Pilot I, and Table 3 gives factor loadings for each item on the CCS.

Based on the report of the validators and the statistical findings, the following revisions were made on the CCS:

1. The name of the instrument was changed to Chemotherapy Expectancy Scale.
2. The original 37 items were reduced to 20.
3. The six-step scale format was changed to a seven-step format.
4. For clarification, several changes were made on the demographic section.

Table 2

Variance Accounted for by Factors of the CCS on PilotI

	Eigenvalue	Percent of the variance	Cumulative percentage
Factor 1	11.76	31.8	31.8
Factor 2	4.19	11.3	43.1
Factor 3	1.90	5.1	48.2
Factor 4	1.75	4.7	53.0
Factor 5	1.39	3.8	56.7
Factor 6	1.24	3.4	60.1
Factor 7	1.13	3.1	63.2
Factor 8	1.08	2.9	66.1

N = 103

Table 3

Principal Component, Varimax Rotated Factor Loadings
for the CCS on Pilot I

Item	<u>Factor Loadings</u>							
	1	2	3	4	5	6	7	8
2	<u>.83</u>							
5	<u>.83</u>							
3	<u>.81</u>							
1	<u>.78</u>							
20	<u>.76</u>							
13	<u>.76</u>							
30	<u>.75</u>							
23	<u>.71</u>							
14	<u>.69</u>							
4	<u>.67</u>							
9	<u>.66</u>	.46						
15	<u>.56</u>		.43					
32	<u>.56</u>							
19		<u>.80</u>						
16		<u>.76</u>						
18		<u>.66</u>						
27		<u>.62</u>						
24		<u>.61</u>						
36		<u>.51</u>						
26		<u>.41</u>						
29		<u>.40</u>						
8			<u>.73</u>					
7			<u>.67</u>					

(table continues)

	<u>Factor Loadings</u>							
Item	1	2	3	4	5	6	7	8
6				<u>.85</u>				
22			.41	<u>.55</u>				
28				<u>.51</u>				.42
21				<u>.44</u>				
12					<u>.70</u>			
11					<u>.69</u>			
17		.42			<u>.50</u>			
31						<u>.64</u>		
37						<u>.49</u>		
25							<u>.66</u>	
10		.41					<u>.65</u>	
34								<u>.80</u>

N = 103

All but two items (i.e., word pairs) loaded on one or more factors at .4 or above. The decision for retaining items was based on validator ratings and the factor analysis. Word pairs were selected from all but Factor 6 for the revised instrument. Nine items came from Factor 1, three from Factor 2, two each from Factors 3, 4, and 5, and the only item on Factor 8 was also retained. Using the data collected during Pilot I, for evaluating the revised instrument, the Chemotherapy Expectancy Scale had an alpha of .88.

Factor analysis of the revised instrument identified three factors which accounted for 65.7% of the variance. Factor 1 (Expectation or attitude about outcome) contained 7 items loading at .58 to .81. Factor 2 (Fear or apprehension about the treatment) had six items loading at .65 to .88, and Factor 3 (Danger or hazard of the medication) contained seven items with a loading level of .46 to .78). Table 4 depicts the variance accounted for by the three factors, the factor loadings, and the item names for the revised instrument using Pilot I data. Cronbach's alpha for each of the three new factors was: Factor 1 (.86), Factor 2 (.81), and Factor 3 (.70).

Table 4

Principal Component, Varimax Rotated Factor Loadings
for Revised Cancer Chemotherapy Scale on Pilot I

Item	<u>Factor Loadings</u>		
	1	2	3
Proven--Unproven	<u>.81</u>		
Acceptable--Unacceptable	<u>.81</u>		
Helpful--Harmful	<u>.79</u>		
Successful--Unsuccessful	<u>.79</u>		
Healthy--Unhealthy	<u>.78</u>		
Strong--Weak	<u>.59</u>	.54	
Good--Bad	<u>.59</u>		
Worthless--Valuable		.88	
Feared--Not feared		<u>.82</u>	
Hopeful--Hopeless		<u>.78</u>	
Positive--Negative		<u>.76</u>	
Wanted--Unwanted	.43	<u>.67</u>	
Painless--Painful		<u>.65</u>	
Advisable--Inadvisable			.78
Toxic--Nontoxic		-.45	<u>.75</u>
Safe--Risky	-.53		<u>.64</u>
Reliable--Doubtful		-.43	<u>.64</u>
Repairing--Damaging	.47		<u>.63</u>
Sure--Unsure			<u>.61</u>
Pleasant--Unpleasant			<u>.46</u>
Rotated eigenvalue	6.82	4.67	1.65
Percent of total variance	34.1	23.4	8.2
Cumulative percent	34.1	57.5	65.7

N = 103

Note: Minimal meaningful loading = .40, with highest
loading underlined.

Pilot II

The second pilot was conducted for further testing of psychometric properties of the Chemotherapy Expectancy Scale (CES), the adequacy of the Chemotherapy Follow-up Questionnaire (CFQ), and the feasibility of the study. All participants in Pilot II were cancer patients, many of whom had already received or were receiving chemotherapy. Cancer patients who returned one or both questionnaires included: (a) 10 patients in an oncologist's office, (b) 6 in a hospital outpatient clinic, (c) 34 from two cancer support groups, and (d) 10 from individual resources. Three individuals who were given questionnaires did not return them. The office and hospital setting were both in the same locale, a city of approximately 100,000 population in south-central United States. The support group participants resided within a metropolitan area (population-several million) in central United States or in a south-central city of approximately 65,000 population. Individual participants were from these same areas. Two participants were receiving their first treatment. All others had been on chemotherapy for at least 2 months or had concluded their chemotherapy protocol. Because participants had

already received chemotherapy, instructions for the CES varied from those for the final study in the following ways: (a) for completion of the CES, individuals were asked to think about how they felt about chemotherapy when they were first told they needed the treatments, and (b) both instruments were filled out at the same time. Otherwise there was no major difference in the directions given.

Statistics included frequency counts, reliability, and factor analysis of the CES. Frequency counts were also completed for items on the CFQ. The CES was answered by 60 participants. Of this number, 47 also completed the CFQ. All questionnaires were included in the analyses.

Demographically, the total sample was composed of 44 females and 14 males. Two participants did not indicate their gender. The vast majority (47) were Caucasian, two were Hispanic, and 11 did not answer the question. Ages ranged from 29 to 70 years. Only six participants had less than 12 years of education. Mean years of education was 14.07. The family yearly income for 12 participants was less than \$15,000, while 13 had an income of \$50,001 or more. Location of cancer included breast (27), lung (4), colon (3), blood and other nonsolid

cancers (11); three did not answer the question. Table 5 gives the demographic information for the total sample (N = 60).

Participants were again asked to identify the three sources of information that most influenced their expectancy (about chemotherapy) prior to their cancer diagnosis. Forty-eight participants answered this question; 18 (37.5%) identified doctors as the first source of information, and 13 (27.1%) indicated having had chemotherapy most influenced their expectancy. Only 1 (2.1%) person reported that nurses were the most important information source. Seven participants (14.6%) gave nurses as the second most important information source, and 11 (22.9%) identified nurses as the third most important information source that had influenced their expectancy about chemotherapy. Table 6 shows the information sources in rank order based on frequency and percentage of the first most important information source. Second and third choices are also listed.

Table 5

Characteristics of the Sample on Demographic Variables
by Frequencies and Percents for Chemotherapy Expectancy
Scale on Pilot II

Demographic Variable	Frequency	Percent
Gender		
Female	44	73.3
Male	14	23.3
Missing	2	3.3
Ethnicity		
White	47	78.3
Hispanic	2	3.3
Missing	11	18.3
Age - in Years		
29 - 38	9	15.0
39 - 48	14	23.3
49 - 58	18	30.0
59 - 68	14	23.3
69 - 78	3	5.0
Missing	2	3.3
Education Level		
4 years	2	3.3
6 years	1	1.7
9 years	1	1.6
10 years	1	1.7
11 years	1	1.6
12 years	12	20.0
13 - 16 years	19	31.7
17 - 20 years	9	15.0
More than 20 years	1	1.7
Missing	13	21.7

(table continues)

Demographic Variable	Frequency	Percent
Occupation*		
Higher executive, major professionals	1	1.7
Business managers, lesser professionals	11	18.3
Administrative personnel, minor professionals	5	8.3
Clerical & sales workers, technicians	12	20.0
Skilled manual employees	4	6.7
Machine operator, semi-skilled employees	3	5.0
Unskilled employees	5	8.3
Retired or Not Employed	8	13.3
Missing	11	18.3
Income		
Less than \$15,000	12	20.0
\$15,000 - \$25,000	7	11.7
\$25,001 - \$50,000	16	26.7
\$50,001 or more	13	21.6
Missing	12	20.0
Cancer Type		
Breast	27	45.0
Lung	4	6.7
Colon	3	5.0
Blood, lymph, other systemic	11	18.3
Other solid	12	20.0
Missing	3	5.0

N = 60

Note. *Occupation categorized according to Hollingshead (1957).

Table 6

Three Most Important Information Sources, before Diagnosis of Cancer, that Influenced Expectancy about Chemotherapy by Number and Percent of Participants in Pilot II

<u>Source of information</u>	<u>First source</u>		<u>Second source</u>		<u>Third source</u>	
	Number of participants	Percent of participants	Number of participants	Percent of participants	Number of participants	Percent of participants
Doctors	18	37.5	9	18.8	9	18.8
Have had chemotherapy	13	27.1	3	6.3	3	6.3
Family member had chemotherapy	11	22.9	8	16.7	2	4.2
Word-of-mouth	4	8.3	5	10.4	7	14.6
Nurses	1	2.1	7	14.6	11	22.9
Other sources	1	2.1	3	6.3	4	8.3
Professional books/ journals	0	0.0	6	12.5	2	4.2
Newspapers and magazines	0	0.0	2	4.2	4	8.3
Television	0	0.0	1	2.1	4	8.3
Radio	0	0.0	0	0.0	0	0.0

n = 48

Five factors, accounting for 69.2% of total variance, emerged from a factor analysis of the CES. The factor loading criterion was .4. Factor 1 (Outcome expectations) with eight items represented 40.1% of the variance. Factor 2 (unnamed) contained four items and accounted for 10.1% of the total variance. Factor 3 (Treatment apprehension) representing 7.2% of the total variance had three items. Factor 4 (unnamed) with two items and Factor 5 (Medication hazards) with three items accounted for 5.9% and 5.7% of the total variance. All items loaded on at least one of the five factors, with several loading on more than one factor. Table 7 shows the variance accounted for by the five factors and Table 8 gives factor loadings and item names for each individual scale on Pilot II.

Cronbach's alpha reliability for the total instrument was .91. The alpha coefficients for each factor were: Factor 1 (.90), Factor 2 (.77), Factor 3 (.66), Factor 4 (.72), and Factor 5 (.08). Several respondents had difficulty in deciding how to rate the strong--weak word pair. This pair also was the only item with a negative loading on the factor analysis. By eliminating the strong-weak scale from Factor 5, the coefficient alpha became .45. For the final study, aggressive-passive

Table 7

Variance Accounted for by Factors of the CES on PilotII

	Eigenvalue	Percent of the variance	Cumulative percentage
Factor 1	8.02	40.1	40.1
Factor 2	2.09	10.5	50.5
Factor 3	1.44	7.2	57.7
Factor 4	1.17	5.9	63.6
Factor 5	1.13	5.7	69.2

N = 60

Table 8

Principal Component, Varimax Rotated Factor Loadings
for Chemotherapy Expectancy Scale on Pilot II

Item	<u>Factor Loadings</u>				
	1	2	3	4	5
Successful--Unsuccessful	<u>.86</u>				
Proven--Unproven	<u>.84</u>				
Reliable--Unreliable	<u>.82</u>				
Worthless--Valuable	<u>.70</u>	.42			
Advisable--Inadvisable	<u>.66</u>				
Positive--Negative	<u>.55</u>	.54			
Safe--Risky	<u>.45</u>				.44
Acceptable--Unacceptable	<u>.44</u>	.41			
Good--Bad		<u>.78</u>			
Hopeful--Hopeless		<u>.71</u>			
Helpful--Harmful		<u>.56</u>		.55	
Wanted--Unwanted		<u>.54</u>	.41		
Pleasant--Unpleasant			<u>.75</u>		
Feared--Not Feared			<u>.73</u>		
Sure--Unsure	.50		<u>.57</u>		
Damages--Repairs				<u>.84</u>	
Healthy--Unhealthy	.41		.44	<u>.63</u>	
Painless--Painful					<u>.74</u>
Nontoxic--Toxic				.48	<u>.59</u>
Strong--Weak					<u>-.58</u>

N = 60

Note: Minimal meaningful loading = .40, with highest loading underlined.

was used to replace this item. This word pair was one of the original 37 items validated by the expert panel.

Of the 47 respondents to the CFQ, 83% reported receiving information about the chemotherapy regimen from the doctor, 68.1% received information from the nurse, and 19.1% also included other sources. Included in the other sources mentioned were the American Cancer Society, books and pamphlets, and others who had received chemotherapy. Participants were asked to mark all sources that applied. In answer to the question about how much information was given by the nurse(s), 44.7% marked "large amount", 36.2% "some", and 19% "little or none". The amount of information given by nurses is depicted on Table 9 by frequency and percent.

As for the actual information received, all respondents were told about the frequency of treatments. The percent of participants receiving the other types of information varied, with the fewest (66%) receiving information about how it would feel while getting the treatment. Ten participants (21.3%) also reported receiving other information not included in the list of choices. Table 10 gives the information received by number and percent of participants.

Table 9

Amount of Chemotherapy Information Received from Nurse
by Number and Percent of Participants on Pilot II

Amount of information received from nurse	Number of participants	Percent
Large amount	21	44.7
Some	17	36.2
Little or none	9	19.1

n = 47

Table 10

Information Received about the Chemotherapy Regimen
by Number and Percent of Participants on Pilot II

Information received	Number of participants	Percent
Frequency of treatment	47	100.0
How treatment given	44	93.6
Blood work, other required tests	42	89.4
Side effects of medicine	41	87.2
What treatments expected to accomplish	38	80.9
Length of treatment	36	76.6
How to relieve side effect	32	68.1
How it feels to get treatment	31	66.0
Other information received	10	21.3

n = 47

Note: Participants were instructed to mark as many
responses as applied.

Most participants (91.5%) were encouraged to ask questions. Only two participants (4.3%) reported receiving unwanted information. On the scale of one to seven, 33 participants (70.2%) checked seven or the highest score for overall adequacy of information. The mean score was 6.19 with a standard deviation of 1.50.

The majority of the participants (70.2%) had a support person present during the treatments; however, only 28 (59.6%) reported that this was encouraged. The support person most frequently present was the spouse. Table 11 shows the support person present, with number and percent of participants. Of those who did not have someone with them, only two indicated that they would have liked to have someone present. The support activity "just sat with me" was checked by the greatest number (20) of participants. Table 12 gives the support activities indicated as most helpful by number and percent of participants.

Fifty-three percent of the participants felt they received a "large amount" of support from the nurse(s); however, 7 (14.9%) reported receiving "little or none" (see Table 13). Most helpful nursing actions included explanations, frequent checking, treated me as an intelligent person, and caring attitude. Nursing actions

Table 11

Support Person Present during Chemotherapy Treatment
by Number and Percent of Participants on Pilot II

Support person	Number of participants	Percent
Spouse	33	70.2
Daughter	8	17.0
Friend	8	17.0
Other	7	14.9

n = 47

Note: Some participants gave more than one support person.

Table 12

Most Helpful Support Activity Reported by Participants
by Number and Percent of Participants on Pilot II

Support activity	Number of participants	Percent
Just sat with me	20	42.6
Talked to me	14	29.8
Listened	7	14.9
Held my hand	5	10.6
Other	9	19.1

n = 47

Note: Some participants gave more than one activity.

Table 13

Support Received from Nurse during Chemotherapy Regimen
as Reported by Number and Percent of Participants on
Pilot II

Amount of support received from nurse	Number of participants	Percent
Large amount	25	53.2
Some	13	27.7
Little or none	7	14.9
Missing	2	4.3

n = 47

that were identified as least helpful included hurrying in and out, not checking enough, having to wait for treatment, multisticks, and giving too few explanations. On a scale of one to seven, 61.7% of the participants scored seven, the highest possible score, for overall adequacy of support ($M = 6.33$, $SD = 1.17$).

Overall reported adherence was 80.9%, with 9 (19.1%) participants missing one or more parts of the total regimen. However, five participants did not answer one or more of the adherence questions. Six Six participants (12.8%) reported missing treatments; four did not answer the question. Two participants (4.3%) missed lab work or other tests and three participants (6.4%) missed keeping scheduled appointments. Reasons given for missing treatments included complications such as pneumonia, and blood count too low. Two participants reported they quit because they didn't think they [treatments] helped. One stated "my cancer is terminal," and the other participant wrote "It kept me totally exhausted all of the time." Several individuals who reported missing part(s) of the regimen did not indicate why. Two participants made comments about why they completed the regimen as required. The comments were:

"Simple, it was my only chance for survival."

"I don't want to be a coward!"

The Pearson product-moment correlation was used to examine relationships between adherence and each of the variables support, information, and expectancy. There was a weak, significant ($r = .27$, $p < .05$) positive correlation between expectancy and adherence. No relationships were shown between adherence and the variables perceived adequacy of support and perceived adequacy of information. Pearson r for adherence with perceived adequacy of support was $.02$ ($p = .44$), and with perceived adequacy of information $-.002$ ($p = .50$). Table 14 gives the correlation matrix for the four variables support, information, expectancy, and adherence.

Table 14

Correlation Matrix of Variables Support, Information, Expectancy, and Adherence on Pilot II

	Support	Information	Expectancy	Adherence
Support	1.00			
Information	.54**	1.00		
Expectancy	.06	.35**	1.00	
Adherence	.02	-.002	.27	1.00

* = $p < .05$, ** = $p < .01$ (1-tailed)

Pearson r was used to test for relationships between adherence and selected demographic characteristics. The only correlation at a significant level was age, which had an inverse relationship with adherence ($r = -.35$, $p < .05$). See Table 15 for correlation matrix of demographic variables with adherence.

Table 15

Correlation Matrix of Demographic Variables with Adherence on Pilot II

	Adherence	Age	Gender	Income	Health	Education
Adherence	1.00					
Age	-.35*	1.00				
Gender	-.04	-.03	1.00			
Income	.20	-.18	-.01	1.00		
Health	.21	-.34*	.18	.16	1.00	
Education	.13	-.01	.31*	.40*	-.02	1.00
* $p < .05$ ** $p < .01$ (2-tailed)						

Stepwise multiple regression analysis was run with adherence as the dependent variables with support, information, expectancy, and the demographic characteristics for the independent variables. Expectancy entered on the first step using .10 significance, and age entered on the first step using .05 significance

level. The amount of variance accounted for was $\underline{R}^2 < 1\%$ for expectancy, and $\underline{R}^2 = 1\%$ for age; therefore, neither variable was a significant predictor of adherence.

Thirty-six participants answered the last question which asked them to describe their feelings about the chemotherapy experience. Each phrase or statement within the comments was analyzed for feeling tone and coded as negative, positive, or mixed. Most participants expressed one or more of the feeling tones in their comments. Overall there were 61 negative, 57 positive, and 32 mixed feeling tones identified. See Appendix O for Pilot II participant comments.

Treatment of Data

Inferential and descriptive statistical procedures were used for analysis of the data. All data for both pilots and the final study were analyzed using the Statistical Package for the Social Sciences (SPSS-X) (Norusis, 1988). Statistical procedures were selected based on the research hypotheses, research questions, and the collected data.

The hypotheses for the study were:

1. Among adult cancer patients the greater the perceived adequacy of support the greater the adherence to a prescribed chemotherapy regimen.

2. Among adult cancer patients the greater the perceived adequacy of information the greater the adherence to a prescribed chemotherapy regimen.

3. Among adult cancer patients the greater the expectancy of a positive outcome the greater the adherence to a prescribed chemotherapy regimen.

Each hypothesis, for the study, was tested using the Pearson product-moment correlation coefficient (r). The Pearson r is the most commonly used method to measure the relationship between two variables (Munro et al., 1986). According to Munro et al. this statistic determines relationships and their direction but should not be used to infer cause.

In addition to the hypotheses, the following research questions were evaluated:

1. From the cancer patient's perception, how much support is given by the nurse during the chemotherapy regimen.

2. From the cancer patient's perception, how adequate is the overall support received during the chemotherapy regimen?

3. From the cancer patient's perception how much information relative to the chemotherapy regimen is given by the nurse?

4. From the cancer patient's perception how adequate is the overall information received regarding the chemotherapy regimen.

5. What personal characteristics are related to the patient's adherence to the chemotherapy regimen?

The relationships between selected personal characteristics and the concept of adherence were tested by use of Pearson product-moment correlation. Multiple regression analysis was used to assess the effects of the independent variables--social support, information, expectancy, and selected personal characteristics--on the dependent variable, adherence. This technique determines the effects of one predictor variable while controlling for the effects of other independent variables. Personal characteristics examined in relation to adherence were age, gender, education, economic status, cancer stage, and health status.

Polit and Hungler (1985) pointed out that reliability is neither a fixed entity nor a property of the instrument alone. Reliability, Polit and Hungler continued, is a characteristic of the instrument when administered

to a certain sample under certain conditions so it must be calculated for each situation. Also, the psychometric properties of a newly developed instrument need continuing evaluation; therefore, the reliability for the CES was determined using Cronbach's alpha.

A factor analysis was performed to determine the items in each factor and to assist in evaluating construct validity of the CES. Factors were named based on their item content. Reliability for each factor was determined.

Descriptive statistics categorize and summarize demographic and other data, thereby reducing it to a manageable size and making it more meaningful (Munro et al., 1986). Characteristics of the sample were reported using frequencies and appropriate measures for variance. Content analysis provided the methodology for summarizing, classifying, and tabulating responses to the last open-ended questions on the CFQ.

CHAPTER IV

ANALYSIS OF DATA

This chapter presents the results of the data analysis for the study. The response rate and difficulties that arose during data collection are described. Descriptive characteristics of the participants are presented. Reliability and validity of the CES, the results of hypothesis testing, and the answers to research questions are reviewed in relation to the collected data. Findings of the study are summarized.

