A COMPARISON OF PERCEPTIONS OF CANCER PATIENTS AND SIGNIFICANT KEY OTHERS OF PATIENTS' QUALITY OF LIFE AND SYMPTOM DISTRESS

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I am submitting herewith a dissertation written by Hilda Monaghan Porter entitled "A Comparison of Perceptions of Cancer Patients and Significant Key Others of Patients' Quality of Life and Symptom Distress." I have examined the final copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Nursing.

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ABSTRACT

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TEXAS WOMAN'S UNIVERSITY COLLEGE OF NURSING AUGUST 1995

A two-group, nonexperimental descriptive survey was conducted to determine if differences existed in perceptions between cancer patients' and their significant key others' (SKOs') perceptions of the patients' Quality of Life (QOL) and Symptom Distress (SD). The incongruency of perceptions has been attributed to the patients' use of the coping mechanism of downward shifting. When faced with a threatening condition such as cancer, patients, by comparing themselves to less fortunate others, self-enhance their condition and underestimate their symptoms as a means of coping and reducing stress. According to King's model of human transaction, using a coping mechanism potentially affects the congruency of perceptions necessary for goal attainment.

A convenience sample of 70 cancer patients and their designated SKOs were sampled at seven treatment sites. The

A Wilcoxon matched-pairs signed ranks test was used to analyze the QLI-CV total and 4 subscale scores and the SDS total scores. There was no significant difference in the responses of the QLI-CV total or subscale scores. There was a significant difference between the patients and SKO groups on the SDS ($\underline{z}=2.76$, $\underline{p}=.0058$). Sixty percent of the SKO group overestimated the amount of symptom distress experienced by patients. The change in the patients' perceptions produced significant differences between the patients and SKOs groups. Demographically, Protestantism, lower education levels, and lower income were related to the differences in perceptions.

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CHAPTER 1

INTRODUCTION

Traditionally, nurses have informally recognized the importance of the family to the recovery of the patient (Nightingale, 1859/1946); yet historically, the focus of nursing has remained on the care of the individual. With the recognition that increasing acuity and chronicity of illness require greater adaptation for the patient and family, nurses are shifting the focus of care to the family, and "person" in the nursing metaparadigm has been redefined to include the family as the context of care (Anderson & Tomlinson, 1992).

Nowhere is this shift in thinking more important than in the care of cancer patients. In 1994, over 1,208,000 persons were diagnosed with cancer (Boring, Squires, Tong, & Montgomery, 1994). The cost of cancer care accounted for over 10% of the total cost of disease in the United States or 1.3% of the Gross National Product (Cherner, 1993; Sandrik, 1990). Patients admitted to the hospital were more acutely ill, but due to the economics of reimbursement, patients were discharged "quicker and sicker," which placed

the main responsibility for patient care on the family (Baird, 1987; Baird & Mortenson, 1990).

Because this shift of responsibility for patient care has gone from the inpatient hospital setting to the patients' families, it is important to study phenomena that affect the patients and the significant key others (SKOs). One such phenomenon is the patient's use of a coping strategy that has been labeled "downward shifting," or the underreporting of symptomatology. This phenomenon has been attributed to the shift in internal norms that accompany a life-threatening illness (Breetvelt & van Dam, 1991; Festinger, 1954; Wills, 1981). As patients experience a threatening condition such as cancer and their health deteriorates, patients begin to enhance their own subjective well-being by comparing their condition to other patients with like conditions rather than to normal individuals. By changing referent groups, the patients were found to perceive their conditions as being better than others reported their conditions to be (Breetvelt & van Dam, 1991; Gruder, 1977; Larson, Viele, Coleman, Dibble, & Cebulski, 1993; Wills, 1981).

This change in perception, known as downward shifting, alters the patient's perception of reality. Since persons react to each other's perceptions of the situation and to

their own expectations of others in the environment (King, 1981), it is important to learn how the change in the patients' perceptions affect congruency between patients and their SKOs.

The nonverbal behaviors of the patients' downward shifting and the perceptions of the patients and SKOs cannot be directly observed; they can be examined only when the patients and SKOs communicate these behaviors in concrete interactions (King, 1981; Wood & Taylor, 1991). Examining the concept of quality of life (QOL) allowed for a concrete mechanism to study the mutual interaction that resulted when the patient and the SKO express their perceptions of the patient's QOL. Quality of life is a broad multidimensional concept that allows a comprehensive evaluation of cancer patients, centered in their immediate as well as broader environment (Tchekmedyian & Cella, 1990).

Historically, QOL measurement had been conducted by physicians and, until recently, had been limited to the evaluation of the unidimensional concept of functional performance status (Strain, 1990). As QOL studies began to define the broader multidimensional aspects of the concept, it became apparent that a distinct role was emerging for nurses to help the patients and their SKOs improve the

quality of the patients' lives (Padilla et al., 1983; Padilla & Grant, 1985).

The global concept of QOL incorporates many interacting dimensions of a person's life. Ferrans (1990a) defined QOL as "a person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her" (p. 15). This concept includes the domain of health and functioning, the socioeconomic domain, the psychological/spiritual domain, and the family domain. In addition to the four core domains of QOL as defined by Ferrans, the patient's response to the cancer and its treatment as reflected in the concept of symptom distress (SD) (Germino, 1987) and measured by the Symptom Distress Scale (McCorkle & Young, 1978) was used to operationalize the dependent variables for this study.

Quality of life studies have shown that cancer patients have high levels of physical complaints, yet this is not reflected in correspondingly high levels of psychological distress. The cancer patients consistently reported a significantly higher level of QOL than others reported for them despite a deteriorating physical condition (Breetvelt & van Dam, 1991; Curtis & Fernsler, 1989).

While quality of life and symptom distress are subjective for each person and need to be evaluated by the

patients themselves (Schipper, 1990), a survey of the patient's SKO can add a unique perspective on the patient's QOL (Aaronson, 1990). An assessment of congruency of perceptions between the patients and the SKOs on the patient's QOL and SD was the first step in nurses helping the dyad to mutually identify areas of incongruence that may result from the patient's use of the coping strategy of downward shifting. Understanding these incongruencies may help the patient and the SKO to mutually set goals to deal with the patient's health problems and to explore means to move toward these goals. Fostering understanding may help reduce the conflict and stress that occurs when the perceptions of the patient and SKO are incongruent (King, 1981; I. M. King, personal communication, February, 1994).

Problem of Study

The underreporting of symptomatology due to downward shifting has been recognized as a phenomenon in a life-threatening illness. To better understand how response shift contributed to the perceptions of the patients and the SKOs, the problem of the study was to compare the cancer patients' and the SKOs' perceptions of the patients' quality of life and symptom distress.

Rationale

The need to include both the patient and the SKO in the planning and implementation of nursing care is an accepted standard of nursing practice (American Nurses' Association [ANA] & Oncology Nursing Society [ONS], 1987; Joint Commission on Accreditation of Healthcare Organizations [JCAHO], 1992). However, incorporating patient information from both the patient and the caregiver into the nursing care of the oncology patient often poses a dilemma for the nurse. Clinically, when the nurse includes both the patient and the SKO in the assessment process, there is often disagreement regarding the perception of the patient's The patient will often relate less condition. symptomatology and a more positive condition than the SKO will report for the patient (Breetvelt & van Dam, 1991; Curtis & Fernsler, 1989).

This discrepancy of perception is particularly true in home health nursing. One home health nurse related that it is typical for the patients to disagree and correct the SKOs as the SKOs give information to the nurse. Finally, to prevent an argument, the SKOs will stop giving conflicting information, but at the completion of the visit, the SKOs will follow the nurse to the car and insist that their

perceptions are correct (N. Cooper, personal communication, August, 1993).

In trying to deal with the conflicting information, the nurse often feels pulled between the patient and the SKO in a situation that Bowen (Kerr & Bowen, 1988) described as triangulation. This concept was defined as a basis for understanding the interactive processes between the patient and the SKO undergoing a stressful situation such as cancer. In triangulation, the patient and caregiver are involved in an emotional relationship, and as the stress of the illness and anxiety build, a third person (issue or thing) is drawn in to reduce the tension. With the emotional situation confronting the oncology patient, the nurse not only elicits assessment information and implements nursing care, but often serves as an outlet for the SKO and patient to diffuse tension and to express frustrations over the patient's condition (Kerr & Bowen, 1988; Papero, 1990).

The nursing literature stressed the importance of including both the patients and SKOs in the implementation of the nursing process, but no nursing studies were found that evaluated the incongruent assessment of QOL for the oncology patients and the SKOs. The purpose of this study was to understand the nonverbal portion of the interactive processes that occur between the dyad during the patient's

treatment for a life-threatening illness. These nonverbal interactions were made concrete when the patients and SKOs expressed their perceptions of the patients' QOL and SD. Studying QOL and SD allowed for a holistic approach to understanding the patient and the effects of the disease and treatment.

Breetvelt and van Dam (1991) reviewed studies of cancer patients' responses on quality of life questionnaires and concluded that the patients' response shift (downward shifting) was responsible for the patients' higher quality of life scores when physicians', nurses' and caretakers' perceptions of the patients' scores were compared. These comparisons were undertaken to demonstrate that in research studies the initial (pretest) and final (posttest) scores, or the experimental versus the control group, were influenced by response shift, a factor confounding the independent variable. This shift caused an invalid interpretation of the effectiveness of the intervention and was a threat to the internal validity of the study.

Another major purpose of comparison research was to determine the appropriateness of using proxies in health surveys. Maisto, O'Farrell, McKay, Connors, and Pelcovits (1988) studied 36 alcoholics and their wives in a treatment program for a 2-year period. During this time, 23 patients

relapsed. The relapsed data on concordance showed poor consistency (only 17%) between patients' and their spouses' versions of the relapse events, as well as a 27% agreement on the situations related to the relapse. These findings were conjectured to be important when using couple therapy to treat alcoholism, since the discrepancies might lead to increased tensions during an emotionally tense time.

Clipp and George (1992) conducted a study with cancer patients to determine the reliability of spouse informants in research and clinical situations. Thirty couples, married an average of 32 years, were interviewed and compared on the patients' functional performance status, psychological distress, physical symptoms, and marriage quality. Correlations between 14 variable pairs suggested the spouse caregivers agreed with patients on objective observable measures, but disagreed on the subjective aspects of functioning, such as confidence in treatment and marriage quality. Of the caregivers, 46% reported patients more depressed, 39% reported the patients having more pain, 70% reported patients thinking more about the disease, and 42% were more frightened than the patients reported for themselves. The researchers concluded that the caregivers viewed the illness experience more negatively than did the patients. This negative view was ascribed to living

"around-the-clock" with the patients. The caregivers'
negative reporting was attributed to the burden of care and
higher mental health symptoms of persons who provide home
care to the chronically ill. The researchers concluded that
it was necessary to interview both informants to understand
the cancer experience.

Curtis and Fernsler (1989) studied 23 hospice patients and the family primary caregivers' (PCGs) perceptions on the Ouality of Life Index (Padilla & Grant, 1985). Paired t tests between patients and SKOs showed no statistical differences on the total scores ($\underline{t} = 0.24$; $\underline{df} = 22$, $\underline{p} = .81$) or on 13 of the 14 items. However, a significant difference emerged between the patient and the PCG on the scores for pain experience ($\underline{t} = 2.37$; $\underline{df} = 22$; $\underline{p} = .027$). Patients reported significantly less pain than the PCGs reported for This finding suggested that pain is a subjective response and nurses should assess the patients' own pain experiences. Nurses should teach the patients and PCGs about causes and management of pain. Pain scales and medication records should be used throughout the hospice experience. Also, a comparison of means revealed that patients slept better and had less nausea and vomiting than the PCG reported. Patients reported having less fun and less sexual satisfaction than their families reported

for them. The researchers recommended that nurses teach patients and PCGs about symptom management and enhance communications and trust between patients and their PCGs. The need to include both patients and PCGs in the assessment process was recognized, but no reasons for the disparity between the dyad were explored.

In one of the original uses of the Symptom Distress Scale (SDS), McCorkle and Young (1978) compared perceptions of five oncology patients and family members as part of a larger study. They found that in three cases, family members perceived approximately one-third greater symptom distress for the patients than did the patients themselves. While further studies were recommended, no explanations or implications for the discrepancies were made.

Two sources that recognized the differences in perceptions between the patient and the SKOs are self-help books written for the well family members of chronically ill patients. In these books, Felder (1990) and Strong (1988) recognized the frustrations experienced by patients and caregivers and offered emotional support to both members of the dyad. Of particular interest is a quote in which a young woman patient expressed her frustration by stating, "My mom . . refuses to listen to what's really going on with me" (Felder, 1990, p. 222).

A study of the differences in perceptions of the oncology patients' QOL and SD between the patients and the SKOs was not found in published literature. Studying the prospect of incongruencies between patients and SKOs was the initial action in identifying areas of incongruencies that will enable nurses to develop educational interventions to help the dyad to understand these incongruencies.

Conceptual Framework

This study was based on the conceptual framework of King (1971; 1981; 1992; I. M. King, personal communication, February, 1994) and the model of human transaction that is integral to her theory of goal attainment. The theory encompassed a general systems approach that explains the process of human interactions between individuals and groups and that leads to transaction or goal attainment (King, 1981). This model explains the interaction between the patients and their SKO and the importance of accurate perceptions in helping the dyads promote the highest QOL for the patients. King's model serves as a framework for understanding the cancer patients' use of the coping mechanism of downward shifting (Wills, 1981). The model was written from the perspective of the nurse as the provider and the patient as the recipient of care, but being a general systems approach, the concepts and assumptions are

applicable to the relationship between the SKO and the patient as well (I. M. King, personal communication, August, 1991; I. M. King, personal communication, February, 1994).