Description of the Sample

The research design delimited the study sample to adult cancer patients, 18 years of age or older, who were starting a chemotherapy regimen on an outpatient basis. The projected sample size for the study was 60 participants to be obtained in one southern state. Six medical centers and four oncologists' offices were contacted and asked to participate in the study. Of this number, two medical centers and three offices agreed

to collect data for the study. Based on the usual number of patients treated in the agencies, the researcher believed that the desired number of participants could be obtained from these five sites.

After discussing the purpose of the study and the data that were needed, all but one of the agencies elected to have their own personnel hand-out and collect the questionnaires. The general feeling was that an outsider might add to the stress of an already stressful situation. In the one remaining agency, arrangements were made for a doctorally-prepared nurse (living in that community) to be called when a patient agreed to participate in the study. All other data collectors were oncology nurse specialists who worked with cancer patients. Instructions for collecting the data were given to each of the data collectors verbally and in writing. The researcher requested that each data collector keep a record of the number of patients approached, the number of refusals, and the reasons for refusal. All verbalized an understanding of the study and a commitment to collecting the data.

Data for the study were collected from the above agencies for 10 months; however, during this time period only 16 of the CES and 6 of the CFQ had been returned.

At that time, it appeared that additional collection sites were needed. The researcher then received permission from a group of five oncologists in a western state to collect data in their office complex. Even though the researcher requested permission to collect the data herself, the agency preferred to have their own nurses do this. One nurse was identified as the main data collector. As before, both written and verbal instructions were given to this nurse by the main investigator.

At the western site, chemotherapy information packets were given routinely to each new chemotherapy patient. The oncology nurse reviewed the printed information with the patients when it was given to them. During the time that data were collected at this agency, the CES, cover letter, return envelope (stamped and addressed), and address sheet with an additional stamped, addressed envelope were included in the information packet. The study was explained to the patients when they received the information packet and they were invited to participate in the study. Data were collected for 13 months during the second data collection time period. In addition to the western site, two of the original agencies continued to collect data during this time.

In order to maintain confidentiality of participants, the address sheets were returned separately to the researcher. Between 3 to 6 months after completing the CES the second questionnaire (CFQ) was mailed to each participant for whom an address was available. Twenty-seven CFQs were mailed and 17 were returned for a return rate of 62.96% for this mailing. One individual had not received the expected chemotherapy treatments; therefore, a blank form was returned.

Throughout the entire data collection period, the researcher periodically, either by phone or in writing, contacted the various data collectors. Approximately 200 research packets were distributed among the agencies. After a total of 23 months of data collection, 46 of the CES and 17 of the CFQ had been collected. At that time the decision was made to end the study and report the findings on the available data. A summary form (Appendix P) was sent to each data collector to determine the number of questionnaires actually given to patients, the number of persons who had refused to participate in the study, and reasons given for the refusal. Two forms were completed and returned to the researcher. Of the patients who were asked to participate in the study at those sites, only one had refused to complete

the CES; however, not all patients were asked. One of the data collectors stated that she did not approach patients if "there was a definite concern that they might not do the study." The number of patients not asked to participate in the study was unavailable. Although the summary form was not returned, additional patient address forms were received from the western site. Twenty-one more CFQs were then mailed to participants. Two were returned due to wrong address, two individuals had passed away, and 10 completed CFQs were received for a return rate of 66.7%. Two of the completed questionnaires could not be used as they could not be matched with one of the first questionnaires, the CES. A total of 24 CFQs were used for the statistical analyses.

Demographics

The age range for the 28 females and 18 males who completed the CES was 20 to 85 years. The mean age was 56 (SD = 14.78) years. Thirty-nine participants, representing 84.9% of the sample were White, 6 (13%) were Black, and one answer was missing in this category.

The education level of participants ranged from 2 to 19 years. The average years of education was 13.2 (SD = 3.04) years. Of the 46 participants, 33 (71.7%)

were employed, 9 (19.6%) were retired or unemployed, 1 (2.2%) was a college student, and 3 answers were missing in this category. Six participants indicated that the family income was less than \$15,000 per year, while 12 gave their yearly incomes as more than \$50,001.

Over half (24) of the participants who answered the CES also returned the CFQ. There were 13 females and 11 males in this group, all were White. The average age for participants returning the CFQ was 56 years; their average level of education was 14 years. Demographics for both the CES and the CFQ are shown on Table 16.

Table 16

Characteristics of Participants Completing the CES and
CFQ by Frequency and Percent

Variable	<u>CES</u> Frequency	%	<u>CFQ</u> Frequency	%
Gender				
Female	28	60.8	13	54.2
Male	18	39.1	11	45.8
Ethnicity				
White	39	86.7	24	100.0
Black	6	13.0	--	---
Missing	1	2.2	--	---
Age in years				
20 - 29	2	4.4	2	8.3
30 - 39	5	10.8	1	4.2
40 - 49	8	17.4	4	16.7
50 - 59	6	13.0	5	20.8
60 - 69	16	34.7	8	33.3
70 or over	8	17.4	4	16.7
Missing	1	2.2	--	---
Education level				
2 years	1	2.2	--	---
10 years	4	8.7	1	4.2
11 years	3	6.5	3	12.5
12 years	16	34.8	6	25.0
13 - 16 years	14	30.5	9	37.5
17 - 19 years	7	15.1	5	20.8
Missing	1	2.2	--	---

(table continues)

Variable	<u>CES</u>		<u>CFQ</u>	
	Frequency	%	Frequency	%
Highest degree earned				
Master's	5	10.9	4	16.7
Baccalaureate	6	13.0	5	20.8
Associate	1	2.2	--	---
No degree	32	69.6	14	58.3
Missing	2	4.3	1	4.2
Occupation*				
Business managers, lesser professionals	7	15.2	5	20.8
Administrative personnel, minor professionals	12	26.1	5	20.8
Clerical & sales workers, technicians	9	19.6	4	16.7
Skilled manual employees	4	8.7	1	4.2
Machine operator, semi-skilled employees	1	2.2	--	---
Retired or Not				
Employed	9	19.6	6	25.0
College student	1	2.2	1	4.2
Missing	3	6.5	2	8.3
Income				
Less than \$15,000	6	13.0	2	8.3
\$15,001 - \$25,000	15	32.6	3	12.5
\$25,001 - \$50,000	9	19.6	8	33.3
\$50,001 or more	12	26.1	10	41.7
Missing	4	8.7	1	4.2
State				
Southern	17	36.9	9	37.5
Western	29	63.1	15	62.5

N = 46 on CES; n = 24 on CFQ

Note. *Occupation categorized according to Hollingshead (1957).

The participants were asked to specify the type of cancer they had, the stage of the cancer, and what they perceived as their present health status. Breast cancer was the most frequent (41.3%) diagnosis given. Nine other types of cancer were included in the sample. Twelve (26.1%) participants did not give the stage of the cancer. It is possible they did not know the stage since this information is not always discussed with each individual who has cancer. Nine patients reported they were in excellent health, 28 gave their health as good. Only one person reported having poor health. Table 17 displays information concerning the type of cancer, stage of cancer, and perceived health status for all participants ($N = 46$) returning the CES; and for those who also answered the CFQ ($n = 24$).

The question that asked participants to give the three most important influences on their expectancy about chemotherapy (before the actual experience) resulted in the data given in Table 18. Doctors were identified as the most important influence by 17 (40.5%) of participants who answered the question. Only two (4.8%) participants reported nurses as being the most important influence; however, 9 (21.4%) gave nurses as the second most important influence. Four participants did not answer the question.

Table 17

Cancer Type, Cancer Stage, and Perceived Health Status
of Participants by Frequency and Percent

Variable	<u>CES</u> Frequency	%	<u>CFQ</u> Frequency	%
Cancer Type				
Breast	19	41.3	10	41.7
Colon	7	15.2	4	16.7
Lymphoma, Hodgkins	3	6.5	3	12.5
Lung	2	4.3	--	---
Esophageal, stomach	2	4.3	2	8.3
Prostate	2	4.3	2	8.3
Leukemias	2	4.3	1	4.2
Uterus, other female organs	2	4.3	--	---
Karposi's	1	2.2	--	---
Liver or pancreas	1	2.2	--	---
Missing	5	10.9	2	8.3
Cancer Stage				
Stage I	9	19.6	2	8.3
Stage II	13	28.3	8	33.3
Stage III	8	17.4	4	16.7
Stage IV	4	8.7	4	16.7
Missing	12	26.1	6	25.0
Perceived Health Status				
Excellent	9	19.6	6	25.0
Good	28	60.9	13	54.2
Fair	7	25.6	4	16.7
Poor	1	2.2	1	4.2
Missing	1	2.2	--	---

N = 46 on CES; n = 24 on CFQ

Table 18

Three Most Important Information Sources, before Diagnosis of Cancer, that Influenced Expectancy about Chemotherapy by Number and Percent of Participants

Source of information	<u>First source</u>		<u>Second source</u>		<u>Third source</u>	
	Number of participants	Percent of participants	Number of participants	Percent of participants	Number of participants	Percent of participants
Doctors	17	40.5	5	11.9	8	19.5
Friend had chemotherapy	7	16.7	4	9.5	3	7.1
Family member had chemotherapy	6	14.3	3	7.1	1	2.4
Television	4	9.5	5	11.9	2	4.8
Nurses	2	4.8	9	21.4	3	7.1
Newspapers and magazines	2	4.8	7	16.7	5	11.9
Word-of-mouth	1	2.4	3	7.1	12	28.6
Professional books/journals	1	2.4	2	4.8	3	7.1
Other sources	1	2.4	1	2.4	1	2.4
Radio	1	2.4	0	0.0	0	0.0

n = 42

The CFQ, consisting of 22 open- and closed-ended questions, provided the data for the variables support, information, and adherence relative to the chemotherapy regimen. Participants were also asked to identify the cancer drugs they had received. Two individuals received only one drug; all others were treated with multiple chemotherapeutic agents. One participant's regimen included seven different medications. The most frequently used drug, 5-FU, was administered to 16 (66.7%) participants, 15 (62.25%) received adriamycin, and 14 (58.3%) participants received cytoxan. This information is summarized in Table 19. Eight participants reported receiving drugs other than those listed on the questionnaire.

Table 19

Number and Percent of Participants Receiving Each of
the Chemotherapeutic Agents

Chemotherapy Agent	Number of Participants	Percent
Fluorouracil (5-FU)	16	66.7
Adriamycin	15	62.5
Cytosan	14	58.3
Methotrexate	5	20.8
Bleomycin	4	16.7
Vincristine	4	16.7
Etoposide (VP-16)	3	12.5
Cisplatin	2	8.3
Vinblastine	2	8.3
Cytosar-U	1	4.2
Dacarbazine	1	4.2
Daunorubicin	1	4.2

n = 24

Note. Participants were instructed to include all agents received.

Findings

In this section the findings of reliability and factor analysis for the researcher-developed CES are described. The three hypotheses and five research questions are discussed in relation to the statistical analysis of each.

Reliability

Cronbach's alpha was used to measure the reliability of the CES. Results of this test showed that the instrument had high internal consistency. For the total semantic differential scale (20 items), Cronbach's alpha was .91. This finding was in keeping with those obtained on both Pilot I (alpha = .93) and Pilot II (alpha = .91). The revised instrument (Pilot I) yielded an alpha of .88. Table 20 compares the alphas, number of scale items, and sample sizes for each reliability testing of the CES. Results of test-retest reliability completed during Pilot I for a sample size of 58 was .72.

Table 20

Comparison of Cronbach's Alpha for the CES on Pilot I,
Pilot I (revised), Pilot II, and Final Study

	Number of items	Sample size	Cronbach's alpha
Pilot I (original)	37	103	.93
Pilot I (revised)	20	103	.88
Pilot II	20	60	.91
Final study	20	46	.91

The reliability for each of the five factors extracted on the CES ranged from .29 for Factor 5 with 3 items to .89 for Factor 2 having 5 items. Cronbach's alpha for the other factors was as follows: Factor 1 with 5 items, alpha = .86; Factor 3 with 4 items, alpha = .82; and Factor 4 with 3 items, alpha = .71. If either Item 19 or 16 was eliminated from Factor 5, the alpha was raised considerably. Eliminating Item 19 yielded an alpha of .72, and if Item 16 was eliminated the alpha was -.74.

Validity

During Pilot I, items used on the CES were evaluated by a panel of experts for content validity. Construct validity was examined by factor analysis in both Pilot I and Pilot II. Burns and Grove (1987) stated that establishing construct validity of a research instrument may take years of work, and the input of many scientists. The measurement of choice for evaluating construct validity is factor analysis (Munro et al., 1986).

Exploratory factor analysis was used to examine construct validity of the CES. Hair et al. (1987) described two basic models (common and component) of factor analysis. Common factor analysis is based only on common variance. Component factor analysis, also known as principle component factor analysis, considers the total variance including specific variance, common variance, and error variance to arrive at the underlying factor structure (Hair et al., 1987). If the purpose of the factor analysis is to determine the minimum number of factors needed to account for the maximum amount of variance they represent in the original set of variables, the appropriate model to use is component analysis (Hair et al., 1987). Principle component factor analysis was

used to examine the CES. This resulted in five factors that accounted for 74.2% of the variance.

The next step in factor analysis is the mathematical transformation (rotation of factors) into more meaningful clusters. This allows for easier interpretation of the factors. The two most frequently used methods of factor extraction are oblique (nonorthogonal) and varimax (orthogonal). The number of factors to extract is most frequently based on the latent root criterion and was used for the CES. When principal component analysis is used, only factors with eigenvalues (latent roots) greater than 1 are considered significant (Hair et al., 1987).

Both oblique and varimax rotation of factors were conducted for the CES. Hair et al. (1987) stated that varimax rotation identifies factors that are mathematically independent and is a must when the factors are to be used for subsequent statistical analysis. On the other hand, oblique factor rotation represents a more accurate and theoretically meaningful clustering of factors because the underlying dimensions are not assumed to be uncorrelated. Nunnally (1978) recommended that varimax rotation be used with exploratory factor analysis and Munro et al. (1987) specified varimax

rotation for instrument development. Hair et al. (1986) asserted that for sample sizes with less than 100 members, the lowest factor loading that could be considered significant would be .30. For the study, .40 was selected as the factor loading cutoff. If items loaded on more than one factor, the highest loading was selected.

Oblique rotation of the CES identified five factors which are displayed in Table 21. With this rotation, Factor 1 correlated significantly with Factor 4 and Factor 5. Factor 4 correlated significantly with Factor 5 (see Table 22).

Table 21

Principal Component, Oblique Rotated Factor Loadings
for Chemotherapy Expectancy Scale

Item	<u>Factor loadings</u>				
	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
20	<u>.87</u>				
1	<u>.69</u>				
5	<u>.62</u>				
18	<u>.57</u>				.41
13	<u>.49</u>				
10		<u>.77</u>			
19		<u>-.70</u>			
16		<u>.42</u>			
9			<u>.81</u>		
14			<u>.73</u>		
12	.50		<u>.52</u>		
2				<u>-.87</u>	
8				<u>-.76</u>	
6				<u>-.64</u>	
17				<u>-.55</u>	
15					<u>.98</u>
7					<u>.79</u>
3					<u>.67</u>
4					<u>.58</u>
11					<u>.44</u>

N = 46

Note: Minimal meaningful loading + .40, with highest loading underlined.

Table 22

Correlation Matrix for Oblique Rotation of CES

	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
Factor 1	1.00				
Factor 2	.02	1.00			
Factor 3	.19	.08	1.00		
Factor 4	-.35	-.02	-.20	1.00	
Factor 5	.47	-.12	.21	-.36	1.00

Note: Correlations rounded off to two decimal places.

Five factors were also identified with varimax rotation. Items that clustered together were the same as with oblique rotation; however, factor loadings and the factors on which items loaded differed. Factor 1 was the same with both rotations. Factor 2 for oblique loaded on Factor 5 with varimax rotation. Factor 3 for oblique rotation was Factor 4 with varimax rotation, and Factor 4 was Factor 3. Factor 5 on oblique rotation became Factor 2 with varimax rotation. Table 23 gives groupings and factor loadings for varimax rotation of the CES. The variance accounted for by each factor is included.

Table 23

Principal component, Varimax Rotated Factor Loadings
for Chemotherapy Expectancy Scale

Item.	<u>Factor loadings</u>				
	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
20	<u>.82</u>				
1	<u>.71</u>				
5	<u>.69</u>				
18	<u>.63</u>	.46			
13	<u>.60</u>				
15		<u>.86</u>			
7		<u>.78</u>			
3		<u>.68</u>			
4	.42	<u>.64</u>	.43		
11	.48	<u>.56</u>	.42		
2			<u>.81</u>		
8			<u>.78</u>		
6	.47		<u>.69</u>		
17	.49		<u>.61</u>		
9				<u>.81</u>	
14				<u>.75</u>	
12	.51			<u>.56</u>	
10					<u>.79</u>
19					<u>-.68</u>
16					<u>.46</u>
Rotated eigenvalue		8.75	2.18	1.47	1.37
Percent of total variance		43.8	10.9	7.4	6.9
Cumulative percent		43.8	54.6	62.0	68.9

N = 46

Note: Minimal meaningful loading = .40, with highest
loading underlined.

Hypotheses

The hypotheses were:

1. Among adult cancer patients the greater the perceived adequacy of support the greater the adherence to a prescribed chemotherapy regimen.

2. Among adult cancer patients the greater the perceived adequacy of information the greater the adherence to a prescribed chemotherapy regimen.

3. Among adult cancer patients the greater the expectancy the greater the adherence to a prescribed chemotherapy regimen.

Analysis of the three adherence questions showed the sample to be totally adherent to all parts of the chemotherapy regimen; therefore, relationships could not be tested. Table 24 shows the correlation matrix for support, information, expectancy, and adherence. Although two patients missed having their treatments on the scheduled date, it was only because of a low blood count and the treatments were received later. One person missed a scheduled lab work-up and one missed an appointment but both reported being hospitalized at the time. Two participants were no longer receiving chemotherapy because they had completed all scheduled treatments.

Table 24

Correlation Matrix of the Variables Support, Information, Expectancy, and Adherence

	Support	Information	Expectancy	Adherence
Support	1.00			
Information	.87**	1.00		
Expectancy	.15	.16	1.00	
Adherence	" "	" "	" "	" "

* = $p < .05$. ** = $p < .01$ (1-tailed)

Note: " " indicates coefficient could not be computed.

Research Questions

In addition to the hypotheses, participant responses to five research questions were solicited. The research questions were:

1. From the cancer patient's perception, how much support is given by the nurse during the chemotherapy regimen?

2. From the cancer patient's perception, how adequate is the overall support received during the chemotherapy regimen?

3. From the cancer patient's perception, how much information relative to the chemotherapy regimen is given by the nurse?

4. From the cancer patient's perception, how adequate is the overall information received regarding the chemotherapy regimen?

5. What personal characteristics are related to the patient's adherence to the chemotherapy regimen?

There were nine questions on the CFQ designed to gain input from participants about support received during the chemotherapy regimen. The questions sought information about adequacy of support, amount of support given by the nurse, what support was helpful, and what support was not helpful. Eight questions on the CFQ procured the same type information relative to the information that participants received about the chemotherapy regimen.

Analysis of the first four research questions included appropriate frequency counts, central tendency and variance measures. Pearson r and multiple regression could not be employed to check for relationships between selected demographic variables (age, gender, education, income, perceived health status, cancer stage) and adherence because reported adherence was 100% for the

sample. Other findings relative to the analyses are reported in this section.

When asked about nurses' support during the chemotherapy regimen, most participants (19 [79.2%]) reported they received a large amount of support from the nurses; six patients indicated they had received some. The overall score for this question was 2.8, the maximum score possible was 3.

One open-ended question asked was "What did the nurse(s) do that was most helpful for you during the treatments?" Examples of helpful nursing actions or attitudes included:

". . . reassurance that things were going as expected."

". . . talked to me, answered any questions, is very nice."

". . . let me know that if I became ill after treatments to always call and they would be there for me."

". . . cheerful."

". . . encouragement."

". . . friendly and caring, made you feel good."

". . . checking on me [to see] if I was ok
. . . checking on equipment and delivery of the chemo
treatment."

". . . try to make me comfortable."

"Explained what was going into the IV at the time
and how long it would run."

"Kept a positive, uplifting, happy attitude."

"Was very compassionate, positive and congenial
attitude."

"Visiting and making sure I was comfortable."

"They became very supportive friends, encouraging
me while I was down."

"Kept checking to see if everything was ok."

A few of the participants identified nursing
activities or attitude they believed were not helpful.
The least helpful activities were:

"Not saying what she was injecting at the time
or how long it would take."

". . . not knowing how long the treatment would
last."

"Sometimes when they were in a hurry they would
hurry the push IV's and then I would not feel well."

"As an observer (wife writing this) occasionally
I felt we were just a 'job'."

The second research question examined overall adequacy of support and was evaluated on a scale of 1 to 7. A score of 7 represented maximum support; a score of 1 signified minimal support. Seventeen participants scored this question with a 7. The lowest score given was 5; mean score was 6.6, with a standard deviation of .65.

Twelve (50%) individuals reported that they were encouraged to have a support person present during the treatments. In answer to the questions asking who gave this encouragement, 3 (21.4%) of the 12 participants responding to the question said the doctor, 7 participants indicated it was the nurse, and 2 persons stated their spouse.

Fifteen participants had a support person or persons with them for all treatments, six had a support person part of the time. The most frequently identified support person present was the spouse. This answer was given by 15 individuals. Other support people mentioned included son or daughter, friend, parents, and clergy. All three individuals who did not have a support person present indicated they preferred it that way. One participant who had a support person present stated ". . . didn't need him." The support activity given most frequency was "talked to me". Table 25 summarizes the support activities participants felt were most helpful.

Table 25

Summary of Most Helpful Support Activity Reported by
Number and Percent of Participants

Support activity	Frequency	Percent
Talked to me	7	33.3
Just being there	4	19.5
Kept me occupied, made time pass faster	3	14.3
Drove me home	3	14.3
Mental support or encouragement	2	9.5
Prayer	1	4.8
Handed me things	1	4.8
Sometimes made me laugh	1	4.8

n = 21

Note: Some participants gave more than one activity.

In response to who had given information about the chemotherapy regimen, 21 (87.5%) participants indicated that the nurse gave the information; and 18 (75%) participants stated the information was given by doctors. Four participants reported other sources of information including reading material and patients who had already

had chemotherapy. More than one answer could be checked. When asked specifically about the amount of information they had received from the nurse, 20 (83.3%) replied a large amount. The maximum possible score for this question was 3; the mean score was 2.8.

All participants stated they had been encouraged to ask questions. Most frequently, according to 16 (66.7%) participants, it was the nurse who encouraged questions; 13 (54.2%) checked the doctor, and 3 left the answer blank. More than one response could be checked.

On a scale of 1 to 7, 16 (66.7%) participants checked 7 for adequacy of information, six marked 6, and two rated information received with a score of 4. The mean score for this scale was 6.5.

In replying to the question relative to actual information received before the chemotherapy treatments, all participants said they were told the side effects to expect. Twenty-two participants were told how to relieve the side effects, how long the treatments would take, as well as how the treatment would be given and the frequency. Table 26 shows information about the chemotherapy regimen that was given to patients before the treatments started.

Table 26

Information Received about the Chemotherapy Regimen by
Number and Percent of Participants

Information received	Number of participants	Percent
Side effects of medicine	24	100.0
How treatment given	22	91.7
Length of treatment	22	91.7
How to relieve side effects	22	91.7
Frequency of treatment	22	91.7
Blood work, other required tests	21	87.5
What treatments expected to accomplish	18	75.0
How it feels to get treatment	17	70.8
Other information received	3	12.5

n = 24

Note: Participants were instructed to mark as many
responses as applied.

Participants were asked what additional information they would have liked to have known about the chemotherapy treatments. Answers to this question included:

"That it makes your arms so lifeless, and you feel so tired the first few days."

"Was this dose a 'large dose', a 'strong dose', and was this drug the best that I could have received?"

"More information on lab tests especially the 'cancer tests' and what they were looking for and what my results were. . . . not just 'you're doing fine', 'everything is normal', 'normal--what is expected?', . . ."

"How long after receiving treatment the side effects would begin (4-5 hours), how long they would last (24-36 hours)".

"How chemo affects the emotions too."

"How long the treatments last."

When asked if unwanted information was given, only two participants responded "yes." Both participants stated that the pamphlets on each drug gave too much negative info for a newly diagnosed patient. One further stated ". . . it was difficult to reconcile the fact that the drugs I was taking to reduce or eliminate my tumor could also kill me!"

Additional Findings

Polit and Hungler (1987) suggested one appropriate use of qualitative data would be to illustrate the meaning

of descriptions or relationships in quantitative studies. They pointed out that real excerpts from the situation can add a perspective that numbers alone do not show. To this end, the investigator asked the participants to describe the chemotherapy experience in their own words. Data from this open-ended question were analyzed using the content analysis technique. The comments of 23 participants were included in the analysis (see Appendix Q). One individual did not answer the question.

Content Analysis

According to Fox (1976) content analysis is a process for categorizing verbal or behavioral data in order to classify, summarize, and tabulate. The process is carried out at the manifest (direct transcription) or latent (underlying dynamics) level (Fox, 1976). The content analysis for the study was carried out at the manifest level following techniques suggested by Fox (1976).

First the unit selected for analysis was a phrase or statement containing one meaning. Four nurses, two doctorally-prepared and two doctoral candidates, coded each unit as having a positive, negative, or mixed feeling tone. Three coders also identified concepts within the comments and side effects mentioned by the participants.

The feeling tones were scored as 1 for negative, 2 for mixed, and 3 for positive, then averaged to determine the predominate feeling tone for each participants overall comment. To examine for relationships between the expressed feeling tone and items or factors on the expectancy scale, the Pearson r was computed. Feeling tone correlated significantly ($p < .05$) with Item 10 (nontoxic--toxic) and Factor 5 (hazards of medication) which probably reflects the negative comments relative to the side effects.

Finally, units of content were examined for semantic content and patterns or themes. The principal researcher categorized the units accordingly. The initial patterns or themes that were identified as categories all related to the chemotherapy regimen and included (a) expectation at the start, (b) side effects of drugs, (c) the actual treatment experience, (d) supportive relationships, (e) spirituality or faith, (f) emotional impact, (g) control or choices, (h) outcome of the treatments, and (i) knowledge. The investigator and one of the original coders then met to further examine the categories and placement of content within each category. In the last phase of the content analysis the researcher and coder reached a consensus on naming of categories and category

content. The three main categories were (a) prior to chemotherapy (expectancy), (b) actual chemotherapy experience, and (c) outcome of chemotherapy experience. Two of the categories also had subcategories. Included in the actual experience category were the subcategories of (a) physiological side effects, (b) emotional impact, and (c) social aspects which was further divided into support relationships, faith or spirituality, and participation. The last main division--outcomes or chemotherapy experience--was subdivided into emotion and physical. Table 27 displays the main and subcategories with units of content under each.

Table 27

Description of the Cancer Chemotherapy Experience by
Participants for all Categories

PRIOR TO CHEMOTHERAPY EXPERIENCE-EXPECTANCY

- at first I was afraid
- very apprehensive about starting the chemo
- apprehensive about the way I would react
- apprehensive about the side effects
- apprehensive about which ones [side effects] I would get
- wanted to do anything to "cure" my cancer
- wanted to do anything to keep it from recurring
- expected to lose my hair
- thought I was prepared for it [hair loss]
- feared the unknown side effects that possibly would occur
- could endure all the IV's, shots, needles, drugs & pills
- could endure even the hair loss
- it was being sick and vomiting after treatments that I didn't want to face
- had to have positive feelings of the end result of my treatments
- knew I would be nauseous
- thought it [hair loss] would be more gradual
- expected to feel nauseous

ACTUAL CHEMOTHERAPY EXPERIENCE

PHYSIOLOGICAL SIDE EFFECTS

- side effects have been some nausea
- some dizziness
- a little yucky once in awhile but not bad
- the first experience was the worse in terms of side effects

(table continues)

ACTUAL CHEMOTHERAPY EXPERIENCEPHYSIOLOGICAL SIDE EFFECTS

- the 5FU was decreased and all side effects since then have been nominal
- there is only one week out of five that I feel bad
- loss of hair
- stomach sickness
- hair loss
- loss of weight
- became overweight
- treatments did not make me sick
- nausea and sick all over feeling was the worst
- the tiredness
- difficulty sleeping
- didn't realize my whole body would feel that way [nauseous]
- [hair] started falling out 19 days after my first treatment
- [hair] was gone within a week!
- felt very ill during the treatments
- during my first treatment my lung collapsed
- during my 4th treatment I became disoriented and fell
- was fortunate and I wasn't sick that much
- just hated being so tired and worn down for half of the time
- first one was awful
- 2nd one only made me hyper
- 3rd and so on to end about 1/2 as bad as first one
- first one made every bone in me to hurt
- hair started coming out (dark hair at 74 years)
- slowed my heart rate to 2 beats and one miss for a couple of days
- affected my blood sugar very little
- everything I drank for 2 or 3 weeks tasted oily
- no taste with tongue, each treatment same
- never made my stomach sick
- overstimulated me
- removed hair
- loosened plumbing
- made me little lightheaded
- sometimes felt a little sick
- did not have much energy
- mouth sores

(table continues)

ACTUAL EXPERIENCE OF RECEIVING CHEMOTHERAPYEmotional

- most horrible . . . experience
- terrifying
- experience with chemotherapy has not been unpleasant
- no fun
- experience was always positive
- lot different than I had thought
- not a pleasant experience
- as time went by side effects were worse
- as time went by side effects came sooner
- as time went by side effects lasted longer
- most awful thing I've ever gone through
- was comfortable with the procedure
- treatments themselves weren't that bad
- be glad when they are over
- were hard on me
- didn't really like to go for treatment
- wonder if it is doing any good
- sickness was hard to put up with
- kept positive thoughts to get me thru it
- began to dread them
- anxious to be done about halfway through
- just getting psyched up to be sick was hard

ACTUAL EXPERIENCE OF RECEIVING CHEMOTHERAPYSOCIALSUPPORTIVE RELATIONSHIPS

- doctor is very easy to talk to
- [doctor] does not rush me
- [doctor] answers all my questions frankly and to the point
- nurse has been very helpful too
- Drs they made things seem better
- support of friends
- doctor said that at my age it must be more like arthritis but it hurt much more than that (bones)
- nurses made it much easier to do
- doctors made it much easier
- received a lot of support & love

(table continues)

ACTUAL EXPERIENCE OF RECEIVING CHEMOTHERAPYSOCIALSPIRITUALITY AND FAITH

- faith in God
- prayers
- with a dying diagnosis, there was always light at the end
- support of church family

PARTICIPATION (CONTROL) OF PROCESS

- at first I had to read the info they gave me several times trying to keep things straight
- learned too from reading and seminars that breast cancer is not just a local breast cancer
- kept in reasonably good condition
- important to me to keep active
- wish I had done more than I did
- had it all cut off [hair]
- with all its negative--the doctor thought it was the best treatment to start with--and I agreed with him
- that's what medical science has now
- believe tho it was the right choice
- chemo has been my best option so far!

OUTCOME OF CHEMOTHERAPY EXPERIENCEEMOTIONAL

- hope I never have to have chemotherapy again
- everything has worked out well
- fear has lessened
- becoming hopeful of going into remission
- after my last chemo, even tho I knew it was the last one I began to feel real down about how sick it had made my body
- emotional impact of the cancer and chemotherapy is something I certainly won't forget
- will take a long time (if ever) to completely recover from [emotional impact]
- not as bad as I had expected it to be
- was relieved to have them over
- feel the treatments did what they were supposed to do
- happy I went through it
- happy it is over
- feel the chemotherapy is like an insurance policy
(table continues)

OUTCOME OF CHEMOTHERAPY EXPERIENCEEMOTIONAL

- may never need it but if you have it you feel more secure about your life
- think I did well
- has not been bad
- was a hard time in my life
- could have been worse
- wasn't prepared for the emotional impact of my hair loss
- realities of cancer hit me when my hair began to come out by the handfuls
- I cried [because of hair loss]
- sad feelings passed
- very depressing
- loss of hair is bad, in so far as my image
- will definitely keep all my follow-up appts

PHYSICAL

- as received more treatments . . . have felt better
 - at this point in time I hope too that I will recover quickly and completely from the side effects
 - hope to stop feeling sick
 - hope to have enough strength and energy to do what I used to do
 - results have been good
 - bouncing back real well
 - now in remission
 - still little light headed
 - think these 6 treatments (needle and pills) have me in control of this as of now
 - might be in complete remission
 - good--so far removed detectable cancer
 - it [hair] has come back (short) and white
-

Summary

Findings of the study are summarized as follows:

1. The internal reliability for the researcher-developed semantic differential, the CES was .93, .91, .91 over the three testings.
2. The research hypotheses could not be tested; reported adherence to the chemotherapy regimen was 100%.
3. There was a positive nonsignificant ($\underline{r} = .15$) relationship between support and expectancy about the chemotherapy regimen.
4. There was a positive nonsignificant ($\underline{r} = .16$) relationship between information and expectancy about the chemotherapy regimen.
5. Participants reported receiving adequate support during the chemotherapy regimen.
6. Participants reported receiving a large amount of support from the nurses during the chemotherapy regimen.
7. Participants reported receiving adequate information about the chemotherapy regimen.
8. Participants reported receiving a large amount of information about the chemotherapy regimen from the nurses.

9. The relationship between demographic characteristics and adherence could not be tested; reported adherence to the chemotherapy regimen was 100%.

CHAPTER V

SUMMARY OF THE STUDY

The study was conducted to investigate the relationships between and among support, information, expectancy, and adherence to a cancer chemotherapy regimen. Three hypotheses were developed for this purpose. In addition, five research questions were examined to determine whether or not cancer chemotherapy patients perceived they were receiving adequate support and information, the amount of support and information given by nurses, and the predictive characteristics of selected demographic variables on adherence to a chemotherapy regimen. A general summary of the study and pilots; a discussion of the findings, including reliability and validity of the researcher-developed instrument (CES), and conclusions of the study are presented. The chapter concludes with implications and recommendations for further study.

Summary

Data were collected during a timespan of 23 months, using two researcher-developed instruments and a demographic sheet. The Chemotherapy Expectancy Scale (CES) and demographic sheet were answered by 46 participants and the Chemotherapy Follow-up Questionnaire (CFQ) by 24 of these 46 participants. Expectancy was measured by the CES, a semantic differential. In addition to personal characteristics, the demographic sheet also collected information about precancer influences on participants' feelings about chemotherapy. Data relative to the variables--support, information, and adherence--were obtained by the CFQ.

The literature concerning the concepts of social support and information related to cancer was plentiful; however, it was limited for adherence with cancer chemotherapy. Likewise, a number of investigators have examined the concept of expectancy, especially in the field of mental health, but studies were not found that included expectancy with chemotherapy. The concept of adherence has been investigated rather extensively about a variety of patient conditions and related health activities. Only a few studies were found, in the

available literature, that reported adherence in cancer chemotherapy patients. The findings of chemotherapy adherence studies revealed inconsistencies regarding nonadherence to chemotherapy. No studies were found that combined the four concepts of support, information, expectancy, and adherence to a chemotherapy regimen.

Guided by findings of the literature review, a descriptive correlational design was selected to investigate the relationships among social support, information, expectancy, and adherence. The researcher sought to describe and document characteristics about the variables as they related to the chemotherapy regimen and associated nursing interventions.

The theoretical framework for the study was developed by merging the concepts of (a) social support (Kahn, 1979), (b) information (Dodd & White, 1980), (c) expectancy (Sears, 1981), and (d) adherence (Dracup & Meleis, 1982). Formalization of the theoretical framework was based on the definition proposed by Gibbs (1972). The study was conducted in one southern and one western state in six different sites that included four medical offices and two medical centers. Two pilot studies were completed to evaluate the characteristics of the researcher-developed instruments prior to use in the

study. The first pilot consisted of 103 participants from the general public; those in second pilot ($N = 60$) were all cancer patients.

Findings of the study are summarized as follows:

1. The internal reliability for the researcher-developed semantic differential, the CES, was .93, .91, .91 respectively, over the three testings.
2. The research hypotheses could not be tested; reported adherence to the chemotherapy regimen was 100%.
3. There was a positive nonsignificant ($r = .15$) relationship between support and expectancy about the chemotherapy regimen.
4. There was a positive nonsignificant ($r = .16$) relationship between information and expectancy about the chemotherapy regimen.
5. Participants reported receiving adequate support during the chemotherapy regimen.
6. Participants reported receiving a large amount of support from nurses during the chemotherapy regimen.
7. Participants reported receiving adequate information about the chemotherapy regimen.
8. Participants reported receiving a large amount of information about the chemotherapy regimen from the nurses.

9. The relationship between demographic characteristics and adherence could not be tested; reported adherence to the chemotherapy regimen was 100%.

From additional comments provided by the participants when asked to express their feelings about the chemotherapy experience, both positive and negative attitudes were expressed. When analyzed by phrases, the negative comments outweighed the positive comments by about two to one. As expected, severity of the side effects was the topic many participants wrote about. Some acknowledged the value and need for support of family and others. Of note, is the fact that doctors were recognized for supportive activities six times and nurses two times.

Discussion of Findings

Demographic data were similar in Pilot II and the present study in that the majority were White, all were cancer patients and those answering the second questionnaire (CFQ) had all received chemotherapy. However, in Pilot II more participants had completed their treatments before answering either questionnaire (which were answered at the same time), while those in the study answered the CES before or near the start of

the treatments, then completed the CFQ 3 to 6 months later. Both groups were similar to the American Cancer Society's findings in the following ways. Cancer occurs in both genders and all age groups, but the incidence rises during mid-life and beyond. Participants in both Pilot II and the present study consisted of female and male participants, with the age of over half of the sample being 50 years or greater. Breast cancer occurs more frequently than any other single cancer (excluding skin cancer), and again, both groups showed this same tendency. However, the incidence of cancer is higher in males than females, and in both groups more females than males answered the questionnaires.

The research hypotheses stated that the variables of support, information, and expectancy were positively related with adherence to a cancer chemotherapy regimen. Because of the reported 100% adherence rate in the present study, inferential statistics could not be used to test for these relationships. The literature reviewed, however, referred to the growing evidence of the influence of support on adherence behaviors (Becker & Maiman, 1980; DiMatteo & DiNicola, 1982; Haynes et al., 1979). Dunkel-Schetter (1984) found a significant relationship between support and adjustment in cancer patients with a "better"

prognosis but not between support and those with a "poorer" prognosis. Support was not found to be related to, or a predictor of adherence to chemotherapy in Pilot II; however, a moderate to strong relationship was found between support and information. This finding is suggestive of support having some influence on adherence through its shared variance with information. Most participants in the study and in Pilot II reported having support persons with them during the treatments, whether or not it was suggested by health personnel. This indicated the clinical significance of chemotherapy recipients having support available.

Although nurses have not always been identified as a major source of support, the present study most participants indicated they had received a large amount of support from the nurses. This finding is in contrast to that of Bullough (1981), and Dunkel-Schetter (1984) where about 25%-30% of the participants perceived nurses as a significant source of support. Also, only about half of the Pilot II participants stated that they had received a large amount of support from the nurses and 15% reported receiving little or no support from the nurse. In general, the person identified as giving the most support was the spouse, not only in the present

study but also in those studies reviewed in the literature (Dakof & Taylor, 1990; Dunkel-Schetter, 1984). Support activities that participants rated high for all support people included "just being there," "being available," "listening," and comfort measures. Unhelpful nursing activities were "hurrying in and out," "too few explanations," and "multitasks." Results of the present study support the findings of the above mentioned studies.

As with support, participants in the present study felt the nurses had given them a large amount of information. This too is in contrast to Pilot II findings where only 45% of the participants indicated that the nurse had given a large amount of information, and 19% stated they had received little or no information from the nurse. Information giving has been identified as one strategy for improving adherence (Baer, 1986; Becker & Maiman, 1980; Kolton & Piccolo, 1988); however, research linking information and adherence have shown inconsistent results (Haynes et al., 1979). Some studies have found that certain types of information reduce anxiety about aversive procedures (Hartfield, Cason,⁷⁵ & Cason, 1982; Johnson, 1973; Johnson & Leventhal, 1974); other studies have shown that information helped cancer patients meet their personal control needs (Brockopp et al., 1989;

Dennis, 1990). Results of Pilot II did not show a relationship between information and adherence and no other studies were found that linked information and adherence to chemotherapy regimens.

In Pilot II, expectancy showed a significant positive relationship ($r = .27$, $p < .05$) with adherence. This supports Sears (1981) premise that expectancy is an intervening variable that directs action or thought toward specific goals. Although no studies were found that linked expectancy and adherence to cancer chemotherapy, a few investigators have examined the relationship of expectancy with other aversive procedures or outcomes. For example, Council et al. (1988) found a significant relationship between response expectancies and the subsequent motor behaviors of patients with chronic low back pain. Several studies have shown better adaptation to painful or aversive procedures if the patient has accurate expectancies about physical sensations that they could expect during the procedures (Johnson, 1973; Johnson & Leventhal, 1974). Sears (1981) also speculated the relevant information could help make expectancies more precise, and Council et al. in the study cited above suggested the need for clinicians to instill positive expectancies in their patients. The finding in Pilot

II of a significant positive relationship ($r = .35$, $p < .01$) between information and expectancy was supportive of this concept and although the relationship in the present study was not significant, the tendency was there.

Conclusions and Implications

The conclusions concerning the theoretical framework and instruments are discussed. The implications of the present study are related to nursing.

Theoretical Framework

The theoretic model generated for the study could not be tested due to the reported 100% adherence rate in the study sample. The researcher-generated theoretical model was designed to demonstrate relationships between and among the concepts of social support, information, expectancy, and adherence to a prescribed cancer chemotherapy regimen. The model suggested relationship between convoys (social networks) and beliefs and attitudes and between life experiences and beliefs and attitudes, all of which were speculated to impact on support, information, and expectancy relative to cancer chemotherapy. The question that asked participants to identify precancer influence on their feelings about

chemotherapy provided input relative to information available at oTa. Analysis of the propositions indirectly tests the three axioms and three postulates. Participants also were given the opportunity to describe their feelings about the chemotherapy experience but neither convoys, life experiences, nor beliefs and attitudes were directly measured in the study. The study, therefore, does not provide adequate information as to validity of the following intrinsic statements:

Axiom 1. Among adult cancer chemotherapy patients the greater the convoy at To, the greater the life experiences at To.

Axiom 2. Among adult cancer chemotherapy patients the greater the life experiences at To, the greater the beliefs and attitudes at To.

Axiom 3. Among adult cancer chemotherapy patients the greater the convoy and life experiences at To, the greater the beliefs and attitudes at To.

Postulate 1. Among adult cancer chemotherapy patients the greater the convoy at To, the greater the social support at oTa.

Postulate 2. Among adult cancer chemotherapy patients the greater the life experiences at To, the greater the information oTa.

Postulate 3. Among adult cancer chemotherapy patients the stronger the beliefs and attitudes at To, the stronger the expectancy at oTa.

Further studies might provide a means for measuring information about convoys available to cancer chemotherapy patients, and beliefs and attitudes that might contribute to their expectancy toward the procedure.

The first proposition stated that the greater the support the greater the expectancy. Data analysis revealed that those who scored higher on the PASS (perceived adequacy of support scale) also scored higher on the CES (Chemotherapy Expectancy Scale). Although the relationship was not statistically significant, the tendency was there ($\underline{r} = .15, p = .24$). The results of data analysis yielded similar findings relative to the second proposition that stated the greater the information the greater the expectancy. Again, the tendency for this relationship was present, albeit at a nonsignificant level ($\underline{r} = .16, p = .23$). Participants who scored higher on the PAI (perceived adequacy of information) also scored higher on the CES. Of interest is the fact that this last relationship (i.e., information with expectancy) was at a significant level in Pilot II.