Health was the goal of the framework and was defined as the "dynamic life experiences of a human being, which implies continuous adjustment to stressors in the internal and external environment through optimum use of one's resources to achieve maximum potential for daily living" (King, 1981, p. 5). When a person's health is maintained, one is able to perform the activities of daily living, function in a given role, and lead a relatively useful, productive, and happy life.

The conceptual framework was organized to provide a comprehensive view of the three dynamic interacting systems that influence an individual's growth, development, work, and death: the personal, interpersonal, and social systems. While each system is described separately, the functions of each overlap to explain the reciprocal relations of individuals interacting in dyads or groups.

In the personal system, individuals are described as rational and sentient beings. They share common characteristics with other human beings, such as the ability to perceive, to think, and to determine ways to achieve their goals. The concept of perception, defined as each

human being's representation of reality, is central to understanding how a person comes to learn about the world. Through interactions, individuals react to persons, events, and objects in terms of their perceptions, expectations, and Persons interact as total human beings to the events they experience, and they do not always perceive the same events in a similar manner. While individuals share many common experiences, the ways they elect to perceive a specific experience differ. Past experiences, self-concept, biological and educational background, as well as socioeconomic status, influence how one perceives an experience. Because different persons seldom perceive all aspects of a situation, they often make judgments based on incomplete information. In addition, persons react to each other's perceptions of the situation and to their own expectations of others in the environment. Therefore, perceptions are subjective, personal, and selective for each person.

Through perceptions, data are organized, interpreted, and transformed by the mind. This internalization gives meaning to the event, becomes one's image of reality and influences one's behavior. Highly emotional states such as fear, love, anger, sensory overload, illness, pain, and the use of defense mechanisms and coping strategies (I. M. King,

personal communication, February, 1994) can restrict the cues one allows to enter into the perceptual field, which results in a distorted view of reality. The perception of one's health may be different from the signs and symptoms one's behavior manifests to others.

The interpersonal system consists of two or more persons interacting in a situation, which is also known as a human transaction. In the interpersonal system, individuals establish relationships through both verbal and nonverbal behaviors. The behavior of each individual is based on the individual's personal knowledge, needs, goals, expectations, perceptions and past experiences. The family or the dyad of patient and SKO can be considered an interpersonal system, and they enter the health care system when unable to cope with an event or a health problem.

In the process of human transaction (Figure 1), according to King (1971), the first steps entail two individuals perceiving each other, making judgments about the other, taking some mental action as a result of the perceptions and judgments. At that point, they enter the stage of reaction. The two individuals react to each one's perceptions of the situation and to their own expectations of others in the environment. This portion of the interaction is nonverbal and cannot be observed.

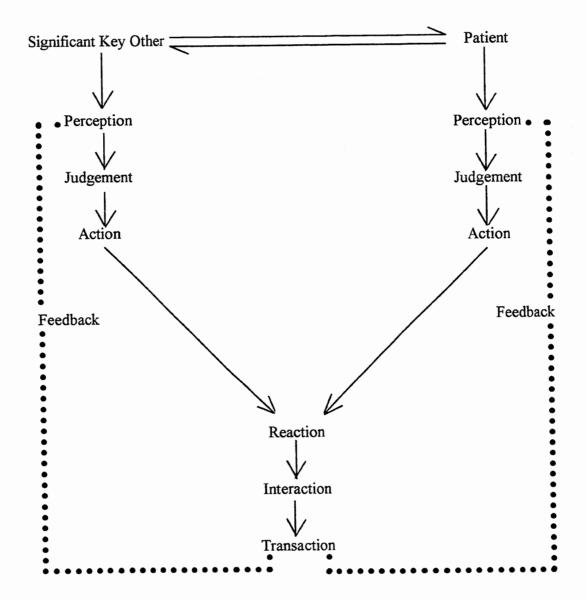


Figure 1. Adaptation of King's Model of a Process of Human Transaction

From: King, I. M. (1971). <u>Toward a theory for nursing</u>. New York: John Wiley and Sons, Inc., p. 92. Adapted by permission; I. M. King, personal communication, February, 1994.

The next step in the process is human interaction. This portion of the model is observable and can be measured. Interactions allow human beings to establish relationships with one another. In the interaction portion, the two individuals mutually identify goals and the means to achieve them. When the goals of the patient and the SKO are incongruent, conflict may occur and increase stress in the individuals and in the situation. Congruent perceptions of each other are important elements in the SKOs' and patients' interaction. If the SKOs are to help the patients, they must have some understanding of how the patients perceive themselves and their current health status. Validating the congruency of perception is the first step toward mutual goal setting and toward exploring means to move toward these goals. When the SKOs and patients agree to a means to implement the goals, they move toward transactions or goal attainment.

Nurses assist the dyad in coping with a health problem or concern about health, which occurs during the feedback phase of the process of human transaction. When the nurse and dyad identify goals to be achieved, the interactions are focused on goals and a positive interpersonal relationship begins to be established. Nursing promotes reciprocally contingent interaction where the behavior of one person

influences the behavior of another person. When nurses help the patients and SKOs to have congruency of perceptions regarding a situation related to the patient's health status, the transactions that occur may provide a measure of the effectiveness of nursing care.

King's model of transaction provides a framework to understand the cancer patients' use of the coping strategy of downward shifting. As patients face a threatening illness, such as cancer, they evaluate their coping skills and enhance their self-image by comparing their conditions to patients with like conditions rather than to normal individuals. Studies have demonstrated that because of this shift in reference groups, patients evaluate their conditions as being better than the ratings of their significant key others (Breetvelt & van Dam, 1991).

While the use of social comparison processes by cancer patients is recognized, the phenomena cannot be directly studied (Wheeler, 1991). Coping strategies are mental non-verbal processes whose use can only be studied when the phenomenon becomes concrete. King's model of transaction explains how the change in the patient's perception affects the interactions between the patient and the SKO. In the first perceptual stage of transaction, the members of the dyad perceive each other, make judgments, take some mental

action, and react to the situation. In the next interactive stage the individuals make their perceptions concrete through communication with another. Unless the dyad has congruent perceptions, it is impossible for them to set goals and to explore means to meet these goals.

Assessing the patient's and SKO's perceptions of the patient's QOL and SD allows for a mechanism to evaluate the interaction process that results from the initial perceptual stage in the process of transaction. Assessing these areas enables the nurse to operationalize changes in the patient's perceptions that took place because of self-enhancement through use of the coping strategy of downward shifting and to determine areas of incongruency that resulted between the patient and the SKO. This operationalizing allows for King's theory to be treated as midrange theory and thereby testable (Fawcett, 1984). Studying social comparison theory within the framework of King's theory also gives direction for nurses to help the patient and the SKO understand the perceptual incongruencies that were found to exist. objective is not to alter the patient's coping strategies, but to understand these incongruencies so the dyad can have the congruency of perceptions that are necessary for mutual goal setting and to move toward these goals (King, 1981).

Assumptions

For the purpose of this study, the following assumptions were made:

- 1. Individuals are perceiving beings (King, 1971).
- Perceptions are subjective, personal, and selective for each person (King, 1981).
- Perceptions are each human being's representation of reality (King, 1981).
- 4. Perceptions are fundamental in all human interactions (King, 1981).
- 5. Congruent perceptions are important elements in interactions (I. M. King, personal communication, February, 1994).
- 6. Congruent perceptions are the first step toward mutual goal setting and toward exploring means to move toward these goals (I. M. King, personal communication, February, 1994).

Research Ouestions

The following research questions were investigated:

1. Do cancer patients have a different perception of their quality of life than their significant key others perceive for the patients as measured by total and subscale scores on the Quality of Life Index-Cancer Version? 2. Do cancer patients have a different perception of symptom distress than their significant key others perceive for the patients as measured by scores on the Symptom Distress Scale?

Definitions

The following terms were defined for use in this study:

- 1. Oncology patient: an individual diagnosed with a solid malignant tumor or hematologic cancer and receiving formally specialized services under the direction of a licensed health professional (Volker, 1992). For the purpose of this study, the oncology patient was defined as a male or female patient over 18 years of age undergoing radiation therapy, chemotherapy, or biological therapy treatments under the direction of a board certified oncologist. The patient can be receiving treatments in an inpatient unit, outpatient office, or clinic setting. The patient's medical diagnosis and Functional Performance Status (Karnofsky & Burchenal, 1949) were included in the study criteria.
- 2. Functional performance status (FPS): a quantitative measure of the activities of daily living of which a person is capable at a given point in time. The use of a performance status scale in a research study or clinical setting allows comparison of not only objective

tumor response, such as tumor size and time since diagnosis, but also the total effect of tumor and treatment on the person's ability to carry on daily activities (Maxwell, 1990). For the purpose of this study, functional performance status was used for sample selection and was operationalized using scores on the Performance Status Scale (Karnofsky & Burchenal, 1949). The Performance Status Scale is measured in increments of 10 points, ranging from 100 points, fully active, to 0 points, dead. Patients with scores between 90 points (able to carry on normal activity; minor signs and symptoms of disease) and 50 points (requires considerable assistance and frequent medical care) were included in the study.

3. Quality of life (QOL): "a person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her" (Ferrans, 1990a, p. 15). This multidimensional construct includes the domains of health and functioning, socioeconomic, psychological/spiritual, and family. For the purpose of this study, quality of life was operationalized using total scores and subscale scores on the Quality of Life Index-Cancer Version (Ferrans, 1990a).

- 4. Significant key other (SKO): the person who can be relied upon to provide social support, comfort, maintenance, and advocacy for the patient (Peteet, 1982). For this study, the SKO was the person designated by the patient as the primary social support while undergoing treatment.
- 5. Symptom distress (SD): the "ability of the individual to perceive or be cognizant of and discern the amount of upset, strain, or physical or mental anguish of the experienced event or symptom" (Rhodes & Watson, 1987, p. 243). For the purpose of this study, symptom distress was operationalized by a score on the Symptom Distress Scale (SDS) (McCorkle & Quint-Benoliel, 1983).

Limitations

Limitations included the use of a convenience sample of male and female cancer patients undergoing treatment for solid tumor and hematologic cancers and the patients' designated SKOs. Using a convenience sample limited the generalizability of the findings to the sample being studied (Abdellah & Levine, 1986). Additionally, the scores of the subjects may have been positively influenced by the effects of history-selection (Kirk, 1982). The patients' inclusion in some treatment protocols depended on the patient having and maintaining a designated functional performance status.

Therefore, subjects and SKOs were at risk for reporting better physical parameters than actually existed.

Summary

Quality of life and symptom management have been proposed as the two main priorities of nursing research by the Oncology Nursing Society (Mooney, Ferrell, Nail, Benedict, & Haberman, 1991). Incorporating these concepts into family-centered care for the oncology patient has posed a dilemma for the nurse. Findings from research have shown that, because of the change in internal norms or downward shifting, the oncology patient reports a higher QOL, despite increased symptoms, than the SKO reports for the patient. This conflicting evaluation of the patient's QOL and SD can lead to stress and misunderstanding between the patient and the SKO (King, 1981). Assessing for congruency of perceptions between the patient and the SKOs on the patient's QOL and SD is the first step in helping the dyad mutually identify areas of incongruence and for the nurse to develop educational interventions to help the dyad to understand these incongruencies. Therefore, King's conceptual model of the process of human transaction was used as a framework in this study. Research questions were formulated, terms were defined, and limitations were identified.

CHAPTER 2

REVIEW OF LITERATURE

The process of human transaction between patients and their significant key others (SKOs) represents a sequence of verbal and nonverbal behaviors that lead to the satisfactory performance of activities of daily living, success in performing activities in one's usual role, and achievement of immediate and long-range goals (King, 1981). This process, integral to goal attainment, becomes threatened whenever one member of the dyad faces a diagnosis of cancer. In response to a threatening condition, such as cancer, and as health deteriorates, patients may enhance their own subjective well-being by changing reference groups and comparing themselves to other patients with like conditions rather than to normal individuals.

Findings from research on cancer patients' perceptions of their illnesses have demonstrated that patients evaluate their conditions as being better than the SKOs and health professionals report for them (Breetvelt & van Dam, 1991; Holmes & Eburn, 1989; Spitzer et al., 1981). This patient coping strategy is known as downward shifting (Festinger, 1954; Wills, 1981). If nurses are to help the dyad of

patient and SKO to attain goals throughout the process of cancer diagnosis and treatment, it is imperative for nurses and the dyad to understand the patient's use of coping strategies that have the potential to alter the congruency of perceptions between the dyad.

The purpose of this chapter is to summarize and evaluate the research literature as it pertains to the use of the coping strategy of downward shifting and the dependent variables of quality of life (QOL) and symptom distress (SD). Social comparison theory (SCT) is reviewed to understand how this coping strategy may affect the congruency of perceptions that are necessary for goal attainment. Since downward shifting cannot be directly observed and evaluated (Wood & Taylor, 1991), further discussion includes the dimensions of quality of life and symptom distress chosen to operationalize the concept and serve as dependent variables for the study. This discussion serves as the basis for relating the research findings to a better understanding of the process of human transaction.

Social Comparison Theory

King's theory of goal attainment postulates that perceptual congruency between patients and their SKOs is imperative if their interactions are to lead to goal attainment. However, congruency can be altered by the

patient's use of coping mechanisms in response to a threatening condition such as cancer (King, 1981). In an effort to understand how the patient's use of the coping mechanism can affect congruency between the dyad, a discussion of Festinger's (1954) social comparison theory is presented.