Burns and Grove (1987) stated there is a tendency to disregard weak correlations in nursing research. Burns and Grove further stated this is similar to a Type II error and that the relationship may have some meaning for nursing knowledge when examined with other variables. The researcher believes that the variables support, information, expectancy, and adherence belong in the proposed chemotherapy outcome model. However, a larger sample is needed to adequately test the proposed relationships. Changing the outcome variable might prove more beneficial in demonstrating the impact of each of the three variables (support, information, and expectancy) on the outcome variable. Substituting a concept such as coping, adaptation, or quality of life for the concept of adherence might provide a more accurate practice-oriented model that would offer directions for nursing interventions during the chemotherapy regimen.

Although the phenomenon of nonadherence has been identified as a formidable problem in health care, the present study did not support the premise in relation to cancer chemotherapy. The high adherence rate in cancer chemotherapy patients has been attributed to the pressure of time, the nature of the disease, and beating the odds (Nehemkis & Gerber, 1986). To this list Taylor et al.

(1984) added the "trappings of medical formality" which make it difficult not to adhere, and spontaneous use of psychological coping mechanisms such as imagery and relaxation techniques. In the present study, participants were predominantly White, middle class, and receiving treatment from private practitioners who followed closely patient adherence to the requirements of the regimen. Two additional factors which may have contributed to the high rate of adherence in the present study are: (a) the sample size was relatively small, and (b) data collectors did not ask patients to participate if they believed it would add to the patients' stress level.

The additional comments of participants in the study identified feelings and attitudes of those undergoing chemotherapy treatments. The comments suggested that overwhelming fear or apprehension characterized the feelings of the participants relative to the chemotherapy regimen. A better approach to meeting the needs of these individuals might be through more extensive qualitative research before additional quantitative research is attempted.

Because studies have shown that expectancies can influence outcomes and because findings in the study showed a positive relationship between information and

expectancy and between expectancy and adherence (Pilot II), nurses should continue to make opportunities to impart health knowledge to their patients and to the general public. The study indicates positive strides have been made in the patient area; however, greater efforts need to be made with the public as evidenced by answers to the precancer information question.

Instruments

The three instruments--Chemotherapy Expectancy Scale, Chemotherapy Follow-up Questionnaire, and demographic data sheet--measured the variables in the study. All instruments were researcher-developed and have shown consistency across the two pilots and final study. The CES, a semantic differential scale, had high reliability on all three testings, with alphas of .93, .91, and .91 respectively. Content validity was established by a panel of experts during Pilot I, and construct validity has been determined through factor analysis in both pilot studies and the present study. Variances accounted for by factors on each analysis were (a) variance for eight factors on Pilot I was 66.1%, (b) variance for five factors on Pilot II was 69.2%, and (c) variance for five factors on the present study was 74.2%. Factor

reliability on Pilot I ranged from .39 to .94 for seven factors, on Pilot II .66 to .90 for four factors, and on the present study .29 to .89 for four factors. Although the make-up of factors has differed some with each sample, certain word pairs have tended to load together throughout. The CFQ and demographic data sheet have yielded consistent answers from participants across the samples.

Recommendations for Further Study

The results of the investigation support the following areas for further study:

1. Further studies are needed to determine if nonadherence to cancer chemotherapy regimens is a reality; and if so, is it more prevalent in a particular population or populations?
2. The Chemotherapy Expectancy Scale should be tested with larger samples of chemotherapy patients with adherence as an outcome variable and also different outcome variables, such as quality of life or adaptation or coping with chemotherapy.
3. Qualitative research is necessary to determine information and support needs of the cancer chemotherapy patient.

REFERENCES

- Achterberg, J. (1985). Imagery in healing: Shamanism and modern medicine. Boston: New Science Library.
- American Cancer Society [ACS]. (1988). Cancer facts & figures-1992 (Report No. 5008-LE). New York: Author.
- ACS. (1992). Cancer facts & figures-1988 (Report No. 5008.92-LE). New York: Author.
- American Nurses Association. (1973). Standards of nursing practice. Kansas City: Author.
- Ash, C. R. (1984). The challenge of patient education. Cancer Nursing, 7, 369.
- Ash, C. R. (1990). The challenge for information. Cancer Nursing, 13, 133.
- Baer, C. L. (1986). Compliance: The challenge for the future. Topics in Clinical Nursing, 7(4), 77-85.
- Basch, C. E., Gold, R. S., McDermott, R. J., & Richardson, C. E. (1983). Confounding variables in the measurement of cancer patient compliance. Cancer Nursing, 6, 265-291.
- Becker, H. S. (1952). Social-class variations in the teacher-pupil relationship. Journal of Educational Sociology, 25, 451-465.
- Becker, H. S. (1963). Outsiders (rev. ed.). New York: Free Press.
- Becker, M. H., & Maiman, L. A. (1980). Strategies for enhancing patient compliance. Journal of Community Health, 6, 113-135.
- Beecher, H. K. (1966). Pain: One mystery solved. Science, 151, 840-841.

- Brink, P. J., & Wood, M. J. (1988). Basic steps in planning nursing research: From question to proposal (3rd ed.). Boston: Jones & Bartlett.
- Brockopp, D. Y., Hayko, D., Davenport, W., & Winscott, C. (1989). Personal control and the needs for hope and information among adults diagnosed with cancer. Cancer Nursing, 12, 112-116.
- Brown, J. (1987). Chemotherapy. In S. L. Groenwald (Ed.), Cancer nursing: Principles and practices (pp. 348-375). Boston: Jones & Bartlett.
- Bullough, B. (1981). Nurses as teachers and support persons for breast cancer patients. Cancer Nursing, 4, 221-225.
- Burish, T. G., & Carey, M. P. (1986). Conditioned aversive responses in cancer chemotherapy patients: Theoretical and developmental analysis. Journal of Consulting and Clinical Psychology, 54, 593-600.
- Burish, T. G., & Lyles, J. N. (1983). Coping with the adverse effects of cancer treatments. In T. G. Burish & L. A. Bradley (Eds.), Coping with chronic disease (pp. 159-189). New York: Academic Press.
- Burns, N. (1984, Spring). Development of the Burns cancer beliefs scale. Monograph of Sigma Theta Tau, Inc., Delta Theta Chapter.
- Burns, N., & Grove, S. K. (1987). The practice of nursing research: Conduct, critique and utilization. Philadelphia: Saunders.
- Cantor, R. C. (1978). And a time to live. New York: Harper and Row.
- Caplan, G. (1974). Support systems and community mental health. New York: Behavioral Publications.
- Caplan, G. (1981). Mastery of stress: Psychosocial aspects. American Journal of Psychiatry, 138, 413-420.

- Caplan, R. D., Robinson, E. R., French, J. R., Caldwell, J. R., & Shinn, M. (1976). Adhering to medical regimens: Pilot experiments in patient education and social support. Ann Arbor: University of Michigan.
- Carmines, E. G., & Zeller, R. A. (1979). Reliability and validity assessment. Beverly Hills: Sage.
- Chang, B., Uman, G., Linn, L., Ware, J., & Kane, R. (1985). Adherence to health care regimens among elderly women. Nursing Research, 34, 27-31.
- Clarke, D. E., & Sandler, L. S. (1989). Factors involved in nurses' teaching breast self-examination. Cancer Nursing, 12, 41-46.
- Close, A. (1988). Patient education: A literature revives. Journal of Advanced Nursing, 13, 203-213.
- Cobb, S. (1979). Social support and health through the life course. In M. W. Riley (Ed.), Aging from birth to death: Interdisciplinary perspectives (pp. 93-106). Boulder, CO: Westview Press.
- Cohen, F., & Lazarus, R. S. (1979). Coping with the stresses of illness. In G. C. Stone, F. Cohen, N. E. Alder (Eds.), Health Psychology: A handbook (pp. 217-254). San Francisco: Jossey-Bass.
- Collins, J., & Hyer, L. (1986). Treatment expectancy among psychiatric inpatients. Journal of Clinical Psychology, 42, 562-568.
- Council, J. R., Adhern, D. K., Follick, M. J., Kline, C. L. (1988). Expectancies and functional impairment in chronic low back pain. Pain, 33, 323-331.
- Dakof, G. A., & Taylor, S. E. (1990). Journal of Personality and Social Psychology, 58, 80-89.
- Dennis, K. E. (1990). Patients' control and the information imperative: Clarification and confirmation. Nursing Research, 39, 162-166.

- DeNour, A. K. (1986). Forward. In K. E. Gerber, & A. M. Nehemkis (Eds.), Compliance: The dilemma of the chronically ill (pp. xi-xiii). New York: Springer.
- Derdiarian, A. (1987). Informational needs of recently diagnosed cancer patients: A theoretical framework. Part 1. Cancer Nursing, 10, 107-115.
- Derdiarian, A. K. (1989). Effects of information on recently diagnosed cancer patients' and spouses' satisfaction with care. Cancer Nursing, 12, 285-292.
- Dickoff, J., James, P., & Wiedenbach, E. (1968). Theory in a practice discipline. Nursing Research, 17, 415-435.
- DiMatteo, M. R., & DiNicola, D. D. (1982). Achieving patient compliance: The psychology of the medical practitioner's role. New York: Pergamon Press.
- DiMatteo, M. R., & Hays, R. (1981). Social support and serious illness. In B. H. Gottlieb (Ed.), Social networks and social support (pp. 117-148). Beverly Hills: Sage Publications.
- Dodd, D., & White, R. M. (1980). Cognition, mental structures and process. Boston: Allyn & Bacon.
- Dodd, M., & Ahmed, N. (1987). Preference for type of information in cancer patients receiving radiation therapy. Cancer Nursing, 10, 244-251.
- Dodd, M. J., & Mood, D. W. (1981). Chemotherapy: Helping patients to know the drugs they are receiving and their possible side effects. Cancer Nursing, 4, 311-318.
- Dracup, K. A., & Meleis, A. I. (1982). Compliance: An interactionist approach. Nursing Research, 31, 31-36.
- Dunkel-Schetter, C. (1984). Social support and cancer: Findings based on patient interviews and their implications. Journal of Social Issues, 40, 77-98.

- Fawcett, J. F., & Downs, F. S. (1986). The relationship of theory and research. Norwalk, CT: Appleton-Century-Crofts.
- Fishbein, M. (1967). Attitude and the prediction of behavior. In M. Fishbein (Ed.), Readings in attitude theory and measurement (pp. 477-492). New York: John Wiley & Sons.
- Fox, D. J. (1976). Fundamentals of research in nursing (3rd ed.). New York: Appleton-Century-Crofts.
- Gardner, K. G., & Wheeler, E. C. (1987). Patients' perceptions of support. Western Journal of Nursing Research, 9, 115-131.
- Garrett, T., Ashford, A., & Savage, D. (1986). Oncology clinic attendance at an inner city hospital. Cancer, 58, 793-795.
- Gibbs, J. P. (1972). Sociological theory construction. Hinsdale, IL: Dryden Press.
- Hair, J. F., Jr., Anderson, R. E., & Tatham, R. L. (1987). Multivariate data analysis with readings (2nd ed.). New York: Macmillan.
- Hartfield, M. T., Cason, C. L., & Cason, G. J. (1982). Effects of information about a threatening procedure on patients' expectations and emotional distress. Nursing Research, 31, 202-206.
- Haynes, R. B., Taylor, D. W., & Sackett, D. L. (1979). Compliance in health care. Baltimore: Johns Hopkins University Press.
- Henshel, R. L. (1982). The boundary of the self-fulfilling prophecy and the dilemma of social prediction. British Journal of Sociology, 33, 511-528.
- Hirt, M., & Genshaft, J. (1980). Information processing deficit. In R. H. Woody (Ed.), Encyclopedia of clinical assessment (Vol. 1, pp. 512-519). San Francisco: Jossey-Bass Publishers.
- Hollingshead, A. B. (1957). Two-factor index of social position. New Haven: Yale Station.

- Hopkins, M. B. (1986). Information-seeking and adaptational outcomes in women receiving chemotherapy for breast cancer. Cancer Nursing, 9, 256-262.
- Hull, C. L. (1930). Knowledge and purpose as habit mechanisms. Psychological Review, 37, 511-525.
- Hull, C. L. (1931). Goal attraction and directing ideas conceived as habit phenomena. Psychological Review, 38, 487-506.
- Itano, J., Tanabe, P., Lum, J., Lamkin, L., Rizzo, E., Wieland, M., & Sato, P. (1983). Compliance of cancer patients to therapy. Western Journal of Nursing Research, 5, 5-20.
- Jacobson, D. E. (1986). Types and timing of social support. Journal of Health and Social Behavior, 27, 250-264.
- Johnson, J. E. (1973). Effects of accurate expectations about sensations on the sensory and distress components of pain. Journal of Personality and Social Psychology, 27, 261-275.
- Johnson, J. E., & Leventhal, H. (1974). Effects of accurate expectations and behavioral instructions on reactions during a noxious medical examination. Journal of Personality and Social Psychology, 29, 710-718.
- Jones, R. A. (1977). Self-fulfilling prophecies: Social, psychological, and physiological effects of expectancies. Hillsdale, NJ: Lawrence Erlbaum Assoc.
- Kahn, R. L. (1979). Aging and social support. In M. W. Riley (Ed.), Aging from birth to death (pp. 77-91). Boulder, CO: Westview Press.
- Kahn, R. L., & Antonucci, T. (1981). Convoys of social support: A life-course approach. In S. Kiesler, J. Morgan, & V. Oppenheimer (Eds.), Aging social change (pp. 383-405). New York: Academic Press.
- Karani, D., & Wiltshaw, E. (1986). How well informed? Cancer Nursing, 9, 238-242.

- Kerlinger, F. N. (1973). Foundations of behavioral research (2nd ed.). New York: Holt, Rinehart and Winston, Inc.
- Kesselring, A., Lindsey, A., Dodd, M., & Lovejoy, N. (1986). Social network and support perceived by Swiss cancer patients. Cancer Nursing, 9, 156-163.
- Klopovich, P. M., & Trueworthy, R. C. (1985). Adherence to chemotherapy regimens among children with cancer. Topics in Clinical Nursing, 7(1), 19-25.
- Kolton, K. A., & Piccolo, P. (1988). Patient compliance: A challenge in practice. Nurse Practitioner, 13(12), 37-50.
- Koocher, G. P. (1986). Coping with a death from cancer. Journal of Consulting and Clinical Psychology, 54, 623-631.
- Krause, M. S., Fitzsimmons, M., & Wolf, N. (1969). Focusing on the client's expectations of treatment. Psychological Reports, 24, 973-974.
- Leininger, M. M. (Ed.). (1985). Qualitative research methods in nursing. Orlando, FL: Grune & Stratton.
- Lewin, K. (1935). A dynamic theory of personality. New York: McGraw-Hill.
- Lin, N., Ensel, W. M., Simeone, R. S., & Kuo, W. (1979). Social support, stressful life events, and illness: A model and an empirical test. Journal of Health and Social Behavior, 20, 108-119.
- Marcia, J. E., Rubin, B. M., & Efran, J. S. (1969). Systematic desensitization: Expectancy change or counterconditioning? Journal of Abnormal Psychology, 74, 382-387.
- Marks, G., Richardson, J. L., Graham, J. W., & Levine, A. (1986). Role of health locus of control beliefs and expectations of treatment efficacy in adjustment to cancer. Journal of Personality and Social Psychology, 51, 443-450.

- Messerli, M. L., Garamendi, C., & Romano, J. (1980). Information as a technique in crisis intervention. American Journal Orthopsychiatry, 50, 728-731.
- Mettler, M. V. (1988). Instrument development: Investigation of psychometric properties of the Chemotherapy Expectancy Scale. Unpublished manuscript.
- Miller, P., Wikoff, R., McMahon, M., Garrett, M., & Ringel, K. (1985). Indicators of medical regimen adherence for myocardial infarction patients. Nursing Research, 34, 269-272.
- Morra, M. E. (1985). Making choices: The consumer's perspective. Cancer Nursing, 8, 54-59.
- Munro, B. H., Visintainer, M. A., & Page, E. B. (1986). Statistical methods for health care research. Philadelphia: Lippincott.
- Nehemkis, A. M., & Gerber, K. E. (1986). Compliance and the quality of survival. In K. E. Gerber & A. M. Nehemkis (Eds.), Compliance: The dilemma of the chronically ill (pp. 73-97). New York: Springer.
- Norusis, M. J. (1988). Introductory statistics guide SPSSX. New York: McGraw-Hill.
- Nunnally, J. C. (1970). Introduction to psychological measurement. New York: McGraw-Hill.
- Nunnally, J. C. (1978). Psychometric theory. New York: McGraw-Hill.
- O'Brien, M. E. (1980). Hemodialysis regimen compliance and social environment: A panel analysis. Nursing Research, 29, 250-255.
- O'Connor, A. P., Wicker, C. A., & Germino, B. B. (1990). Understanding the cancer patient's search for meaning. Cancer Nursing, 13, 167-175.
- Osgood, C. E., & Suci, G. J. (1969). Factor analysis of meaning. In J. G. Snider & C. E. Osgood (Eds.), Semantic differential technique (pp. 42-55). Chicago: Aldine.

- Osgood, C. E., Suci, G. J., & Tannenbaum, P. H. (1967). Measurement of meaning. Urbana, IL: University of Illinois Press.
- Paulen, A. (1981). Patient compliance: Is that what we really want? Cancer Nursing, 4, 179.
- Polit, D. F., & Hungler, B. P. (1987). Essentials of nursing research: Methods and applications. Philadelphia: Lippincott.
- Reynolds, S. A., Sachs, S. H., Davis, J. M., & Hall, P. (1981). Meeting the information needs of patients on clinical trials: A new approach. Cancer Nursing, 4, 227-230.
- Rimer, B. K., Davis, S. W., Engstrom, P. F., Myers, R. E., & Rosan, D. (1988). Some reasons for compliance and noncompliance in a health maintenance organization breast cancer screening program. The Journal of Compliance in Health Care, 3, 103-114.
- Roberts, S. J. (1988). Social support and help seeking: Review of the literature. Advances in Nursing Science, 10, 1-11.
- Sackett, D. L. (1976). Introduction. In D. L. Sackett, & R. B. Haynes (Eds.), Compliance with therapeutic regimens (pp. 1-6). Baltimore: The Johns Hopkins University Press.
- Sears, R. R. (1981). The role of expectancy in adaptation to aging. In S. B. Kiesler, J. N. Morgan, & V. K. Oppenheimer (Eds.), Aging-social change (pp. 407-430). New York: Academic Press.
- Shapiro, A. K. (1959). The placebo effect in the history of medical treatment: Implications for psychiatry. American Journal of Psychiatry, 116, 298-304.
- Shapiro, A. K. (1971). Placebo effects in medicine, psychotherapy, and psychoanalysis. In A. E. Bergin & S. L. Garfield (Eds.), Handbook of psychotherapy and behavior change: An empirical analysis (pp. 439-473). New York: John Wiley & Sons.

- Shelley, S. I. (1984). Research methods in nursing and health. Boston: Little, Brown.
- Silberfarb, P. M., Philibert, D., & Levine, P. M. (1980). Psychosocial aspects of neoplastic disease: II. Affective and cognitive effects of chemotherapy in cancer patients. American Journal of Psychiatry, 37, 597-601.
- Sime, A. M., & Libera, M. B. (1985). Sensation information, self-instruction and responses to dental surgery. Research in Nursing and Health, 8, 41-47.
- Smale, G. G. (1977). Prophecy, behavior and change. London: Routledge & Kegan Paul.
- Stone, G. C. (1979). Patient compliance and the role of the expert. Journal of Social Issues, 35, 34-59.
- Taksuoka, M. M. (1971). Multivariate analysis: Techniques for educational and psychological research. New York: John Wiley & Sons.
- Taylor, S., Lichtman, R., & Wood, J. (1984). Compliance with chemotherapy among breast cancer patients. Health Psychology, 3, 553-562.
- Tilden, V. P., & Galyen, R. D. (1987). Cost and conflict: The darker side of social support. Western Journal of Nursing Research, 9, 9-18.
- Tolman, E. C. (1967). Purposive behavior in animals and men. In R. M. Elliott, G. Lindzey, & K. MacCorquadale (Eds.), The century psychology series. New York: Meredith.
- Turk, D. C., Salovey, P., & Litt, M. D. (1986). Adherence: A cognitive-behavioral perspective. In K. E. Gerber, & A. M. Nehemkis (Eds.), Compliance: The dilemma of the chronically ill (pp. 44-72). New York: Springer.
- Walker, L. O., & Avant, K. C. (1983). Strategies for theory construction in nursing. Norwalk, CT: Appleton-Century-Crofts.

- Waltz, C. F., Strickland, O. L., & Lenz, E. R. (1984). Measurement in nursing research. Philadelphia: F. A. Davis.
- Watson, D., & Kendall, P. C. (1983). Methodological issues in research on coping with chronic disease. In T. G. Burish, & L. A. Bradley (Eds.), Coping with chronic disease: Research and applications (pp. 39-81). New York: Academic Press.
- Weddington, W. W. (1982). Psychogenic nausea and vomiting associated with termination of cancer chemotherapy. Psychotherapy and Psychosomatics, 37, 129-136.
- Wilkins, W. (1973). Expectancy of therapeutic gain: An empirical and conceptual critique. Journal of Consulting and Clinical Psychology, 40, 69-77.
- Wilson, H. S. (1985). Research in nursing. Menlo Park, CA: Addison-Wesley.
- Wolf, S. (1959). The pharmacology of placebos. Pharmacology Reviews, 11, 689-704.
- Wortman, C. B. (1984). Social support and the cancer patient: Conceptual and methodologic issues. Cancer, 53(Suppl. 10), 2339-2362.

APPENDICES

APPENDIX A

Research Review Committee Exemption Form

Member

APPENDIX B

Graduate School Permission Letter

TEXAS WOMAN'S UNIVERSITY
DENTON DALLAS HOUSTON
THE GRADUATE SCHOOL

P.O. Box 22479, Denton, Texas 76204 817/876-3400, 800-338-5755



August 28, 1989

Ms. Marilyn Mettler
1243 28th Lane
Pueblo, CO 81006

Dear Ms. Mettler:

I have received and approved the Prospectus for your research project. Best wishes to you in the research and writing of your project.

Sincerely yours,

Leslie M. Thompson

Leslie M. Thompson
Dean for Graduate Studies
and Research

dl

cc Dr. Helen Bush

APPENDIX C

Chemotherapy Expectancy Scale

Code Number _____

CHEMOTHERAPY EXPECTANCY SCALE

The purpose of this scale is to measure the expectations that you have about cancer chemotherapy. On the next page are pairs of words with opposite meanings. All of the words could be used to describe chemotherapy. For each pair of words, mark the space that most nearly reflects your present feelings. See examples below.