Festinger (1954) developed social comparison theory as an attempt to explain how individuals learn about themselves through comparison with others. He theorized that human beings are motivated by an innate drive to compare their abilities and opinions with others as a means of evaluating their own self-worth. Festinger assumed that this drive had basic survival value. His presentation was an attempt to describe why persons used comparisons, with whom comparisons were made, and to explain what effects comparisons had on the individuals (Suls, 1977). Festinger's initial theory served as a paradigm for further research that explained the protective coping mechanism of self-enhancement through comparison with less fortunate others known as downward shifting (Taylor & Lobel, 1989; Wills, 1981; Wood & Taylor, 1991).

Festinger (1954) hypothesized that individuals first attempt to evaluate their opinion and abilities through objective, nonsocial means, such as judging one's running

ability by comparing the time taken to run a given distance against another person's time. When objective means are not available, persons gain information to evaluate their opinions and abilities through comparison with others. Festinger purported that one typically chooses a comparison person who is superior on a given dimension to provide information that will help one improve on that dimension (i.e., upward comparison). When choosing a comparison other, Festinger assumed persons tend to make comparisons with others who have similar opinions and abilities rather than to compare with others who are too divergent from their own position. When there are no persons available with similar ability and opinions, persons search until they find someone close to their own opinion and ability to have information they deem useful for comparison. As the behavior being compared becomes more important and more relevant to individuals, they are more motivated to reject discrepant behavior and to try to achieve uniformity with a referent group closer to their own status.

Festinger's (1954) original work posited a distinction between abilities and opinions. When one compares one's abilities with another person's, a unidirectional drive upward exists; thus one could always rate one's own abilities as better than actual performance and one could

always rank one's ability as better than those with whom one is comparing oneself. Also, the process of comparing abilities is ongoing and therefore unstable, with one never reaching a point of equilibrium.

In relation to opinion, Festinger (1954) hypothesized that one could compare one's opinions with another's or with the groups and decide if one was right or wrong. The upward drive to judge oneself as better than another on opinion does not exist, so one could attain a state of equilibrium when comparing one's opinion with others. In his original writings, Festinger did not specify how the comparison other could be chosen, but he did indicate that persons could be more attracted to a situation where others are closer to them on opinion and abilities and less attracted to divergent situations. This attraction would lead the individuals to choose comparisons reasonably close to themselves and to actively reduce discrepancies between themselves and divergent others by ceasing to compare themselves to others who are very different from themselves. Also, once superior or inferior status had been determined, there would be an attempted cessation of competition with those who had been deemed incomparable.

Throughout the original paper, Festinger (1954) presented research findings from his previous work with

informal social communication or the functioning of groups as well as new research to substantiate the theory (Festinger, 1950; Festinger, Torrey, & Willerman, 1954; Hoffman, Festinger, & Lawrence, 1954). This original research documented the inclination of individuals to seek uniformity with a group.

In earlier research with groups, Festinger (1950) had examined the effects of the group on opinions and determined that human organisms have a reality-testing behavior.

Humans have an ongoing drive to test the correctness or incorrectness of their opinions and beliefs by comparing them to the opinions of others in the groups of which one is a member. If individuals agree with the group, they feel their opinion is correct; if they disagree with the group, there is a tendency to believe that their opinion is not correct. How important the opinion is to the group and how important the group is to the person will determine the amount of pressure on the person to change the opinion and embrace uniformity with the group.

A subsequent research project was conducted by

Festinger et al. (1954) to determine if subjects were

attracted to groups of high or low attractiveness.

Festinger's methods allowed for an understanding of how

threatened subjects chose groups for affiliation. Forty

college men were placed in groups of four, with each group artificially manipulated to believe they were successful, and 37 men were placed in a low-attractiveness group and given instructions that made the group believe they were less desirable. The students in each group were given a series of tests and the scores artificially manipulated to produce three members of each group with high scores and one member with a low score. In both the high- and lowattraction groups, the three subjects who were told they scored higher measured more attraction to the group than the one subject in each group who was told they had low scores. The results of a t test comparing the successful and the less successful groups demonstrated that the experimental subjects who were in the successful group rated their abilities as higher than the students in the less attractive group (5.9 versus 5.1 on a 7-point scale) (p<.08) (Festinger et al., 1954).

Festinger (1950) had first proposed the theory of informal social communication that attempted to explain the pressures toward uniformity within groups to promote the function and locomotion of groups. Festinger (1954) then developed social comparison theory to explain the motivational drive of individuals to evaluate their own opinions and abilities through comparison with others.

According to Wheeler (1991), Festinger, in testing SCT, published only the previous study on the attractiveness to groups; he then changed to other research interests without publishing research on the other propositions of the theory. Wheeler criticized Festinger and his associates for abandoning social comparison theory without fully developing the theory, but he recognized that it was a logical progression toward the development of Festinger's better-known theory of cognitive dissonance.

While Festinger's research on social comparison theory was limited to the attraction of groups, Schachter (1959) expanded the original Festinger hypothesis to include the affiliation of fear. Schachter's classic study speculated that when one is afraid, one will affiliate with others to reduce the fear. He studied 62 female college psychology students at the University of Minnesota who were divided into two groups. In the high-anxiety manipulated condition, the students ($\underline{n} = 32$) were told they would be exposed to a series of painful electric shocks and then physiologic responses such as blood pressure and pulse rate would be measured. The low-anxiety group ($\underline{n} = 30$) were told that they would be exposed to a series of mild electric shocks that would tickle or tingle and then their physiologic responses would be assessed.

Before beginning the actual shock portion of Schacter's (1959) study, the students were asked to complete a questionnaire stating their preferences for waiting their turn to be shocked "alone," "together," or "don't care." They were also asked if they were willing to continue with the electric shock portion of the experiment. Twenty (62.5%) of the 32 high-anxiety manipulated students chose to wait together with an overall intensity score of +0.88, while 10 (33%) of the low-anxiety group chose to wait together with an overall intensity score of +0.35. In the high-anxiety group, 6 (18.8%) of the 32 subjects refused to continue with the shock portion of the experiment, while all the subjects (n = 30) in the low-anxiety group were willing to continue.

On the basis of his findings, Schachter (1959) postulated that, under conditions of threat, individuals choose to affiliate with others as a means of comparing the appropriateness of their emotional state and need to reduce anxiety. After conducting extensive studies with victims threatened with adverse conditions, Schachter postulated his findings on the affiliation of fear. First, the affiliation tendency is positively related to the states of anxiety and hunger, and secondly, the affiliation tendency is highly directional with anxious subjects only wanting to be with

those in a similar plight. While there has been inconclusive evidence in the replication of portions of the fear-affiliation studies, Schachter's research led to the understanding of stress-reducing benefits of affiliation.