If you generally feel that chemotherapy is important, you would place the mark in the following way:

IMPORTANT X :__:__:__:__:__ UNIMPORTANT

If you generally feel that chemotherapy is unimportant, you would place the mark in the following way:

IMPORTANT __:__:__:__:__:__ X UNIMPORTANT

If your feelings about chemotherapy are between the two extremes, mark the space that you think most clearly shows your feelings. People have many different feelings about cancer chemotherapy. There are no right or wrong answers. Please respond with the first thought that comes to mind.

Please do not mark more than one space, or the answer will not count.

Please do not mark on the dots between the lines, or the answer will not count.

If you will participate in the study PLACE THE LAST FOUR DIGITS OF YOUR SOCIAL SECURITY NUMBER in the upper right hand corner on the line after Code Number. If you do not wish to participate you may return the questionnaire unanswered. This will in no way affect the treatment you receive.

Part II of this form contains questions relating to you personally. Please answer all of these questions to the best of your ability.

THE INFORMATION PROVIDED WILL BE KEPT STRICTLY CONFIDENTIAL. DO NOT PUT YOUR NAME ON ANY SHEET. THE FORMS ARE CODED FOR THE PURPOSE OF PAIRING THIS QUESTIONNAIRE WITH THE ONE THAT YOU WILL ANSWER AT A LATER DATE.

COMPLETION AND RETURN OF THIS QUESTIONNAIRE INDICATES YOUR CONSENT TO PARTICIPATE IN THE STUDY.

Please mark (with X) the space that most nearly shows your feelings about chemotherapy as you start(ed) the treatments.

CHEMOTHERAPY

[illegible]

Part II: BACKGROUND INFORMATION

Please respond to the following items by checking the appropriate space or writing in the space provided.

1. BEFORE your experience with chemotherapy which of the following three (3) information sources had the most influence on your feelings about cancer chemotherapy? Put a "1" next to the source that had the most influence on your feelings about cancer chemotherapy. Put a "2" next to the source that had the second strongest influence and a "3" next to the source that had the third strongest influence. Mark 3 spaces only.

<input type="checkbox"/> Family member had chemotherapy	<input type="checkbox"/> Radio
<input type="checkbox"/> Friend had chemotherapy	<input type="checkbox"/> Newspapers/Magazines
<input type="checkbox"/> Nurses	<input type="checkbox"/> Professional books/journals
<input type="checkbox"/> Doctors	<input type="checkbox"/> Word-of-Mouth
<input type="checkbox"/> Television	<input type="checkbox"/> Other _____

2. What kind of cancer do you have? _____

3. In what stage is the cancer? I _____ II _____ III _____ IV _____

4. What treatment(s) have you had or will you have for the cancer?

☐ Surgery
☐ Radiation
☐ Chemotherapy
☐ Other _____ (Example: immunotherapy, imagery, relaxation...)

4. How do you currently view your health status?

☐ Excellent
☐ Good
☐ Fair
☐ Poor

5. EDUCATION: _____ (years of school completed) HIGHEST EARNED DEGREE: _____

6. What is (or was) your occupation? _____

7. **ETHNICITY**

☐ Asian
☐ Black
☐ Hispanic
☐ White
☐ Other _____

8. **FAMILY INCOME:**

☐ Less than \$15,000/year
☐ \$15,001 - \$25,000/year
☐ \$25,001 - \$50,000/year
☐ Greater than \$50,001/year

9. **GENDER**

☐ Female
☐ Male

10. **AGE**

_____ Nearest year

THANK YOU FOR PARTICIPATING IN THIS STUDY

APPENDIX D

Chemotherapy Follow-up Questionnaire

Code Number _____

CHEMOTHERAPY FOLLOW-UP QUESTIONNAIRE

These questions constitute the second part of the study in which you are participating. Please answer each item to the best of your ability. THE INFORMATION PROVIDED WILL BE KEPT STRICTLY CONFIDENTIAL. DO NOT PUT YOUR NAME ON ANY SHEET. PLACE THE LAST FOUR DIGITS OF YOUR SOCIAL SECURITY NUMBER IN THE UPPER RIGHT HAND CORNER.

1. What chemotherapy agent(s) did you receive? (Check all that apply)

<input type="checkbox"/> Adriamycin	<input type="checkbox"/> Dactinomycin	<input type="checkbox"/> Plicamycin
<input type="checkbox"/> Asparaginase	<input type="checkbox"/> Daunorubicin	<input type="checkbox"/> Streptozocin
<input type="checkbox"/> Bleomycin	<input type="checkbox"/> Etoposide (VP-16)	<input type="checkbox"/> Vinblastine
<input type="checkbox"/> Carmustine (BCNU)	<input type="checkbox"/> Floxuridine (FUDR)	<input type="checkbox"/> Vincristine
<input type="checkbox"/> Cisplatin	<input type="checkbox"/> Fluorouracil (5-FU)	Other _____
<input type="checkbox"/> Cytosar-U	<input type="checkbox"/> Methotrexate	_____
<input type="checkbox"/> Dacarbazine	<input type="checkbox"/> Mitomycin	_____
	<input type="checkbox"/> Nitrogen Mustard	

2. Which of the following information was given to you BEFORE you started the chemotherapy treatments? (Check all that apply)

☐ Side effects of the medicine

☐ How to relieve the side effects of the medicine

☐ How it would feel to get the treatment (For example: The medicine will cause a burning sensation while you are receiving it)

☐ How long each treatment would take

☐ How often treatments would be given

☐ What treatments were expected to accomplish (For example: The medicine you will receive should slow or stop the growth of the cancer)

☐ How the treatment would be given (For Example: The medicine will be added to fluids which will be given through your veins)

☐ Blood work or other tests required during, between or after receiving the treatments

☐ Other information received

3. Who gave you the information about your chemotherapy treatments? (Check all that apply)

☐ doctor

☐ nurse

☐ other _____

COMPLETION OF THE QUESTIONNAIRE INDICATES YOUR CONSENT TO PARTICIPATE IN THE STUDY

4. How much information did the nurse(s) give regarding your treatments? (Check one space only)
- _____ Large Amount _____ Some _____ Little or None
5. Were you encouraged to ask questions?
- _____ yes If yes, who encouraged this? _____
- _____ no
6. What additional information would have been helpful? _____
- _____
- _____
7. Did you receive information that you did not want or need?
- _____ yes
- _____ no
8. If you answered the above question yes, please explain. _____
- _____
- _____
9. How would you rate OVERALL the information you received BEFORE starting the treatments? (Check one space only)
- Adequate ____:____:____:____:____:____ Inadequate
10. Were you encouraged to have someone with you during the chemotherapy treatment?
- _____ yes If yes, who encouraged this _____
- _____ no
11. Did you have someone with you during the treatment? (If you answer this question NO, please skip to question #14)
- _____ yes
- _____ no
12. If the answer to question #11 is yes, who was with you?
- _____
13. If somebody was with you during the treatments, what did this person do that was:
- MOST helpful _____
- LEAST helpful _____
14. If nobody was with you during the treatments, would you have liked someone to be with you?
- _____ yes
- _____ no

15. How much support was given by the nurse(s) during the chemotherapy treatments? (Check one space only)

_____ Large Amount _____ Some _____ Little or None

16. What did the nurse(s) do that was MOST helpful for you during the treatments? _____

17. What did the nurse(s) do that was LEAST helpful for you during the treatments? _____

18. How would you rate OVERALL the support you received DURING the chemotherapy treatments? (Check one space only)

Adequate ____:____:____:____:____:____:____ Inadequate

19. I have kept my scheduled appointments during the past several months.

_____ All of them _____ Some of them _____ None of them

Reason for missing _____

20. I have had the prescribed blood work and other tests during the past several months.

_____ All of them _____ Some of them _____ None of them

Reason for
missing _____

21. I have received the scheduled chemotherapy treatments during the past several months.

_____ All of them _____ Some of them _____ None of them

Reason for
missing _____

22. In your own words briefly describe your feelings related to your experiences with chemotherapy treatments.
(You may write on back)

PLEASE BE SURE THE LAST FOUR DIGITS OF YOUR SOCIAL SECURITY NUMBER ARE ON THE CODE LINE ON PAGE ONE

THANK YOU FOR PARTICIPATING IN THE STUDY

APPENDIX E

Cancer Chemotherapy Scale

The purpose of this study is to measure the expectations that various people have in relation to cancer chemotherapy. Listed on the following pages are pairs of words, with opposite meanings, each of which might be used in describing cancer chemotherapy. For each pair of words please check the space that most nearly reflects your present feeling about cancer chemotherapy. For example, if you generally feel that chemotherapy is very important, you would mark the scale as follows:

On the other hand if your feelings about chemotherapy are that it is slightly unimportant, you would mark the scale in the following way:

The spaces on each of the scales relating to cancer chemotherapy have the same ratings as in the examples. Please read each pair of words and select the first thought that comes to mind. There are no right or wrong answers. Please mark in one space only.

If you wish to participate in this study please continue. If you do not wish to participate you may return the instrument unanswered.

Place the last four digits of your social security number in the upper right-hand corner of this page. This code number is for the purpose of comparing your responses of today with those you make at a latter date. This will help to establish the reliability of the instrument.

Part II of this instrument contains questions relating to you and your personal experiences with cancer chemotherapy.

CHEMOTHERAPY

[illegible]

CHEMOTHERAPY						
appropriate:	very	quite	slightly	slightly	quite	inappropriate
unoffensive:						offensive
toxic:						nontoxic
aggressive:						passive
healthy:						unhealthy
devitalizing:						vitalizing

Part II. DEMOGRAPHIC INFORMATION

1. Sex: ☐ 1. female
☐ 2. male
2. Health Status: ☐ 1. excellent
☐ 2. good
☐ 3. fair
☐ 4. poor
3. Age: ☐ 1. nearest year
4. Have you ever been diagnosed as having any form of cancer
☐ 1. yes
☐ 2. no

If yes, what kind? _____
5. Has a close relative or friend ever been diagnosed as having cancer?
☐ 1. yes
☐ 2. no
6. Have you ever received chemotherapy for treatment of cancer?
☐ 1. yes
☐ 2. no
7. If the answer to question 6 is yes, who was your greatest source of support?
☐ 1. family member _____ (spouse, child, sister, brother,.....)
☐ 2. close friend
☐ 3. nurse
☐ 4. doctor
☐ 5. other _____

8. Has a close relative or friend ever received chemotherapy for treatment of cancer?

____ 1. yes
____ 2. no

If yes, please identify who you feel gave them the most support.

9. In your own words briefly describe your feelings related to your experiences with chemotherapy treatments.(you may write on back)

10. From the following list, select the three sources that have had the most influence on your present feelings about cancer chemotherapy. Rank order your answers from 1 to 3, with 1 indicating the most influence. (Select three only)

____ 1. Having chemotherapy myself
____ 2. Family or friend having chemotherapy
____ 3. Television
____ 4. Radio
____ 5. Newspapers and magazines
____ 6. Professional books or journals
____ 7. Nurses
____ 8. Doctors
____ 9. Word-of-mouth
____ 10. Other _____

11. What is (or was) your occupation? (Please be specific, i.e., librarian, salesman, teacher, M.D., R.N.....)

12. Please feel free to make comments or suggestions about this instrument.

Thank you for participating in this study

APPENDIX F

Health Agency Permit Form

TEXAS WOMAN'S UNIVERSITY
COLLEGE OF NURSING

AGENCY PERMISSION FOR CONDUCTING STUDY*

THE _____
GRANTS TO Marilynn V. Mettler, R.N., M.S.

a student enrolled in a program of nursing leading to a Doctoral Degree at Texas Woman's University, the privilege of its facilities in order to study the following problem.

In adult outpatient cancer chemotherapy patients, do significant relationships exist between and among expectancy, information, support, selected demographic factors and adherence to a prescribed chemotherapy regimen? Second, based on client perception how much information and support does the nurse provide before and during the chemotherapy regimen?

The conditions mutually agreed upon are as follows:

1. The agency (may) (may not) be identified in the final report.
2. The names of consultative or administrative personnel in the agency (may) (may not) be identified in the final report.
3. The agency (wants) (does not want) a conference with the student when the ~~report~~ is completed. (Telephone conference is satisfactory)
4. Other _____

Date: 6/15/88

Marilynn V. Mettler
Signature of Student

Helene A. Bush
Signature of Agency Personnel
Via - President
Signature of Faculty Advisor

* Fill out and sign three copies to be distributed as follows:
Original - Student: First Copy - Agency; Second Copy - TWU College of Nursing.

TEXAS WOMAN'S UNIVERSITY
COLLEGE OF NURSING

AGENCY PERMISSION FOR CONDUCTING STUDY*

THE Office of Dr. Robert DeLizio, Wichita Falls, Texas

GRANTS TO Marilynn V. Mettler

a student enrolled in a program of nursing leading to a Doctoral Degree at Texas Woman's University, the privilege of its facilities in order to study the following problem.

In adult outpatient cancer chemotherapy patients, do significant relationships exist between and among expectancy, information, support, selected demographic factors and adherence to a prescribed chemotherapy regimen? Second, based on client perception how much information and support does the nurse provide before and during the chemotherapy regimen?

The conditions mutually agreed upon are as follows:

1. The agency (may) (may not) be identified in the final report.
2. The names of consultative or administrative personnel in the agency (may) (may not) be identified in the final report.
3. The agency (wants) (does not want) a conference with the student when the report is completed.
4. Other Conference if desired by
Student

Date: June 15, 1988

Robert De Lizio MD
Signature of Agency Personnel

Marilynn V. Mettler
Signature of student

Heleen A. Burt
Signature of Faculty Advisor

* Fill out and sign three copies to be distributed as follows:
Original - Student: First Copy - Agency; Second Copy - TWU College of Nursing.

TEXAS WOMAN'S UNIVERSITY
COLLEGE OF NURSING

AGENCY PERMISSION FOR CONDUCTING STUDY*

THE _____
GRANTS TO Marilynn V. Mettler, R.N., M.S.

a student enrolled in a program of nursing leading to a Doctoral Degree at Texas Woman's University, the privilege of its facilities in order to study the following problem.

In adult outpatient cancer chemotherapy clients, do significant relationships exist between and among expectancy, information, support, selected demographic factors and adherence to a prescribed chemotherapy regimen? Second, based on client perception, how much support and information does the nurse provide during the chemotherapy regimen.

The conditions mutually agreed upon are as follows:

1. The agency (may) (may not) be identified in the final report.
2. The names of consultative or administrative personnel in the agency (may) (may not) be identified in the final report.
3. The agency (wants) (does not want) a conference with the student when the report is completed.
4. Other _____

Date: _____

Signature of Agency Personnel

Marilynn V. Mettler
Signature of student

Helen B. Buch
Signature of Faculty Advisor

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TEXAS WOMAN'S UNIVERSITY
COLLEGE OF NURSING

AGENCY PERMISSION FOR CONDUCTING STUDY*

THE _____
GRANTS TO Marilynn V. Mettler, R.N., M.S.

a student enrolled in a program of nursing leading to a Doctoral Degree at Texas Woman's University, the privilege of its facilities in order to study the following problem.

In adult outpatient cancer chemotherapy patients do significant relationships exist between and among support, information, expectancy, and adherence to a prescribed chemotherapy regimen? Second, based on patient perception how much support and information does the nurse provide before and during the chemotherapy regimen?

The conditions mutually agreed upon are as follows:

1. The agency (~~may~~) (may not) be identified in the final report.
2. The names of consultative or administrative personnel in the agency (~~may~~) (may not) be identified in the final report.
3. The agency (~~wants~~) (does not want) a conference with the student when the report is completed.
4. Other _____

Date: 5-18-90

Signature of Agency Personnel _____


Signature of student _____


Signature of Faculty Advisor _____

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TEXAS WOMAN'S UNIVERSITY
COLLEGE OF NURSING

AGENCY PERMISSION FOR CONDUCTING STUDY*

THE Pikes Peak Cancer Specialists

GRANTS TO Marilynn Mettler

a student enrolled in a program of nursing leading to a Doctoral Degree at Texas Woman's University, the privilege of its facilities in order to study the following problem.

SOCIAL SUPPORT, INFORMATION, EXPECTANCY, AND ADHERENCE
IN OUTPATIENT CANCER CHEMOTHERAPY PATIENTS

The conditions mutually agreed upon are as follows:

1. The agency (may) (may not) be identified in the final report.
2. The names of consultative or administrative personnel in the agency (may) (may not) be identified in the final report.
3. The agency (wants) (does not want) a conference with the student when the report is completed.
4. Other _____

Date: 5/6/91

Diana Wall, RN
Signature of Agency Personnel

Marilynn Mettler
Signature of student

Helen A. Bush
Signature of Faculty Advisor

* Fill out and sign three copies to be distributed as follows:
Original - Student: First Copy - Agency; Second Copy - TWU College of Nursing.

TEXAS WOMAN'S UNIVERSITY
COLLEGE OF NURSING

AGENCY PERMISSION FOR CONDUCTING STUDY*

THE _____
GRANTS TO Marilynn V. Mettler

a student enrolled in a program of nursing leading to a Doctoral Degree at Texas Woman's University, the privilege of its facilities in order to study the following problem.

The purpose of the study is to examine relationships among the variables social support, information, expectancy, and adherence to a prescribed chemotherapy regimen. Also to be examined is the adequacy of social support and information; and social support and information given by nurses. Individual responses will be anonymous.

The conditions mutually agreed upon are as follows:

1. The agency (may) (may not) be identified in the final report.
2. The names of consultative or administrative personnel in the agency (may) (may not) be identified in the final report.
3. The agency (wants) (does not want) a conference with the student when the report is completed.
4. Other Contact person for liaison is Cathy Berendts, Oncology C.N.S.

Date: 6-25-90

Signature of Agency Personnel

Signature of student

Signature of Faculty Advisor

* Fill out and sign three copies to be distributed as follows:
Original - Student: First Copy - Agency; Second Copy - TWU College of Nursing.

APPENDIX G

Verbal Explanation Chemotherapy Expectancy Scale

VERBAL EXPLANATION TO PARTICIPANT

1. Researcher: Marilyn Mettler
Doctoral Student - Texas Woman's University
2. Study topic: How social support, information, expectancy, and adherence relate to cancer chemotherapy. Also included will be an examination of:
 - a. the kinds of support and information that are most helpful or least helpful for those who receive chemotherapy.
 - b. how much support and information nurses give to those who receive chemotherapy, and
 - c. the most helpful and least helpful nursing actions.
3. As a participant you will fill out two questionnaires, one today and a second one in about three months.

The second questionnaire will be mailed to you. A stamped, addressed envelope will be included for returning the questionnaire.

Directions for marking the answers are on each questionnaire.

Completion of the questionnaires will indicate your permission to participate in the study.

Individual information will be kept strictly confidential. Only group data will be recorded. No names will appear in any printed materials.

Please do not put your name on either questionnaire. You will seal your questionnaire in an envelope before returning it to the researcher (research assistant).

Your name and address (on the separate sheet) will be used only for mailing the second questionnaire.

The code number (on questionnaires) is for the purpose of keeping your two questionnaires together.
4. Participants must be 18 years of age or older.

Your participation is invited and is voluntary. You may withdraw from the study at any time.

Your participation or nonparticipation in the study will in no way affect the treatment you receive.
5. The cover letter with the first questionnaire, contains much of this same information.

The cover letter is for you to keep.
6. Do you have any questions?

THANK YOU FOR YOUR CONSIDERATION OF THE STUDY

APPENDIX H

Cover Letter of Chemotherapy Expectancy Scale

Dear Participant:

I am a doctoral student at Texas Woman's University in Denton. I am also a former cancer and chemotherapy patient. My study relates to the expectations that individuals have about chemotherapy. I am interested in learning more about the kinds of information and support that patients prefer relative to this treatment. The results of this study will provide valuable information about the needs of those who receive chemotherapy.

The Chemotherapy Expectancy Scale, is to be completed prior to your first chemotherapy treatment. It contains twenty pairs of words that are frequently associated with chemotherapy. You will mark one space to reflect your feelings for each pair of words. Complete directions are with the scale. People have different views on the subject. There are no right or wrong answers. It should take less than 15 minutes to complete the forms including the one page of questions that relate to you personally. After answering the questionnaire, seal it in the envelope and return as instructed.

The second questionnaire will be mailed to you approximately three months after you start the chemotherapy treatments. This questionnaire consists mostly of items that can be answered with a check mark. A few questions will ask for personal comments. Your input is very important and may enhance the care of future chemotherapy patients. It should take only about 20 minutes of your time for this questionnaire. Once you have completed the answers, you will mail these forms to me in a stamped-addressed envelope that is included with the questionnaire.

To be included in the study, you must be 18 years of age or older. Participation is voluntary. The information you provide will be completely confidential. The code numbers are for the purpose of pairing the two questionnaires. Thank you for participating in the study.

Sincerely,

Marilynn Mettler, R.N., M.S.

APPENDIX I
Participant Address Sheet

Dear Participant:

Please print your name and address in the space provided. This information will be used to send the second questionnaire to you in about three months. In order to keep your answers confidential, do not place the address sheet in the envelope with your completed questionnaire. Please return to researcher (research assistant) separately.

Thank you.

Marilynn Mettler

PARTICIPANT - FINAL STUDY

NAME _____ DATE _____

ADDRESS _____

CITY _____ STATE _____ ZIP _____

APPENDIX J

Cover Letter for
Chemotherapy Follow-up Questionnaire

Marilynn Mettler
P. O. Box 23115-TWU
Denton, TX 76204

Dear

This is the second questionnaire for the study in which you are participating. When you have completed the answers please return it to me in the enclosed stamped envelope.

Again I appreciate greatly your interest in this project. To improve patient care it is most important that we have input on their needs. If I can answer any questions about the study or your participation, I can be reached by telephone (817) 898-4017 or at the address above. Thank you for participating.

Sincerely,

Marilynn Mettler, R.N., M.S.

APPENDIX K

Verbal Instructions Cancer Chemotherapy Scale

VERBAL EXPLANATION - CANCER CHEMOTHERAPY SCALE

1. RESEARCHER: MARILYNN METTLER, R.N.
DOCTORAL STUDENT - TEXAS WOMAN'S UNIVERSITY
2. Study Topic: Instrument development to measure beliefs (expectancy) about cancer chemotherapy. The purpose of this pilot study is to help establish validity and reliability of instrument. In the final study the Cancer Chemotherapy Scale will be given to individuals (with cancer) who are to have chemotherapy as one form of treatment. Hopefully the information from the final study will assist health personnel to better meet the needs of those who must have chemotherapy
3. As a participant in the pilot study you will check one of six spaces between a pair of terms with opposite meaning. The second part of the questionnaire requires some checking, and some short answers. Specific directions are on the questionnaire. In about two weeks, you will repeat the first part of the questionnaire (i.e., chemotherapy scale). It should take only about 20 minutes today and less than that the second time.
4. The code number (upper right corner) is the last four digits of your social security number. This number is needed in order to compare your first and second answers. This is one method for checking reliability of an instrument. So that your answers remain anonymous, no other identification should be put anywhere on the questionnaires.
5. Participation in this study is voluntary and you may withdraw at any time. You must be 18 years of age or older to participate.
6. Completion of the questionnaire indicates your consent to participate, and to permit publication of the results of the study.
7. If you prefer not to participate you may return the forms unanswered.
8. Are there any questions?

THANK YOU FOR YOUR CONSIDERATION OF THIS RESEARCH PROJECT

APPENDIX L

Cover Letter
Cancer Chemotherapy Scale

Dear Participant:

I am a doctoral student at Texas Woman's University in Denton, Texas. Presently I am developing a research instrument to measure expectations related to cancer chemotherapy. You are invited to participate in a pilot study which will assist me in establishing the reliability and validity of this instrument. Ultimately it is hoped that information received from this instrument will assist health personnel to better meet the needs of individuals receiving cancer chemotherapy.

To participate in this study you are asked to complete a short questionnaire, and to check spaces on the scales related to chemotherapy. This same procedure will be repeated approximately two weeks later. It should require only about 20 minutes each time. Participation in this study is completely voluntary and you may withdraw at any time.

The only identification, on any of the forms, will be the last four digits of your social security number that you will write in the upper right-hand corner of the first page of the instrument. This number is needed in order to compare your first and second answers as one method for checking the reliability of the instrument. After this comparison is completed, the numbers will be cut from the forms. Your responses will remain completely anonymous.

Completion of this questionnaire indicates consent to participate in, and to permit publication of the results of this study. If you prefer not to participate, you may return these forms unanswered. Thank you for your consideration of this research project.

Sincerely,

A handwritten signature in cursive script, appearing to read 'Marilynn Mettler', written in dark ink.

Marilynn Mettler, R.N., M.S.
Doctoral Student, TWU

APPENDIX M

Participant Comments - Pilot I

IN YOUR OWN WORDS BRIEFLY DESCRIBE YOUR FEELINGS RELATED TO
YOUR EXPERIENCES WITH CHEMOTHERAPY TREATMENTS.

001 MY SISTER IN LAW TOOK CHEMOTHERAPY FOR FOUR YEARS BEFORE SHE DIED. I WAS GLAD THAT SHE MADE THE DECISION. I HAVE BEEN ASSOCIATED WITH MANY PATIENTS ON CHEMOTHERAPY, SOME VERY SUCCESSFUL. I FELT GREAT THAT THEY HAD CHEMO CHOSEN THIS ROUTE--SOME WHO WERE NOT SUCCESSFUL, EVEN THOUGH IT WAS PAINFUL TO SEE THEM SEVERLY SICK I ALWAYS FELT THE CHOICE WAS RIGHT. I PRESENTLY TAKE METHOTREXATE 10 MG WEEKLY P.O. IT WAS A VERY DIFFICULT DECISION, I HAVE SEVERE RHEUMATOID ARTHRITIS. I HAD BEEN ON GOLD THERAPY FOR TEN YEARS AND THIS HAD STOPPED WORKING. MY DECLINE HAD BEEN VERY RAPID. I FELT THAT I HAD NO CHOICE. AT FIRST IT MADE ME VERY SICK BUT WITH TIME MY BODY BECAME ACCUSTOMED TO THE DRUG AND I HAVE HAD GREAT SUCCESS. MY VERY DEAR FRIEND WHO STARTED THE SAME THERAPY HAD NO PROBLEMS AT FIRST BUT SHE DEVELOPED PNEUMONIA AND DIED (THAT IS ONE RISK THAT IS LISTED) I FELT GRIEVED AND FEARFUL HOWEVER EVEN KNOWING THE RISKS I FELT THANKFUL FOR THE LAST FEW MONTHS I HAVE NOT FELT THIS WELL FOR MORE THAN 10 YEARS. I KNOW THE RISK IS STILL THERE BUT I AM GLAD THAT I MADE THAT CHOICE.

I AM SURE THAT MY ANSWERS TO THE ABOVE QUESTIONS IS INFLUENCED BY THIS EXPERIENCE.

002 I FEEL THAT AS A NURSE, I MUST RESPECT ALL PATIENTS DECISIONS REGARDING THEIR CHOICE OF TREATMENT FOR CANCER. EVEN THOUGH THE TREATMENT IS SOMETIMES PAINFUL, CAUSING NAUSEA & VOMITING & ALOPECIA, I ADMIRE THE PATIENTS WHO TRY TO PROLONG THEIR LIVES BY WHATEVER TREATMENT IS AVAILABLE. I HAVE NOT WORKED WITH PATIENTS TAKING CHEMOTHERAPY IN SEVERAL YEARS AND I REALIZE THAT THERE HAVE BEEN CHANGES AND IMPROVEMENT SINCE THEN.

003 I WAS VERY ANXIOUS ABOUT EACH TREATMENT. HAD NO NAUSEA THOUGH. STILL (5 1/2 YEARS LATER) HAVE NEGATIVE THOUGHTS REGARDING THE CHEMO. TRY TO AVOID TALKING ABOUT IT AND AM GLAD WHEN PEOPLE DON'T SEND OTHERS TO ME TO GIVE ADVICE, SUPPORT, ETC. BEFORE THEY RECEIVE CHEMO.

004

005

006 I HAVE NOT RECEIVED TREATMENTS MYSELF BUT KNOW OF OTHERS WHO HAVE. I FEEL CHEMOTHERAPY IS SORT OF THE BEGINNING OF THE END WITH MOST EVERYONE I HAVE SEEN TAKING IT. THE CANCER IS USUALLY QUITE BAD AND CHEMO STOPS IT FOR AWHILE SO I FEEL THE TREATMENTS ARE POSITIVE BUT THE CANCER SEEMS TO WIN. I HAVE ONLY KNOWN ONE PERSON WHO DID NOT HAVE THE UNPLEASANT SIDE EFFECTS EXCEPT FOR HAIR LOSS. HE THOUGHT HE WAS "CURED" BUT DIED WITHIN A MONTH. THOSE ARE THE PEOPLE YOU HEAR ABOUT MOST BUT OTHERS HAVE BEEN RELIEVED OF CANCER FOR YEARS BECAUSE OF IT.

007

008 I WORK IN CT & SEE POST CHEMOTHERAPY PT'S AND HEAR THEIR STORY.

009 THE TREATMENT IS WORSE THAN THE DISEASE. ONE LEARNS TO VOMIT SO MUCH THAT WHEN THE VOMITING STOPS ONE MISSES IT AND FEELS THERE IS SOMETHING WRONG. NO MEDICATION STOPS THE VOMITING. IF I SHOULD HAVE A REOCCURANCE OF THE DISEASE, I WOULD SERIOUSLY CONTEMPLATE NO TREATMENT

010 THE EFFECTIVENESS OF CHEMOTHERAPY IS UNQUESTIONABLE. THE EFFECTS OF CHEMOTHERAPY ARE QUESTIONABLE. HOPEFULL RESEARCH IN GENETIC ENGINEERING USING AGENTS TAGGED SPECIFICALLY TO BODY ORGANS WILL RESULT IN CHEMOTHERAPY WITH A LESS OVERALL TOXIC AND DEBILITATING EFFECT.

011 PATIENTS SHOULD NOT EXPERIENCE ANY NEGATIVE EFFECTS FROM THOSE DRUGS. SHOULD WORK ON CA CELLS ONLY AND NOT HEALTHY ONE.

012 ITS SCARY, DEPRESSING, VERY HARD ON YOUR BODY. YOU ARE SICK AS THE DEVIL BUT IT'S A CHANCE YOU HAVE TO TAKE. IT WORKS FOR SOME PEOPLE AND WHEN IT'S YOUR LIFE YOU'RE TALKING ABOUT YOU HAVE TO TAKE EVERY CHANCE TO GET WELL OR TO PROLONG LIFE. WHEN YOU'RE THE FAMILY OR FRIEND SOMETIMES YOU HAVE TO FORCE YOURSELF TO SMILE AND GO AROUND THEM, THEY'RE SO SICK AND LOOK SO BAD AND YOU CAN'T FACE WHAT'S HAPPENING TO THEM, BUT YOU HAVE TO BE THEIR SUPPORT SYSTEM. YOU HAVE TO HELP THEM GO ON THEY CAN'T DO IT ALONE.

013 THERE HAVE BEEN CASES WHEN THE TREATMENTS HAVE CURED THAT I KNOW OF & HAVE TALKED TO. MY DAD LIVED 8 MOS WITH CHEMO TREATMENTS. THEY ONLY WEAKENED HIM & DID NOT PROLONG HIS LIFE.

014

015 CHEMOTHERAPY IS RISKY AND NOT AN AVENUE OF TREATMENT PERSONALLY. INDIVIDUALS MAY WISH TO PURSUE THE CHEMOTHERAPY ROUTE, BUT I BELIEVE IT TO BE EXPERIMENTAL AT BEST AND NOT WHAT I WOULD ELECT FOR MYSELF. IN MOST CASES CHEMOTHERAPY IS INITIATED AS A "LAST DITCH" EFFORT POST OPERATIVELY. I DON'T WANT TO TRADE QUANTITY FOR QUALITY.

016 APPRECIATE SIDE EFFECTS WHICH ACCOMPANT THERAPEUTIC VALUES

BELIEVE IT IS SUCCESSFUL MODE OF TUMOR/MALIGNANT GROWTH

EXPERIENCE ANXIETY WHEN ADMINISTERING DUE TO LIMITED INSERVICE, ETC IN ONCOLOGY

017 HOPEFULNESS, DEPRESSION, DENIAL, SCARY, FRIGHTENING, NAUSEATING, LOSS OF HAIR, BURNING, SIMILARITY IN MEDICATION NAMES AND A NURSES MISINTERPRETATION OF DRUG NAME CAUSED WRONG MEDICATION TO BE GIVEN--MAKING PATIENT VERY NAUSEATED--WEAK ILL FEELING. END RESULTS WORTH WHILE--3rd STAGE HODGKINS--COMPLETE REMISSION ACHIEVED. ONE YEAR LATER STILL APPEARS CURED.

018 MY EXPERIENCES WITH MY FRIEND RECEIVING CHEMOTHERAPY WERE VERY HOPEFUL. SHE HAD A VERY STRONG WILL TO LIVE AND WOULD DO WHATEVER IT TOOK TO PROLONG HER LIFE. SHE DID LIVE A VERY PRODUCTIVE LIFE FOR MANY YEARS, SO IN HER CASE IT WAS GOOD.

019 IN CERTAIN APPROPRIATE TYPES OF CANCER IT OFFERS HOPE WHERE THERE WAS VERY LITTLE. SIDE EFFECTS ARE DIFFICULT FOR PATIENT AND FAMILY. NURSES OF ONCOLOGY UNIT ARE BETTER PREPARED TO DISCUSS WITH FAMILY THAN IS USUAL MEDICAL STAFF MEMBER. SUPPORT GROUP OF PREVIOUS PATIENTS IS MOST SUPPORTIVE OF VARIOUS MECHANISMS.

020 DEPENDS ON TYPE OF CANCER. IF PATIENT DESIRES AND IS INFORMED OF ALL RISK.

021 I HAVE NOT HAD A LOT OF EXPERIENCE WITH CHEMO BUT I FEEL THAT IT IS IMPROVING WITH TIME AND IF I HAD CANCER I WOULD WANT CHEMO WITH THE HOPES OF LENGTHENING MY LIFE.

022 MIXED FEELINGS. HAVE SEEN IT MAKE PATIENTS VERY SICK AND HAVE ALSO SEEN IT HELP THEM.

023 MY BROTHER SUFFERED TERRIBLY FROM THE TREATMENTS AND DIED ANYWAY.

024 I REALLY HAVE HAD NO PERSONAL TOUCH WITH CHEMOTHERAPY. I HAVE HAD FRIENDS WHO HAVE GONE THROUGH CHEMO AND HAVE BEEN MISERABLE. I HAVE TO WONDER IF THE QUALITY OF LIFE OUTWEIGHS THE QUANTITY IN THESE CASES. I HAVE KNOWN CASES WHERE CHEMO HAS WORKED BUT THEY SEEM TO BE SO FEW AND FAR BETWEEN.

025 I AM AN R.N. & HAVE GIVEN CHEMOTHERAPY. I HAVE SEEN ITS DEVASTATING EFFECTS BOTH POSITIVE AND NEGATIVE. FOR ME THE FEELINGS & RELATIONSHIPS I'VE HAD WERE ALL POSITIVE.

026 OVERALL-POSITIVE. CAN BE VERY MUCH AN ORDEAL FOR
PERSON RECEIVING TREATMENT. VARIES WITH EACH SITUATION.

027 ONLY EXPERIENCE IS WITH FRIENDS. I FEEL THAT IT IS
EXTREMELY DEBILITATING AND NOT PARTICULARLY SUCCESSFUL.

028 HAD 2 CLOSE FRIENDS [&] RELATION--ONLY PROLONGED THE
DIEING FOR 6 MONTHS (6 MONTHS OF HELL).

029 HAVE NOT EXPERIENCED ENOUGH TO MAKE AN ADEQUATE
STATEMENT.

030 NOT FAMILIAR EXCEPT TO A CHILD'S EXPERIENCE WHO WAS AT
THE HOSPITAL WHEN MINE WAS THERE FOR SOMETHING ELSE.

031 THE WOMAN I KNOW WHO HAD CANCER WAS THE MOTHER OF A
FRIEND OF MINE. SHE HAD HAD REOCCURRING CANCER FOR YEARS.
FIRST IN THE BREAST & THEN ALL OVER. THE CHEMOTHERAPY
TREATMENTS WERE HELPFUL FOR AWHILE THOUGH THE TREATMENTS LEF
HER WEAK, NAUSEATED, & WITH SOME HAIR LOSS.

032 I BASICALLY NO NOTHING ABOUT IT--ONLY WHAT I SEE ON TV

033 BROTHER HAD EXTREME STRONG DOSES OF CHEMO IN STERILE
ROOM AT _____[HOSPITAL] FOR 45 DAYS. HE LIVED ANOTHER 8
YEARS TO AGE 62. I GAVE HOPE TO OTHERS WHO KNEW HIM--WHEN
THEY WERE DIAGNOSED.

034 I HAVEN'T HAD ANY PERSONAL EXPERIENCE.

035 I DON'T REALLY KNOW AT THIS POINT.

036 I HAVE KNOWN SOME PEOPLE TO REACT VIOLENTLY TO THE
TREATMENTS AND OTHERS TO REACT MILDLY TO THE TREATMENT.

037 EVERYONE I KNOW HAS BEEN MADE VERY UNCOMFORTABLE AND
STILL DIED.

038 I'VE ONLY HAD FRIENDS & RELATIVES WITH THIS TREATMENT,
SO I FEEL THESE ANSWERS ARE FROM A DISTANT VIEWPOINT.

039 A NECESSARY EVIL IN TREATING CANCER AT THIS TIME. IT
CAUSES ADDITIONAL PHYSICAL REACTIONS THAT ARE SEVERE, SUCH
AS HAIR LOSS, SORE, AND SICKNESS. IT IS USED TO KILL OFF
CANCER CELLS POSSIBLY PERMANENTLY OR AT LEAST MAY ALLOW
REMISSION. THE PATIENT SUFFERS A LOT PHYSICALLY &
EMOTIONALLY BUT HE'S NO GUARANTEE OF THE RESULT.

040 NO EXPERIENCE, JUST HEARSAY, GOOD AND BAD.

041 I FEEL THEY ARE THE LAST RESORT AND WHEN YOU GET
CHEMOTHERAPY TREATMENTS, YOU MOST LIKELY DO NOT HAVE MUCH
LONGER TO LIVE OR MUCH HOPE OF OVERCOMING THE CANCER.

042 GIVES THE PERSON HOPE. IT LOWERS SELF-ESTEEM. PT.
FEELS SO BAD FOLLOWING THE TR. YOU WISH THERE WAS SOMETHING
YOU COULD DO FOR THEM.

043 IT IS USUALLY THE SIGNAL OF THE 'END'. WITH THE SIDE
EFFECTS (i.e., HAIR LOSS, WT LOSS, ETC.) COMES A POOR SELF
IMAGE, DEPRESSION, AND GENERAL PHYSICAL AND MENTAL DECLINE.
PERSONALLY, I WOULD CHOOSE NOT TO RECEIVE CHEMOTHERAPY,
RATHER TO PASS ON WITH DIGNITY AND HOPE FOR ETERNAL PEACE.

044 I WOULD HATE TO TAKE IT BUT PROBABLY WOULD IF IT WERE THE ONLY ALTERNATIVE; THESE PATIENTS GET SO SICK FROM THE CHEMO, IT WEAKENS THEM. "IF IT DOESN'T KILL YOU IT MIGHT HEALT YOU."

045 MY BRONTER-IN-LAW HAD A MALIGNANT BRAIN TUMOR. AFTER CHEMO AND THE REMOVAL OF THE TUMOR, HE WAS TAKEN HOME BY HIS MOTHER WHO TOOK TOTAL CARE OF HIM UNTIL HIS DEATH SEVERAL MONTHS LATER. AFTER HIS SURGERY HE NO LONGER RECEIVED CHEMOTHERAPY.

046 I AM CURRENTLY WATCHING A FRIEND RECEIVE CHEMOTHERAPY. SHE WAS GOING TO _____[HOSPITAL]; SHE FELT THEY TREATEDE HER AS A RESEARCH SPECIMEN. HER SIDE EFFECTS WERE TERRIBLE, AND SHE RECIEVED LITTLE SUPPORT FROM DOCTORS AND NURSES. IT SEEMS THAT AT A TIME ONE IS FEELING SO MISERABLE, SOME COMPASSION IS NEEDED.

047 CHEMOTHERAPY TREATMENTS CAN PROLONG LIFE BUT CAN HAVE DEVASTATING SIDE EFFECTS.

048 MIXED EMOTIONS. I HAVE SE4EN HOW SICK '(NAUSEA) IT CAN MAKE A PERSON. LOOSING THEIR HAIR AND 90 ON...I DON'T KNOW IF I WOULD WANT IT.

049 SAD, DEPRESSING, WONDERING IF IT IS WORTH IT.

050 I HAVE SEEN POSITIVE REACTIONS--HOWEVER--WORKING IN HOSPITAL WHAT I SEE IS IT'S USE TO PROLONG THE LIFE OF PATIENTS--THAT IS, TO GIVE THEM 4 MORE MONTHS THAN THEY WOULD OTHERWISE HAVE.

051 I BELIEVE IT IS WORTHWHILE BUT DOES CAUSE SOME DISCOMFORT. I WOULD ADVISE IT IF THERE WAS NO OTHER TREATMENT TO USE.

052 I FEEL THAT IT PROLONGS LIFE. BUT THE SIDE EFFECTS ARE
SOMETIMES TOO PAINFUL FOR THE PERSON TO EVEN WANT TO LIVE.

053 IT IS HELPFUL IN THAT IT "GOT RID" OF MY FRIEND'S
CANCER, BUT IT WAS DETRIMENTAL TO HER APPEARANCE--MOST OF
HER HAIR FELL OUT--DRASTIC WEIGHT LOSS (POSSIBLY FROM CANCER
ITSELF).

054 CHEMOTHERAPY DOES HELP SOME OF THE PT LIVE LONGER BUT
THEY DON'T REALY LIVE IN A HEALTH WAY.

055 I AM A CHEMOTHERAPY/ONCOLOGY NURSE AND I FIND
CHEMOTHERAPY CAN BE QUITE HELPFUL IN DESTROYING CANCER
CELLS, BUT IT ALSO DESTROYS HEALTHY CELLS AND IS VERY
DANGEROUS. THE SIDE EFFECTS ARE OFTEN MORE INTOLERABLE THAN
THE DISEASES.

056 CONSIDERING THE CLIENT'S OPTION (WITH CANCER), I FEEL
IT OFFERS HOPE FOR A TERMINAL ILLNESS. BUT I HATE TO WATCH
THE CLIENT GO THROUGH THE SIDE EFFECTS.

057 WHILE THERE IS LIFE THERE IS HOPE. CHEMOTHERAPY,
ALTHOUGH THE SIDE EFFECTS CAN BE DEVASTATING IS A POSITIVE
FORM OF TREATMENT, RESULT-ORIENTED AND A MEANS TOWARD
ACHIEVING RECOVERY. TEMPORARILY EXPERIENCING PAIN IS WORTH
THE LIFE IT GENERATES AS LONG AS THE DIGNITY AND QUALITY
STILL REMAINS AFTER THE REBUILDING PROCESS.

058 MY WIFE IS UNDERGOIN CHEMOTHERAPY. SUCCESS TO DATE HAS
NOT BEEN CONCLUSIVE.

059 AFTER COLON CANCER, I HAD 8 TREATMENTS, ONE EACH MO FOR
6-7 DAYS IN HOSPITAL. THE NURSES AND DOCTORS AT
HOSP IN _____ WERE WONDERFUL TO ME. I
DETERMINED TO COOPERATE. MY HAIR CAME OUT AND WAS
DEVASTATING. I WAS WEAK AND TIRED. MY MOUTH BROKE OUT BUT
I STILL KEPT MY APPETITE. I OWE MY RECOVERY TO TREATMENT
AND POSITIVE THINKING.

060 MOST OF THOSE I'VE SEEN WHO HAD CHEMOTHERAPY WERE
FRIGHTENED, FELT INVADDED, THOUGHT IT MAY BE GOOD, BUT
UNPLEASANT. FELT THEY HAD NO CHOICE, BUT BASICALLY DID NOT
LIKE THE TREATMENT BECAUSE OF SIDE EFFECTS.