The next development in social comparison theory came in an understanding of the coping mechanism known as downward comparison. While Festinger's (1954) original social comparison theory had broad ramifications, he believed the application of the theory would be limited to the single dimension of self-evaluation through comparison with a similar superior other (i.e., upward comparison). Wills (1981) described another application of social comparison theory, that of helping people deal with different types of threatening situations, such as cancer. In situations where misfortune or frustration have occurred that could not be altered by the individual, one's subjective well-being will be decreased, and one coping strategy to restore it would be to compare oneself with another person who is in a worse condition. Wills theorized that a favorable comparison between the self and another less fortunate individual makes one feel better about one's own situation and enhances one's self-image or worth (i.e., downward comparison). Under ordinary circumstances, people dislike observing negative effects in others, but when

threatened, subjects feel better if they can compare themselves with others who are unfortunate, and they consistently select such persons for affiliation. These comparisons decrease stress and protect the ego by enhancing one's subjective well-being and coping strategy (Gibbons & Gerrard, 1991).

Gibbons and Gerrard (1991) summarized the selfenhancing benefits of downward comparison:

- Mood state can be enhanced by realizing things could get worse, but are not at present.
- Optimism is improved by realizing others have a worse condition and have survived and that one's coping skills are better than another person's.
- Self-esteem can be boosted by downward comparison on behaviors such as coping abilities.
- 4. The sense of deviance can be reduced by realizing that others share the same fate.

Besides enhancing well-being, downward comparison can increase one's belief in one's coping ability and lead to more effective coping (Affleck, Tennen, Pfeiffer, Fifield, & Rowe, 1987). This form of coping has been labeled emotional-focused coping (Lazarus & Folkman, 1984), and, while not directly eliminating the threat, it allows the person to decrease the anxiety associated with the threat.

Downward comparison requires two processes for selfenhancement to be effective. First, the patients must
choose an appropriate target or manufacture a hypothetical
target if a concrete one is not available. Second, the
patients must choose appropriate dimensions for evaluating
themselves. By selecting a dimension for comparison that
they feel confident about, such as coping effectiveness or
good prognosis, patients cognitively construct the elements
needed for effective self-enhancement through downward
comparison (Taylor, Buunk, & Aspinwall, 1990).

To determine the effects of various coping strategies, Wood, Taylor, and Lichtman (1985) interviewed 78 breast cancer patients contacted through a private oncology practice. Subjects ranged in age from 29 to 78 years (M = 53 years). The mean level of education was one year of college. The group was skewed toward the middle and upper socioeconomic classes. Of the women, 75 had undergone surgery for breast cancer; 35% (26) had a lumpectomy, 3% (2) had a simple mastectomy, 39% (29) had a modified radical mastectomy, 12% (9) had a Halsted radical mastectomy, and 12% (9) had bilateral surgery. Length of time since surgery varied from 2 months to 16 years (25.5 months median). Tape-recorded interviews lasting 1.5 to 2 hours were conducted. Topics covered included the woman's

cancer experience and its treatment, attributions about cancer and its controllability, life changes and changes in close relationships, questions related to fear and emotional reaction, compliance with medical regime, and social comparison processes. The patients were asked to complete the Lache-Wallace Scale of Marital Adjustment. The patients' adjustment to illness and physical status was assessed by the interviewer.

The social comparison questions covered three categories: (a) contacts with potential comparison others,

- (b) impressions about other patients' coping, and
- (c) comparisons made. When the data were transcribed, it became apparent that 64% (50) of the 78 subjects had made comparisons outside of the social comparison portion of the interview. Women used comparisons spontaneously, and these comparisons were felt to be a natural reaction on the part of the patients (Wood et al., 1985).

Results of Wood et al.'s (1985) interviews demonstrated that women had a high exposure to both media and social sources for cancer information, with 90% (70) stating they had read a newspaper or magazine article on cancer survivors. This exposure would give the patients role models of good adjustors available for upward comparison. In regards to the adjustment portion of the interviews, only

16.4% (13) said others were adjusting in a similar manner, 8.2% (6) said others adjusted better, and 60.3% (47) indicated that others were coping more poorly. In relation to downward comparison, 60% (47) said that another patient was coping less well and 80% (62) said that they were adjusted at least "somewhat better" than another patient. In relation to upward comparisons, the 78 patients rarely compared themselves with others with similar physical status and life situations. Patients did compare themselves to other cancer patients. While 90% (70) of the patients said they had upward comparisons available through personal contact or the media, the patients chose downward comparison. This shift was a predictable finding since downward comparison predicts that patients under threat are more likely to use a downward comparison. Interesting findings from the study were that while downward comparisons predominated, upward comparisons were also used. Another finding was that women compared their adjustment as being very good compared with "fellow sufferers". These comparisons were made with a fabricated standard rather than to a specific target. Wood et al. concluded that the necessity to compare with a specific target is overstated and the use of nonspecific comparison targets may be understated by researchers.

In a study of arthritis patients, Blalock, deVellis, deVellis, and Sauter (1988) examined patients' satisfaction with their physical abilities and the types of social comparisons that were made when evaluating abilities. A total of 75 female patients diagnosed for one or more years with rheumatoid arthritis (RA) were interviewed for approximately 60 minutes. Measures of physical disability, psychological well-being, and predictors of psychological well-being were assessed. Two social comparison measures were part of the questions to evaluate psychological wellbeing. Subjects were first asked with whom they would most likely compare themselves, RA people or non-RA people. second section asked the patients with whom they would compare themselves if they were having performance difficulties, RA or non-RA patients. In relation to the general comparison question, 72% (54) said they preferred to compare themselves to non-RA patients. In relation to experiencing performance difficulties, 62% (47) chose to compare themselves with other RA patients.

In a subsequent report, Affleck, Tennen, Pfeiffer, and Fifield (1988), using Blalock et al.'s (1988) sample of 75 patients, examined the accuracy of patients' responses to a social comparison questionnaire, the association of social comparison theory conclusions, and their psychosocial

adjustment as rated by health care providers. Multiple regression analysis between the patient and caregivers on comparative disease activity showed that patients who expressed more favorable views of their comparative disease activity were rated as adjusting better to their illness by the caregivers, independent of age, education, income, illness duration, actual disease activity, and the accuracy of their disease activity comparison ($\underline{R} = 0.45$; $\underline{F}(8, 67) = 2.08$; $\underline{p}<.05$).

Affleck and Tennen (1991) reported on a second part of the above study by Blalock et al. (1988). The researchers let 57 patients choose a file to read about a patient doing better or doing worse then they were. Consistent with downward comparison, 66% (37) of the subjects chose files of patients who were more ill and over 90% (51) wanted to know about patients experiencing more pain. When comparing coping skills, patients preferred comparisons with persons who were coping better than they were. This use of both upward and downward comparisons by the same patients under different circumstances collaborates the findings of Wood et al. (1985) in the study of breast cancer patients.