061 A COMBINATION OF APPRECIATION THE TREATMENT WAS
AVAILABLE AND TOTAL DESPAIR AT HAVING SUCH AN ASSAULT ON THE
FUNCTIONS OF MY BODY. THE LESSER OF TWO APPARENT EVILS.

062 NECESSARY, UNPLEASANT, PAINFUL, WEAKENING,
DAMAGING--LEFT ME WITH NUMBNESS, SKIN ALLERGIES, AND HAD TO
HAVE CATARAC SURGERY (LENS IMPLANT IN RIGH EYE. IT ALL LEFT
ME WITH FEAR AND PRAYING I NEVER HAVE TO GO THROUGH IT
AGAIN. I HAD TO GO THROUGH IT 3 TIMES/CYCLES. FIRST MOPP,
2ND AVBD, AND 3RD NISO, DEMORALIZING WHEN ALL MY HAIR WAS
LOST.

063 HAVEN'T TRIED THIS YET, IT WILL BE NEXT.

064 MY CHEMOTHERAPY IS SELF-APPLIED WITH A JYPODERMIC
NEEDLE. IT PRESENTS NO DIFFICULTY TO ADMINISTER AND HAS
PROVIDED PALLIATIVE EFFECTS.

065 I'VE HEARD NOTHING BUT HORROR STORIES ABOUT THE SIDE
EFFECTS AND FEEL IT'S A LAST RESORT IN MANY CASES.

066 WHEN I TOOK 2 ROUNDS OF CHEMOTHERAPY I KNEW IT HAD A
40% CHANCE OF WORKING. I WAS HOPEFUL BUT VERY SCARED OF
SIDE EFFECTS. THE SIDE EFFECTS WERE VERY HARSH.

067 SET POSITIVE GOAL. HAVE FAITH & BELIEVE CHEMO IS A
HEALING SOUGCE AND NECESSARY AND ABOVE ALL--PRAY AND HAVE A
VERY STRONG DESIRE TO LIVE.

068 MISERABLE

069 I VIEWED AN HOUR-LONG PROGRAM A WEEK OR TWO AGO ON
CHEMOTHERAPY TREATMENTS IN CHILDHOOD CANCERS. OTHER THAN
THAT; MAGAZINE ARTICLES, AND INFORMATIVE TELEVISION
FREQUENTLY.

070 MY MOTHER WAS HORRIBLY SICK!!!

071 MY GRANDDAUGHTER RECEIVED CHEMOTHERAPY FOR A BRAIN
TUMOR, UNSUCCESSFULLY. SHE BECAME VERY OPPOSED TO TAKING IT
BECAUSE OF THE PAIN OF VENIPUNCTURE SO SHE WAS FINALLY PUT
ON ORAL MEDICATION WHICH WAS ALSO UNSUCCESSFUL. IN
RETROSPECT, IF IT HAD BEEN MY DECISION I WOULD SAY NO TO HER
TAKING IT.

I WOULD NOT HAVE CHEMO

I FELT THAT IT REALLY WAS WORTHLESS, IT PROLONGED HER LIFE
ABOUT 9 MO TO A YEAR & SHE SEEMED TO BE IN MUCH PAIN DURING
THIS TIME.

072 I FEE THERE ARE INSTANCES WHEN CHEMOTHERAPY CAN DO
WONDERFUL THINGS. I FEEL EACH PERSON SHOULD BE ALLOWED TO
MAKE THEIR OWN DECISIONS REGARDING THE USE OF CHEMOTHERAPY.
IF THERE IS NO HOPE OF EXTENDING LIFE FOR A LONG TIME & IT
BE A "QUALITY" LIFE, I MIGHT PERSONALLY DECIDE TO REFUSE IT
BUT IF THERE IS SOME HOPE FOR CURE & PROLONGING A USEFUL
LIFE--GO FOR IT.

APPENDIX N

Validator Letter and Rating Form

April 11, 1988

Dear

Thank you for agreeing to serve as an expert to validate the enclosed instrument. This newly developed tool evolved from my concept analysis of expectancy. A copy of the theoretical framework, so far developed, and conceptual map are enclosed.

Although I developed this instrument to meet the requirements of a course in which I am presently enrolled, the chair of my dissertation committee felt it might also be used to collect data for my final study, hence the need for expert validation. For a pilot, in progress to validate the instrument, 250 copies of the tool have been distributed. The sample includes nurses, nursing students, a cancer support group, other health workers, and the general public. To date, ninety-three questionnaires have been returned.

Please use the enclosed rating form to validate the extent to which the instrument measures the attributes of expectancy as related to chemotherapy. I would appreciate comments on the content, format, and relevancy of the items. Feel free to comment directly on the instrument as well as on the rating form. I am grateful for any input, you share, related to each aspect of the instrument.

Upon completion, please return the validator response form and the instrument in the pre-addressed stamped envelope. Your return response by April 25, 1988 is respectfully requested.

Again, thank you for sharing your expertise, time, and energy. I am excited about the project and your willingness to assist. Please feel free to contact me regarding questions. You may reach me evenings at 817-898-4869. Because I am living in a dormitory, the call cannot be collect, but I will be happy to reimburse you if you will just include the amount of the call when you return the materials.

Sincerely,

Marilynn V. Mettler, R.N., M.S.
Texas Woman's University, P.O. Box 22205, Denton, TX 76204

Enc.: 1. Expectancy Assessment Tool
2. Participant letter and consent form
3. Validator Response Form
4. Theoretical framework and mapping

DATED MATERIAL:
PLEASE RETURN BY
APRIL 25, 1988

VALIDATOR RESPONSE FORM - CHEMOTHERAPY EXPECTANCY SCALE

DIRECTIONS: Rate the relevance of each pair of items to expectancy with chemotherapy. Place an X in the most appropriate column.

Items	Very Relevant	Quite Relevant	Slightly Relevant	Not Relevant
1. helpful---harmful				
2. proven---unproven				
3. beneficial--detrimental				
4. strong---weak				
5. successful-unsuccessful				
6. unfair---fair				
7. acceptable-unacceptable				
8. good---bad				
9. hopeful---hopeless				
10. painless---painful				
11. destructive--- constructive				
12. feared---not feared				
13. winning---losing				
14. reliable--unreliable				
15. wrong---right				
16. pleasant---unpleasant				
17. sure---unsure				
18. cheerful---gloomy				
19. gentle---harsh				

Please make comments about open-ended questions and demographics
directly on instrument or in the space below.

Other comments

APPENDIX O

Participant Comments - Pilot II

Question: In your own words briefly describe your feelings related to your experiences with chemotherapy treatments.

001 DREAD COMING IN FOR TREATMENT. S/E OF JOINT AND FEET SWELLING, JOINT ACHING. LOST WEIGHT FROM VOMITING AND DIARRHEA. LOST HAIR. FEEL BAD 3 WEEKS AFTER TREATMENT. MOUTH SORES AND NOSEBLEEDS.

002 AT FIRST VERY FEARFUL BECAUSE OF LISTENING TO OTHERS (i.e., SICKNESS AND LOSS OF HAIR) HUSBAND (NEW) VERY SUPPORTIVE. HAVE FOUND OUT WHAT'S REALLY IMPORTANT IN LIFE. TIRED FOR 2 DAYS AFTER RECEIVING TREATMENT. HAD HAIR LOSS. (5TH TREATMENT--EVERY 3 WKS)

003 SEVERE PAIN IN ELBOWS RELIEVED BY NTG. LOST A LITTLE BIT OF HAIR AFTER FIRST TREATMENT.

004 I REALIZE THAT THE TREATMENTS ARE FOR MY WELL-BEING IN THE FUTURE BUT SOMETIMES, ESPECIALLY WHILE I WAS VOMITING, I WOULD WONDER ABOUT IT. OVERALL, I RECEIVED PLENTY OF SUPPORT AND INFORMATION BEFORE AND DURING MY TREATMENTS. I ALSO WOULD RECOMMEND THAT ANYONE WITH CANCER SHOULD GO AHEAD AND HAVE CHEMOTHERAPY, IF RECOMMENDED BY THEIR DOCTORS. THERE IS A CERTAIN AMOUNT OF RELIEF IN KNOWING THAT ANY STRAY CANCER CELLS WILL BE ZAPPED BY THE CHEMO.

005 FELT THAT NURSES AT _____ HOSPITAL WERE MORE INFORMATIVE THAN HERE. TAKE RESPONSIBILITY FOR MY OWN CARE. MEDICATION WAS DECREASED BY _____ HOSPITAL AND YET LOCAL PHYSICIAN DID NOT KNOW. LOST HAIR AND HAD GENERALIZED ACHING.

Q06 NO PROBLEMS. I HAD SOME PROBLEM TAKING THE DECADRON PILLS AND WOULD HAVE TO EAT AFTER TAKING THEM TO REMOVE TASTE. I LOST MY HAIR BUT IT WILL GROW BACK. I WOULD RATHER THAT MY HUSBAND NOT BE WITH ME WHEN THE IV IS STARTED. HE THINKS IT HURTS ME A LOT AND I HARDLY FEEL ANYTHING. THE CHAIR IS COMFORTABLE.

Q07 NOT AS SCARY AS I PICTURED IT TO BE. USEFUL. SIDE EFFECTS--NOT REAL ALERT 3-4 DAYS AFTER TREATMENT.

Q08 MISSING

Q09 I ALWAYS FELT VERY SECURE IN MY TREATMENT. THE DOCTOR AND NURSE WERE ALWAYS VERY REASSURING; ALSO THE PEOPLE I TOOK TREATMENT WITH WERE VERY FRIENDLY.

Q10 MISSING

Q11 SOME WEAKNESS, NAUSEA, HAIR LOSS, WEIGHT LOSS. SOME CHEMICAL BURN TO MY HAND.

Q13 CHEMOTHERAPY MAY NOT BE THE MOST PLEASANT THING I HAVE HAD BUT IF THAT IS WHAT IS NEEDED TO STAY ALIVE, I CAN "LIVE" WITH IT.

Q14 MISSING

Q15 I HAVE EXPERIENCED FEW SIDE EFFECTS. THE CANCER HAS METASTASIZED DURING THE TREATMENTS, LEAVING ME TO WONDER ABOUT THE EFFECTS OF TREATMENT.

Q16 MISSING

Q17 I AM ON EXPERIMENTAL PROTOCOLS FOR THE TYPE OF LUNG CANCER I HAVE (METASTASIS TO MY OTHER LUNG). I HAVE BEEN ON THREE DIFFERENT CHEMO REGIMENS WITH NO SUCCESS. I AM NOW READY THIS MONTH TO START MY 4TH REGIMEN WHICH WILL BE 5FU (MUCH LARGER DOSAGE GIVEN BY PUMP) AND VP-16. I'M STILL FEELING POSITIVE ABOUT CHEMO SINCE IT IS THE ONLY TREATMENT AVAILABLE. WE ARE WORKING TOWARD SLOWING DOWN CANCER GROWTH.

Q18 I WAS VERY MUCH AGAINST CHEMOTHERAPY AFTER MY SURGERY BUT WAS TOLD I WOULD DIE WITHOUT IT. MY ONCOLOGIST TOLD ME OF A FEW OF THE SIDE EFFECTS BUT NOT ALL. HE DID NOT MENTION I MIGHT NEED BLOOD AT SOMETIME NOR DID HE SAY WHAT TO DO ABOUT SIDE EFFECTS UNTIL THEY OCCURRED. MAYBE THAT IS BECAUSE NOT ALL PEOPLE EXPERIENCE THE SAME REACTION AND THE INFORMATION WOULD HAVE BEEN OVERWHELMING IN THE BEGINNING, ESPECIALLY TO SOMEONE WHO RESISTED TREATMENT. I ALSO DID NOT REALIZE THAT TREATMENT TIME WOULD BECOME LONGER AS I PROGRESSED, DUE TO HYDRATION AFTER CHEMOTHERAPY AND WANTING ME TO STAY AND EAT TWO MEALS TO MAKE SURE I WOULD KEEP FOOD DOWN. I REALIZE IT IS FOR MY OWN PROTECTION.

Q19 WILL NOT CONSENT TO ANY MORE TREATMENTS JUST TO PROLONG THE CONDITION

Q20 I HATED GOING FOR THE TREATMENTS, BUT AFTER A WHILE I BEGAN TO FEEL DEPENDENT ON THEM. IT WAS SCARY WHEN THEY ENDED. I WAS TREATED IN A SMALL TOWN AND THERE WAS NO SENSE OF FIGHTING SPIRIT OR SOLID HOPE. I ALWAYS FELT AS IF EVERYONE WAS WALKING ON EGGHELLS. BECAUSE OF MY DETERMINATION TO GET WELL, I DID NOT ALLOW THIS TO DISCOURAGE ME. I READ e.o., COPING MAGAZINE--WHICH I FOUND FOR MYSELF!, THE SIMONTON BOOKS, SCHERTEIG'S BOOK. I WROTE MY OWN BOOK (GETTING BETTER), GOT MYSELF A COUNSELOR, AND LEARNED BIOFEEDBACK. I TOOK THE ATTITUDE THAT MEDICINE WAS AN IMPORTANT PART OF MY HEALING--BUT NOT THE ONLY PART, NOT EVEN NECESSARILY THE MOST IMPORTANT PART. THAT HELPED MAKE WHAT WENT ON IN THE DOCTOR'S OFFICE NOT SEEM SO INADEQUATE. I HAD COMPETENT MEDICAL TREATMENT, BUT IT WAS PRIMARILY MEDICAL, IN THE DOCTOR'S OFFICE.

021 I HAVE A PORT-A-CATH IN THE HEPATIC ARTERY. CHEMO IS GIVEN WITH A PUMP AND I AM ON CHEMO 20 DAYS AT A TIME, OFF 21 DAYS. LITTLE OR NO SIDE EFFECTS WITH CHEMO. CHEMO HAS NOT BEEN AS BAD AS EXPECTED. AFTER CHEMO FOR 9 WEEKS A CAT SCAN SHOWS A SMALL REDUCTION IN SIZE OF TUMOR. FEELINGS WERE THAT IF I DID NOT HAVE SIDE EFFECTS MAYBE IT WASN'T DOING ANY GOOD. NOW THAT THE TUMOR IS REDUCED, I FEEL GREAT! NO SIDE EFFECTS AND ITS WORKING. A WEEK BEFORE THE CAT SCAN WAS BAD--WORRYING, WONDERING, ETC.

022 THERE MUST BE A BETTER WAY. NOT ENOUGH DOLLARS OR RESEARCH IS BEING SPENT ON FINDING A LESS BARBARIOUS MEANS OF TREATMENT.

023 MISSING

Q24 I HAD 6 MONTHS OF A PROTOCOL CALLED SYNCHRONIZED CHEMOTHERAPY AS AN OUTPATIENT, THEN 4 DAYS A MONTH FOR THREE MONTHS AS AN INPATIENT. MY FIRST EXPERIENCE, THE FIRST MONTH AS AN OUTPATIENT WAS POOR. THE CYCLE WAS A DAY-1 AND DAY-8 FOR THE CHEMO EACH MONTH--ADRIAMYCIN AND CYTOXAN ON DAY-1 AND METHOTREXATE AND 5FU ON DAY-8. BETWEEN DAYS 1 AND 8, I TOOK TAMOXIFEN AND DAY-7, PREMARIN. THE CRITICAL PART WAS AFTER DAY-8, TO TAKE LEUCOVORAN RESCUE, OTHERWISE, STOMATITIS WOULD DEVELOP. WHEN THE FIRST NURSE GAVE THE INSTRUCTIONS SHE SOUNDED AS THOUGH SHE WAS GIVING A LECTURE. ALSO, THERE WAS A ONE HOUR BREAK BETWEEN THE METHOTREXATE AND 5FU. FOR THAT ONE HOUR DURING THE ONE MONTH I SAT IN THE SAME CHAIR AND DID NOT MOVE. SHE THOUGHT THE NEEDLE MIGHT COME OUT. SHE WAS EVEN CONCERNED ABOUT HANDLING A MAGAZINE. THE ROOM WAS VERY COLD AND I DREADED GOING BACK, PARTICULARLY DREADED HAVING HER THERE. I ASKED FOR ANOTHER THERAPIST. THEY HAVE TWO OFFICES AND MY EXPERIENCE AFTER THAT WAS COMPLETELY DIFFERENT. THE SECOND NURSE WAS VERY RELAXED. AFTER THE METHOTREXATE, SHE WOULD TAPE THE BUTTERFLY AND MY SISTER AND I WOULD LEAVE THE OFFICE FOR AN HOUR TO GET A CUP OF COFFEE OR COKE.

AS I MENTIONED BEFORE, INITIALLY, I BEGAN TO FEEL AS THOUGH I WAS BEING DISCIPLINED FOR SOMETHING I HAD DONE (HAD GOTTEN CANCER). THERAFTER, WITH THE SECOND NURSE, I FELT I WAS ACCOMPLISHING SOMETHING POSITIVE IN MY FIGHT TO BUY SOME TIME, MAYBE EVEN BE ONE OF THE MIRACLES WITH SURVIVAL. I AM A STAGE IV BREAST CANCER WITH A POOR PROGNOSIS BUT HAVE HAD VERY GOOD RESULTS WITH THE CHEMO. I WILL PROBABLY NEXT HAVE A MASTECTOMY AND RADIATION.

I HOPE THIS HAS BEEN HELPFUL.

P.S. AFTER MY FIRST MONTH, I DID DEVELOP STOMATITIS. WHEN THE NURSE GAVE THE INSTRUCTIONS FOR THE RESCUE, I WANTED TO WRITE DOWN THE SCHEDULE, BUT SHE SAID I WAS TO DO THAT LATER BECAUSE I MIGHT PULL OUT THE NEEDLE BY WRITING. I WAS NOT ABLE TO SEE HER AFTER THE SESSION AND THOUGHT I HAD IT STRAIGHT. I LOST ABOUT A WEEK OF WORK BECAUSE OF THE STOMATITIS. IT WAS A HORRIBLE EXPERIENCE.

THE NURSES IN THE HOSPITAL WERE VERY SUPPORTIVE AND SWEET, AS WAS MY SECOND OUTPATIENT NURSE.

025 HAD MINOR SIDE EFFECTS BUT QUITE TIRED FOR 10 DAYS TO 2 WEEKS AND DIDN'T WANT MUCH TO EAT THE REST OF DAY OF TREATMENT. I WAS WORRIED THAT THEY ON ONE OCCASION THEY MIXED THE FLUID AND HELD IT OVERNIGHT BECAUSE THERE WASN'T TIME TO DO IT THAT AFTERNOON. I WAS DISTRESSED THAT THE TREATMENT WAS TERMINATED FOR I FELT IT HAD HELPED (ACTUALLY THE NODES IN THE NECK GREW RAPIDLY AFTER TREATMENT STOPPED).

026 -- 039 MISSING

040 IT WAS NOT BAD AT ALL. I QUICKLY LEARNED TO USE THE ANTI-NAUSEA SUPPOSITORIES & THUS WAS NOT SICK WITH IT. I DIDN'T LOSE MY HAIR. HOWEVER, I'M THANKFUL IT'S OVER!

041 I AM GOING TO DO ALL I CAN TO FIGHT THE CANCER--ASK QUESTIONS, TRY NEW TREATMENTS IF ADVISED BY DOCTORS, READ ABOUT NEW TREATMENTS--BE HAPPY AND GO ON WITH MY LIFE FOR AS LONG AS POSSIBLE--HOPE FOR A CURE, BUT NOT DISPAIR--I KNOW WHERE I AM GOING AFTER THIS LIFE.

042 IT WAS VERY SCARY AND MADE ME TERRIBLY SICK FOR ABOUT 24 HRS.

043 MISSING

Q44 CHEMO WASN'T VERY PLEASANT BUT I DIDN'T HAVE A CHOICE AND I WAS VERY THANKFULL AND STILL AM THAT THERE IS SOMETHING AVAILABLE TODAY. EVEN FOR ME ANYWAY, THE SIDE EFFECTS WERE HORRIBLE. MANY TIMES I ASKED THEM TO PLEASE STOP. BUT I FINISHED ALL OF THEM. 8 LONG MONTHS. WITH THE HELP OF MY BEST FRIEND MY HUSBAND. MY DOCTOR AND OTHER FAM MEMBERS, AND FRIENDS. THERE WAS NOT ONE TIME THAT I WASN'T THANKFULL FOR ALL THE MED KNOWLEDGE THEY HAVE TODAY.

TODAY I FEEL GREAT. I'M NOT OUT OF THE WOODS YET. BUT LIFE COULD NOT BE BETTER.

THANK YOU MARILYNN FOR LETTING ME HELP YOU. IF YOU NEED ANY MORE INFO FEEL FREE TO LET ME KNOW. I HAVE HAD RECONSTRUCTIVE SURG IN THE MEAN TIME. THAT TRUELY MAKES ME FEEL WHOLE AGAIN AND PROUD TO BE A WOMAN. FOR ME THAT WAS ONE OF THE BEST THINGS I DID FOR MYSELF--RECONSTRUCTIVE SURGERY. THANK YOU.

Q45 CHEMOTHERAPY PROVIDED ME WITH A FEELING THAT I WAS DOING SOMETHING TO HELP MYSELF BEYOND SURGERY.

MY EXPERIENCES WITH CHEMO WERE NOT NEGATIVE. THE DR & NURSES WERE MOST HELPFUL AND FRIENDLY AND VERY POSITIVE. THAT IS MOST IMPORTANT. I DEVELOPED AN IMPORTANT CLOSENESS WITH THEM. AT THE TIME CHEMO WAS HORRIBLE, BUT I WOULD DO IT AGAIN IF NECESSARY.

Q46 POSITIVE EXPERIENCE DUE TO SUPPORT OF FAMILY, FRIENDS, & MEDICAL PERSONNEL. CHEMOTHERAPY WAS A CHOICE ON MY PART, NOT PARTICULARLY RECOMMENDED BY MY INITIAL PHYSICIANS.

Q47 I'M THANKFUL THE HEALTH CARE SYSTEM IS SO ADVANCED TODAY THAT CHEMOTHERAPY IS AN OPTION FOR ME IN MY FIGHT TO SURVIVE CANCER.

048 THE EXPERIENCE WAS TERRIBLE. IT KEPT ME TOTALLY
EXHAUSTED ALL THE TIME. HAD 4 UNITS OF BLOOD, EVERY SIDE
EFFECT. MY CANCER IS TERMINAL & I DON'T THINK IT HELPED AT
ALL.

049 MY FEELINGS ABOUT CHEMO WERE POSITIVE. I WANTED THE
TREATMENT. I'D SEEN IT WORK FOR OTHER PEOPLE. THE FIRST
SESSION WAS OK TO GO TO. BUT IT MADE ME SO SICK I DIDN'T
THINK I WOULD SURVIVE THE TREATMENT. MY HAIR ALL CAME OUT
IN LESS THAN 2 DAYS THREE WEEKS AFTER THE TREATMENT. THE
SECOND TREATMENT WAS THE HARDEST TO GO FOR. IT'S HARD TO
TAKE A MEDICINE TO GET BETTER WHEN IT MAKES YOU FEEL SO
SICK. I WOULD NOT HAVE CONTINUED IF I DIDN'T THINK IT WAS
WORTH IT. THE SIDE EFFECTS WERE A SIGN TO ME THAT THE
MEDICINE WAS DOING WHAT IT WAS SUPPOSED TO. I DIDN'T FEEL
GOOD FOR THE YEAR OF TREATMENT. IT WAS A HARD JOB.

I FELT WELL INFORMED AND MY QUESTIONS WERE ANSWERED AS
WELL AS POSSIBLE. THE DR. WAS ALWAYS AVAILABLE WHEN NEEDED.
THE NURSE MIXED THE DRUGS IN MY PRESENCE WHICH I WANTED, AS
IT ALLOWED ME TO PARTICIPATE. BUT SHE TALKED ABOUT SO MANY
OTHER THINGS IT TENDED TO DISTRACT HER FROM THE PROCEDURES.
SHE MADE ERRORS SEVERAL TIMES WHICH WERE CORRECTED. SHE MAY
HAVE BEEN TRYING TO "DISTRACT" ME BUT THAT WASN'T NECESSARY.
MY PARTICIPATION WAS A HELP. KNOWING THINGS HELPED TO
REMOVE SOME OF THE FEARS.

I NEEDED TO FEEL IN CONTROL. I NEEDED TO KNOW I HAD
THE CHOICE TO ACCEPT THE TREATMENT OR NOT.

RELAXATION--MEDITATION--AND IMAGERY WERE ALSO IMPORTANT
TO ME. THEY PROVIDED A DISCIPLINE TO FOCUS THOUGHTS AND
ENERGY IN A POSITIVE WAY. HELPED ME TO FEEL IN CONTROL
INSTEAD OF A VICTIM.

READING AND TALKING TO OTHERS ABOUT THEIR EXPERIENCES
WAS ALSO A HELP. IT LET ME KNOW I WASN'T THE ONLY ONE WHO
HAD THOSE FEELINGS. I WASN'T ALONE.

Q50 THE PROCESS WAS FRIGHTNING AND CAUSED SOME SICKNESS AND WEAKNESS. HOWEVER, I FEEL VERY FORTUNATE THAT I WAS NOT EXTREMELY SICK, DID NOT LOOSE ALL MY HAIR OR OTHER SEVERE SIDE EFFECTS. HOWEVER, I DID GAIN APPROX 40 LBS. WHICH HAS BEEN DIFFICULT TO LOOSE.

Q51 MISSING

Q52 I BELIEVE I ONLY BECAME ILL WITH CHEMO TREATMENTS TOWARD THE END OF TREATMENTS AND THEN IT WOULD BE ON THE WAY TO THE HOSPITAL, SO IT HAD TO BE PSYCHOSOMATIC. I FELT THE TREATMENTS WERE A NECESSARY EVIL THAT HAD TO BE ENDURED IN ORDER TO GET WELL.

Q53 MISSING

Q54 WHEN THE DR TOLD ME I "HAD TO HAVE" CHEMOTHERAPY I WAS DEVASTATED. HE DID NOT EXPLAIN THE TREATMENT AT ALL EXCEPT THAT IT WOULD BE FOR 26 WEEKS. FOR ME CANCER MEANT DEATH AND CHEMOTHERAPY MEANT SUFFERING AND THEN DEATH.

I ENVISIONED TREATMENTS OF 10-12 HRS, PAINFUL, VERY SICK AFTERWARDS ALL THE TIME. THIS WAS BASED ON MY ONLY EXPERIENCES WITH CHEMO--A SISTER-IN-LAW WHO DIED AND A FRIEND WHO DIED.

IT WOULD HAVE BEEN HELPFUL TO ME TO HAVE HAD A DETAILED EXPLANATION OF THE PROCESS DURATION AND TIME OF TREATMENTS AND THE BOOK CHEMOTHERAPY AND YOU. THIS BOOK IS PUBLISHED BY U S DEPT OF HEALTH & HUMAN SERVICES AND IS INFORMATIVE, CLEAR AND UNDERSTANDABLE. THIS INFO WOULD HAVE HELPED ME MAKE A MORE INTELLIGENT DECISION AND WOULD HAVE MADE IT A LOT EASIER. IT WOULD ALSO HAVE ALLAYED MY FEARS.

ALSO, IT WOULD HAVE BEEN HELPFUL TO TALK TO SOMEONE WHO HAD LIVED THROUGH THE TREATMENTS--GIVING PROOF IT WAS POSSIBLE TO SURVIVE AND LIVE A NORMAL LIFE. THIS PERSON SHOULD BE CAREFULLY SELECTED AND TRAINED, POSITIVE, OBJECTIVE AND HONEST.

Q55 MISSING

Q56 IN THE BEGINNING OCT. I WAS OPTIMISTIC. BUT SINCE JULY, WHEN A STRONGER TREATMENT WAS ADVISEABLE I'M DISCOURAGED YET TRY TO BE HOPEFUL & NOT BOTHER OTHER PEOPLE WITH MY FEELINGS. MY PROBLEM WAS DISCOVERED TWO WEEKS BEFORE THE DEATH OF MY HUSBAND WITH CANCER--I LIVE ALONE & HAVE NO CHILDREN SO AM SURE THAT CONTRIBUTES TO MY SOMETIMES FEELINGS OF HOPELESSNESS.

Q57 I STARTED MY TREATMENT AUGUST. I HAD FLU-LIKE SYMPTOMS IN SEPTEMBER AND WAS REALLY WEAK FOR ABOUT 2 WEEKS. I MISSED THE CHEMO FOR 2 WEEKS IN SEPT. I DIDN'T MISS AGAIN UNTIL NOW. AFTER I WAS OFF OF THE VINCRISTINE AND PREDNISONE I WAS OVER THE WORST TIME. I MISSED MORE TREATMENTS IN DEC. ALSO JAN. MY 6 MONTHS WAS UP IN FEB. I HAVE HAD BLOOD WORK, BONE SCAN, XRAY SINCE THEN. I GO BACK IN SEPT FOR CHECK.

I LOST AT LEAST 25 LBS, ALSO MY HAIR GOT VERY THIN.

MY FEELINGS ARE THAT I DIDN'T REALLY HAVE A CHOICE.

Q58 DREAD TO TAKE TREATMENT BUT FEEL IF I DON'T TAKE THEM I KNOW WHAT WILL BE THE OUTCOME. I FEEL THE OFC DOES NOT TAKE COMPLAINTS & SYMPTOMS SERIOUS, TO MATTER OF FACT ABOUT TREATMENTS.

Q59 I WAS WORRIED ABOUT THE TREATMENTS AND THE WAY I WOULD FEEL. NOW I KNOW THAT I HAD EXCELLENT ADVICE AND ENCOURAGEMENT FROM MY DOCTOR & NURSES.

I HAD TWELVE TREATMENTS. AFTER NINE TREATMENTS I HAD DEVELOPED BLOOD CLOT IN MY AORTA. I HAD BY-PASS SURGERY AND FINISHED MY TREATMENTS. I WAS DISMISSED WITH NO SIGNS OF CANCER. ALL TESTS NEGATIVE.

Q60 THE TREATMENT PROVIDED BY MY ONCOLOGY NURSES WAS SUPERB WITHOUT EXCEPTION. HOWEVER, AMONG SOME OTHER NURSES GENERALLY, I FOUND A LACK OF UNDERSTANDING AND COMPASSION FOR THE UNIQUE NEEDS AND CONCERNS OF CANCER PATIENTS.

APPENDIX P

Data Collectors - Summary Form

SUMMARY QUESTIONNAIRE

Please answer the following questions (s best you can) that relate to the project Social Support, Information, Expectancy, and Adherence in Outpatient Cancer Patients Receiving Chemotherapy.

1. Were all of the Expectancy Scales handed out? _____
2. If the answer to #1 is no, how many questionnaires are left?

3. Approximately how many clients/patients refused to take part in the study? _____
4. What were the main reasons given for not wanting to answer the questionnaires?

5. Did the client/patient answer the Expectancy Scale
_____ while in the office/hospital.
_____ take it home to answer.
6. Did each individual that said they would answer the Expectancy Scale also receive the Name/Address sheet? _____
7. Were the address sheets completed
_____ in the office/hospital.
_____ taken home to complete
8. Did any client/patient that answered the first (CES) questionnaire decide not to complete the chemotherapy regimen? _____
9. If the answer to #8 is yes, what reason(s) were given?

10. Any general comments you would like to make?

THANK YOU

Question: In your own words briefly describe your feelings related to your experiences with chemotherapy treatments.

001 SIDE EFFECTS HAVE BEEN SOME NAUSEA, SOME DIZZINESS, A LITTLE YUCKY ONCE IN A WHILE BUT NOT BAD

002 A MOST HORRIBLE AND TERRIFYING EXPERIENCE

03 THE FIRST TREATMENT WAS THE WORST IN TERMS OF SIDE EFFECTS. THE 5FU WAS DECREASED AND ALL SIDE EFFECTS SINCE THEN HAVE BEEN NOMINAL. THE DOCTOR IS VERY EASY TO TALK TO, SHE DOES NOT RUSH ME AND ANSWERS ALL MY QUESTIONS FRANKLY AND TO THE POINT.

THE NURSE HAS BEEN VERY HELPFUL ALSO.

ALL IN ALL MY EXPERIENCE WITH CHEMOTHERAPY HAS NOT BEEN UNPLEASANT. I WILL, HOWEVER, BE GLAD WHEN THEY ARE OVER! I'M ON A WEEK, FOUR WEEKS OFF SCHEDULE SO THERE IS ONLY ONE WEEK OUT OF FIVE THAT I FEEL BAD.

004 I HOPE I NEVER HAVE TO HAVE CHEMOTHERAPY AGAIN. IT IS NO FUN.

005 MY EXPERIENCE WAS ALWAYS POSITIVE. EVERYTHING HAS WORKED OUT REALLY WELL.

006 AT FIRST I WAS AFRAID BUT AS I HAVE RECEIVED MORE TREATMENTS AND HAVE FELT BETTER EACH TIME MY FEAR HAS LESSENED AND NOW I AM BECOMING HOPEFUL OF GOING INTO REMISSION.

007 IT WAS A LOT DIFFERENT THAN I HAD THOUGHT. AFTER TALKING TO THE DRS THEY MADE THING SEEM BETTER. WITH A DYING DIAGNOSIS THERE WAS ALWAYS LIGHT AT THE END.

008 ITS NOT A PLEASANT EXPERIENCE--LOSS OF HAIR, STOMACH SICKNESS, LOSS OF WEIGHT. BUT WITH ALL ITS NEGATIVE--THE DOCTOR THOUGHT IT WAS THE BEST TREATMENT TO START WITH--AND I AGREED WITH HIM.

009 I BECAME OVERWEIGHT. TREATMENT DID NOT MAKE ME SICK.

010 I WAS VERY APPREHENSIVE ABOUT STARTING THE CHEMO--HOW I WOULD REACT, THE SIDE EFFECTS, HOW BAD THEY WOULD BE, WHICH ONES I WOULD GET, ETC. THE NAUSEA AND SICK ALL OVER FEELING WAS THE WORSE, ALONG WITH THE TIREDNESS, DIFFICULTY SLEEPING. AT THE BEGINNING I HAD TO READ THE INFO THEY GAVE ME SEVERAL TIMES TRYING TO KEEP THINGS STRAIGHT. AS TIME WENT ON THE SIDE EFFECTS CAME SOONER, WERE WORSE, & LASTED LONGER. AFTER MY LAST CHEMO, EVEN THO I KNEW IT WAS THE LAST ONE I BEGAN TO FEEL REAL DOWN ABOUT IT AND HOW SICK IT HAD MADE MY BODY. I BELIEVE, THO IT WAS THE RIGHT CHOICE. I WANTED TO DO ANYTHING TO "CURE" MY CANCER OR KEEP IT FROM RECURRING AND THAT'S WHAT MEDICAL SCIENCE HAS NOW. AT THIS POINT IN TIME I HOPE TOO THAT I WILL RECOVER QUICKLY AND COMPLETELY FROM THE SIDE EFFECTS AND TO STOP FEELING SICK AND HAVE ENOUGH STRENGTH AND ENERGY TO DO WHAT I USED TO DO. I LEARNED TO FROM READING AND SEMINARS THAT BREAST CANCER IS NOT JUST A LOCAL BREAST CANCER--DO SURGERY AND ADJUVANT THERAPY THAT'S IT--BUT A SYSTEMIC DISEASE. I WILL DEFINITELY KEEP ALL MY FOLLOW UP APPTS.

011 EVEN THOUGH THE RESULTS HAVE BEEN GOOD, THE CHEMO THERAPY HAD TO BE THE MOST AWFUL THING I'VE EVER GONE THROUGH. I KNEW I WOULD BE NAUSEOUS, BUT DIDN'T REALIZE THAT MY WHOLE BODY WOULD FEEL THAT WAY. I EXPECTED TO LOSE MY HAIR, BUT THOUGHT IT WOULD BE MORE GRADUAL. IT STARTED FALLING OUT 19 DAYS AFTER MY 1ST TREATMENT AND WAS GONE WITHIN A WEEK! I ALSO WASN'T PREPARED FOR THE EMOTIONAL IMPACT OF MY HAIR LOSS. I THOUGHT I WAS, BUT I WASN'T. I COULD NOT HAVE MADE IT THROUGH THE PROCESS AT ALL WITHOUT MY FAITH IN GOD AND THE PRAYERS & SUPPORT OF OUR CHURCH FAMILY AND FRIENDS. THE EMOTIONAL IMPACT OF THE CANCER AND CHEMOTHERAPY IS SOMETHING I CERTAINLY WON'T FORGET AND WILL TAKE A LONG TIME (IF EVER) TO COMPLETELY RECOVER FROM.

012 FEARED THE UNKNOWN SIDE EFFECTS THAT POSSIBLY WOULD OCCUR. I COULD ENDURE ALL THE IV'S, SHOTS, NEEDLES, DRUGS & PILLS EVEN THE HAIR LOSS. IT WAS BEING SICK AND VOMITING AFTER TREATMENTS THAT I DIDN'T WANT TO FACE. I WAS FORTUNATE AND WASN'T SICK THAT MUCH. THE REALITIES OF CANCER HIT ME WHEN MY HAIR BEGAN TO COME OUT BY THE HANDFULS. I CRIED. THOSE SAD FEELINGS PASSED, KNOWING THAT IT WAS GOING TO GROW BACK. I HAD TO HAVE POSITIVE FEELINGS OF THE END RESULT OF MY TREATMENTS.

013 I FELT VERY ILL DURING THE TREATMENT. DURING MY FIRST TREATMENT MY LUNG COLLAPSED. DURING MY 4 TREATMENT I BECAME DISORIENTED AND FELL. BUT NOW AFTER ALL THE TREATMENTS AM BOUNCING BACK REAL WELL.

014 I WAS RELIEVED TO HAVE THEM OVER. I BEGAN TO DREAD THEM AND WAS ANXIOUS TO BE DONE ABOUT HALFWAY THROUGH. I WAS COMFORTABLE WITH THE PROCEDURE, I JUST HATED BEING SO TIRED AND WORN DOWN FOR HALF OF THE TIME. I KEPT IN REASONABLY GOOD CONDITION THROUGHOUT. IT WAS IMPORTANT TO ME TO KEEP ACTIVE, I WISH I HAD DONE MORE THAN I DID. THE TREATMENTS THEMSELVES WEREN'T THAT BAD, JUST GETTING PSYCHED UP TO BE SICK WAS HARD.

015 BOB WAS NOT TALKATIVE REGARDING FEELINGS. HE HAD FAITH IN HIS DOCTOR AND TRUSTED THAT THIS WAS THE BEST AND ONLY THING HE COULD DO. HE KNEW DEATH WAS INEVITABLE YET HOPED FOR THE BEST. AS A WIFE, I COULD NOT HELP THINKING "WHY PROLONG THE AGONY?" HAD THERE BEEN SOME HOPE FOR RECOVERY AND A DECENT LIFE AFTER, I'D HAVE BEEN MORE ENTHUSED ABOUT CHEMO, BUT JUST TO LENGTHEN HIS LIFE A FEW MORE MONTHS AND WATCH A ONCE ACTIVE HARD WORKING PERSON WASTE AWAY, WAS TO ME A WASTE OF MONEY. LUCKILY NEARLY 100% WAS PAID FOR THROUGH INSURANCE. MR. K. WORE A PUMP AND DID NOT RECEIVE EXTREMELY LENGTHY TREATMENTS.

 016 I WONDER IF IT IS DOING ANY GOOD. I TOOK CHEMO 1989 THROUGH FEB 1990. THEN RADIATION IN '91 & NOW MORE CHEMO. I HAVE BREAST CANCER. I AM NOW WONDERING IF CHEMO AND MESSAGE MAY BE DONE AT THE SAME TIME TO IRRIGATE THE BODY SO THAT THE CHEMO CAN WORK. I THINK IT IS A NATIONAL DISASTER THAT 1 IN 9 WOMEN WILL HAVE BREAST CANCER. THESE ARE MOTHERS, WIVES, WORKERS, PEOPLE TRYING TO BE GOOD PEOPLE AND THEN 'BOOM' 47,000 DEATHS IS A LOT IN ONE YEAR. CHEMO HAS BEEN MY BEST OPTION SO FAR!.

 017 MISSING

018 MY FIRST ONE WAS AWFUL. 2ND ONE ONLY MADE ME HYPER. 3RD & SO ON TO END ABOUT 1/2 AS BAD AS FIRST ONE. MY MULTI-MYLOMA IS NOW IN REMISSION. MY FIRST OF SIX TREATMENT WAS 2350 COUNT. MY LAST WAS 900. MY NEXT CHECK (LAST ONE FOR A WHILE, WILL BE LOWER).

THIS IS HOW IT MADE ME FEEL. THE FIRST ONE MADE EVERY BONE IN ME TO HURT. MY HAIR STARTED COMING OUT (DARK HAIR AT 74 YEARS). I HAD IT ALL CUT OFF AND IT HAS COME BACK (SHORT) AND WHITE. IT SLOWED MY HEART RATE TO 2 BEATS AND ONE MISS FOR A COUPE OF DAYS. I HAVE SEVERE HEART TROUBLE AND TYPE ONE DIABETES, ALSO. IT AFFECTED MY BLOOD SUGAR VERY LITTLE.

EVERYTHING I DRANK FOR 2 OR 3 WEEKS TASTED OILY. NO TASTE WITH TONGUE. EACH TREATMENT SAME. MY DOCTOR SAID THAT HE BELIEVED THAT AT MY AGE IT MUST BE MORE LIKE ARTHRITIS BUT IT HURT MUCH MORE THAN THAT. (BONES)

I THINK THESE 6 TREATMENTS (NEEDLE AND PILLS) HAVE ME IN CONTROL OF THIS AS OF NOW. MIGHT BE IN COMPLETE REMISSION. MY DOSAGE WAS A SMALL BAG OF ? WITH NEEDLE THEN FOR THAT DAY AND THREE FOLLOWING DAYS WAS.

PREDNISONE-2 EACH DAY-4 DAYS IN ALL-8 PILLS
 CYTOXAN-4 EACH DAY-4 DAYS IN ALL-16 PILLS
 ALKERAN-5 EACH DAY-4 DAYS IN ALL-20 PILLS

I HOPE YOU CAN READ THIS AND IT IS UNDERSTANDABLE AND IT HAS HELPED YOU. ANY FURTHER QUESTIONS FEEL FREE TO ASK.

 019 VERY DEPRESSING

020 GOOD - THEY WERE HARD ON ME, BUT SO FAR REMOVED
DETECTABLE CANCER & NEVER MADE MY STOMACH SICK. THEY
OVERSTIMULATED ME, REMOVED HAIR, LOOSENEED PLUMBING, & MADE
ME & STILL LITTLE LIGHTHEADED.

021 I had expected to be nauseous--they had told me after
5-9 days I might be & had given me medicine for it. I
sometime felt a little sick & did not have much energy, gut
on the whole I think I did well & it was not as bad as I had
expected it to be.

022 I DIDN'T REALLY LIKE TO GO FOR TREATMENT. I REALIZED
I MUST TAKE THE TREATMENT AND THE NURSES AND DOCTORS MADE IT
MUCH EASIER TO DO. I FEEL THAT THE TREATMENTS DID WHAT THEY
WERE SUPPOSED TO DO. I'M HAPPY I WENT THOUGH IT--I'M HAPPY
IT IS OVER.

023 I FEEL THE CHEMOTHERAPY IS LIKE AND INSURANCE POLICY.
YOU MAY NEVER NEED IT BUT IF YOU HAVE IT YOU FEEL MORE
SECURE ABOUT YOUR LIFE.

024 LOSS OF HAIR IS BAD, IN SO FAR AS MY IMAGE. SICKNESS
IS AT TIMES HARD TO PUT UP WITH, BUT [EXCEPTION] OF THOSE
TWO ITEMS CHEMO HAS NOT BEEN BAD.

ANSWERED CFQ BUT NOT CES

025 IT WAS A VERY HARD TIME IN MY LIFE, BUT STILL COULD
HAVE BEEN WORSE. I RECEIVED A LOT OF SUPPORT & LOVE, & KEPT
POSITIVE THOUGHTS TO GET ME THRU IT.

026 MOUTH SORES