Molleman, Pruyn, and van Knippenberg (1986) undertook a research project to directly test the relevance of social comparison theory on the uncertainty and anxiety experienced

by cancer patients. Adult male and female cancer patients (N = 418) being treated or followed-up in an outpatient clinic in the Netherlands were included. Two hypotheses predicted (a) patients who experienced a deficiency of information about the illness and treatment would prefer to obtain information from experts, and (b) if insufficient information was available from experts, the patients' need to compare themselves with fellow patients increased. Uncertainty was measured by selecting three questions with a 4-point scale. Questions concerned the extent to which the patients needed information about the illness and the therapy and whether they thought that they knew too little about illness and therapy. Anxiety was operationalized through use of a modified version of the State-Trait Anxiety Inventory. The scale has 36 questions with a 4-point scale; 18 questions refer to situational anxiety and 18 refer to dispositional anxiety. Other questions dealt with the accessibility of expert health care resources, the need for social comparison, preferred comparison targets, and informativeness and consequence of interacting with other patients.

In relation to uncertainty, Molleman et al. (1986) documented that 85% (310) patients preferred to get their information from expert sources and 15% (55) preferred

nonexpert sources. When expert information was unavailable, the need for social comparison increased, and fellow patients were considered more informative as uncertainty increased. Patients who were similar were considered more informative than fellow patients who were different.

Relevant to anxiety, a significant relationship was found by Molleman et al. (1986) between the various levels of situational anxiety and the need for interaction with other patients ($\underline{F}(4, 312) = 3.09$; $\underline{p}<.03$). The need for social interaction increased as situational anxiety increased from low to moderate levels of anxiety (low $\underline{M} = 2.40$; moderate $\underline{M} = 2.74$) and then decreased dramatically with high and very high levels of anxiety (high $\underline{M} = 2.56$; very high $\underline{M} = 2.20$). The need for interaction with fellow-patients proved to be greatest in patients who experienced moderate situational anxiety.

Conclusions drawn by Molleman et al. (1986) indicated that contact with fellow-patients can be useful in reducing anxiety. The more similar the patients' experiences, the more appropriate will be the comparison. This finding has implications for self-help groups, and it was recommended that health care facilitators structure groups to allow for patients with comparable anxiety.

Hinds and Martin (1988) studied 58 adolescent oncology patients in an attempt to understand how they achieved hopefulness during their cancer experience. This hopefulness allowed the patients to be protected from incapacitating despair. Using grounded theory, the researchers identified four sequential phases that helped the teens achieve hopefulness: cognitive discomfort, distraction, cognitive comfort, and personal competence.

Cognitive discomfort was found by Hinds and Martin (1988) found to occur immediately after the adolescents became aware of negative thoughts about the illness. The patients put a stop to negative thoughts or reflected on the consequence of the disease and its illness.

The second phase in the process of hopefulness was defined as distraction. The cognitive discomfort thoughts were consciously replaced with more acceptable thoughts that promoted concentration on neutral or positive thoughts and conditions. Nine processes were identified that helped the adolescents purposefully distract themselves from threatening thoughts. "It could always be worse" was one method of distraction. The adolescents were able to acknowledge the seriousness of their own health situation but favorably compare their situations with other possible health outcomes or situations of others. An 18-year old

female with a diagnosis of acute lymphocytic leukemia stated, "Sometimes I tell myself it could always be worse. I could have a brain tumor or I could have lost my legs" (Hinds & Martin, 1988, p. 337). The teens acknowledged self-initiated downward comparisons, but they were emphatic that their effectiveness and meaning were lost if parents or health care professionals tried to use them with the adolescents. The use of the distraction mechanisms was recognized as emotional-focused coping and represented the adolescents' attempts to alter their perceptions of the cancer experience when nothing can be done to directly change the threatening condition.

The third phase of adjustment identified by Hinds and Martin (1988) included cognitive comfort, in which the adolescents experienced periods of solace and lifting spirits and were able to consider possibilities of a future for themselves. The strategies that helped accomplish cognitive comfort included forgetting cancer and hopefulness.

A fourth phase described by Hinds and Martin (1988) as personal competence was also identified. Through commitment to treatment, adaptation to symptoms, and taking care of problems, the adolescents were able to maintain hopefulness,

comfort themselves, and achieve competence in resolving health threats.

Although Hinds and Martin (1988) identified the use of comparisons with others as a means of protecting the adolescents from discomforting thoughts, they did not credit social comparison theory as the source of the material.

While the phenomenon of social comparison theory is recognized as an emotionally focused coping strategy used by cancer patients in various situations, little is known about the benefits of artificially producing opportunities for downward comparisons, such as in self-help groups or the use of modeling for cancer patients (Hagopian, 1993).

The effects of the patients' shift in referent group and self-enhancing their conditions, as well as rating themselves as better than SKOs and health professionals rate them, has been documented in various research settings (Clipp & George, 1992; Holmes & Eburn, 1989; Larson, Viele, Coleman, Dibble, & Cebulski, 1993). Clinically, the effects of this phenomenon can be observed when obtaining assessment information from both the patients and the SKOs. There is often incongruency of information between the patient and the SKO. Studying the differences in perceptions of the patients' QOL and SD will allow for a means to determine if

incongruencies exist and to better understand the process of human transaction necessary for goal attainment.

Quality of Life

In the process of human interactions, individuals react as total human beings to their experiences (King, 1981).

Studying quality of life in cancer patients allows for a means to operationalize these experiences (I. M. King, personal communication, February, 1994).

Definition

Before the concept of quality of life can be operationalized for research, it needs to be defined. However, defining QOL is not an easy task. While different specialists, such as clergymen, philosophers, priests, and physicians, purport to have ideas and opinions of QOL, there is no common meaning, and the term remains elusive (Fallowfield, 1990). In the process of human transaction, King (1981, personal communication, 1994) theorized that individuals react as total human beings to their experiences. Campbell, Converse, and Rogers (1976) stated that "'Quality of Life' is a vague and ethereal entity, something that many people talk about, but which nobody knows very clearly what to do about" (p. 471).

A concept analysis based on a 10-year literature search associated the term quality of life with life satisfaction, well-being and the perception of well-being, and self-esteem. Subjective components included the attitude and feelings of well-being and the ability to achieve personal goals. Objectively, QOL had been defined as physical functioning and, in economic terms, as income bracket and housing (Kleinpell, 1991).

Conceptually, quality of life is defined in a broad overarching context and relates to the satisfaction and well-being a person feels about life including the accomplishing of one's desires (Osoba, 1991). For Calman (1984), QOL is not an absolute. He defined a good quality of life as being "present when the hopes of an individual are matched and fulfilled by experience" (pp. 124-125). Thus, the smaller the gap between the patient's expectations and achievements, the higher the QOL. Other global QOL definitions included the person's statement of the positivity and negativity of attributes that characterize one's life (Grant, Padilla, Ferrell, & Rhiner, 1990). Tchekmedyian and Cella (1990) and Cella and Tulsky (1993) referred to the patients' appraisal of and satisfaction with their current level of functioning as compared to what they perceived to be possible or ideal. Schipper (1990) offered

a global, yet medically oriented, theme when he defined QOL as the functional effect of an illness and its congruent therapy upon a patient, as perceived by the patient.

In an attempt to conceptualize QOL mathematically, Shaw (1977) developed the equation $QL = NE \times (H+S)$. In this representation QOL was equal to the patients' natural endowment (NE), as determined by the patient's physical and intellectual capacities, times the sum of the contribution of the patient's home and family (H) plus the contribution made by the person to society (S). While this definition was developed to be used by physicians rather than to be the subjective appraisal of the patients, Shaw's purpose in defining QOL as a model was to demonstrate that QOL is made up of factors that physicians often ignore in rating QOL.

In a clarification of the proper application of the formula, Shaw (1988) specified that applying the formula can not be a substitute for moral decision making. The formula's purpose was not to serve as an objective measure to quantify data or a subjective means of qualifying the value of life. Rather, the formula helps identify the constructs of QOL in simple terms. Thus, physicians are able to use the formula to reflect on the total concept when making ethical decisions.

For QOL to be operationalized and applied in health care, it is necessary to narrow the scope to issues that are health related and health sensitive (Aaronson, 1990). When conceptualizing QOL, many authors have included as a starting point the three dimensions of health outlined in the World Health Organization (WHO) (1958) definition: physical, mental, and social well-being (Moinpour, Hayden, Thompson, Feigl, & Metch, 1990). Areas such as education and housing are presently beyond the scope of health care, but being a fluid concept, economics, once felt to be outside the health domain, is becoming a factor in QOL evaluation (Schipper, 1990).

Internationally, at the 1986 Portugal Conference on Quality Of Life, QOL and survival were recognized as the two primary aspects of health outcomes (Miettinen, 1987). In the United States, the Food and Drug Administration has stated that researchers must show the QOL benefits as well as the length of survival times to gain approval of new antitumor drugs (Johnson & Temple, 1985).

Bowling (1991) operationalized the definition of QOL within the health domain. Quality of life was defined as the individual's response to the physical, mental, and social effects of illness on daily living which influence the extent to which personal satisfaction with life

circumstances can be achieved. This definition goes beyond physical well-being to include the perception of well-being and self-esteem.

Ferrans (1990a) defined QOL as "a person's sense of well-being that stems from satisfaction and dissatisfaction with the areas of life that are important to the patient" (p. 15). The multidimensional domains included are health and functioning, socioeconomic, psychological/spiritual, and the family. This definition has two unique features. In operationalizing QOL, the patient's satisfaction with the domains of life, as well as the importance of each domain to the patient, are measured (Frank-Stromborg, 1988). While QOL is more than the sum of dimensions, the acceptance of a definition including the discreet dimensions of life allows for an assessment and measurement of the patient's reaction to cancer and cancer treatment and the interrelations of different reactions and overall QOL (deHaes & van Knippenberg, 1985).

Spilker (1990) rejected the need for a common universally accepted definition for QOL. Since there is no single "gold standard" for defining QOL, and the field is diverse and changing, Spilker indicated it would be unfair to limit researchers to a specific narrow definition.

Spilker suggested that researchers choose an acceptable

definition as the basis for a conference or research project and let scientists adapt it as needed.

Methodological Issues

Agreeing on a common definition for quality of life remains problematic, but Selby and Robertson (1987) proposed measuring the variables specified in the WHO's (1958) definition, physical, mental, and social well-being. The authors recommended that these three areas represent the minimal requirements for measuring QOL and that the definition is broad enough to include other areas, such as spiritual aspects, when appropriate.

Besides the three areas specified in the WHO's (1958) definition of health, including the effect of the disease, symptoms and treatment side-effects of cancer patients are standard. In QOL research this area is often operationalized by studying the above three general QOL areas, referred to as domains, and then including issues specific to the study population, such as studying body image disturbances with breast or head and neck cancers and sexual dysfunction with prostate or vulva cancer.

Ultimately, the areas assessed are the functions of the study population, the nature of the treatment, and the type of research being conducted (short- or long-term study of QOL) (Aaronson, 1990).

The Southwest Oncology Group (Moinpour et al., 1990) and the WHO (Jones, Fayers, & Simons, 1987) advocated certain policy recommendations for conducting QOL research in clinical trials. The recommendations included studying the impact of the patient's disease and treatment on the patient's day-to-day living. These groups advocated using separate measures for the physical and emotional functioning and global quality of life. They also recommended studying general and protocol-specific symptoms that relate to the patient population. It was also accepted that at least three or four domains that contribute to QOL should be measured to get a total perspective on the patient's healthrelated QOL. The European Organization for Research on Treatment of Cancer (EORTC) recommended that 12 components be included in the assessment of QOL in clinical trials: pain and pain relief, fatigue and malaise, psychological distress, nausea and vomiting, physical functioning, symptoms and toxic effects, body image, sexual functioning, social functioning, memory and concentration, economic disruption, and global quality of life (Aaronson et al., 1987). This medically-oriented approach does not advocate measuring the patient's aspirations or satisfaction, although these are part of the QOL paradigm and are important in nursing research.

One universally-accepted recommendation is that for the patients' QOL to be valid, it must be a subjective evaluation made by the patients rather than made by a third It is important for the patients to decide if their QOL meets the standards being evaluated (Bowling, 1991). The main contribution of OOL research is that it is the patients' subjective perceptions of the illness within the domains studied. The patients' perception of their illness experience, how they feel, look, and function, may be more important than the actual reality. This view extends the perspective of the illness experience to include reality as experienced by the patient. While surrogates can be helpful where patients have memory losses or are too sick to participate, their information should not be interpreted with patient data, but should be considered separately (Ferrans, 1990b).

Selecting the type of instrument to use for measuring QOL is controversial. The Southwest Oncology Group recommended categorical scales, while the EORTC suggested either a continuous Visual Analogue Scale (VAS) or a Categorical Scale. The VAS is a fixed-length line, often 10 centimeters long, with the ends of the line being labeled with bi-polar words describing the extremes of the variable being measured. This type of scale represents the

continuum of the variable being measured (Clark & Fallowfield, 1986).

Categorical scales are more familiar, require less instruction, and are easier for the subjects to interpret and for the researcher to score. If incorrectly constructed, a scale with too many categories can make the categories unclear, and too few choices can leave the subject without an appropriate choice. A scale with 4 or 5 categories is considered appropriate (Moinpour et al., 1990).

Another measurement issue relates to appropriateness of patient self-administered questionnaires. Using self-administered methods excludes patients who cannot read or write for either educational, cultural, or health reasons.

Also, when the questionnaires are not fully completed, it is impossible to discover if this is due to random omission or to the patient not wishing to answer the questions.

However, self-administered questionnaires reduce the cost of the study and are recommended in clinical trials to reduce the work burden on the staff (Fletcher, 1988).

Interview-administered questionnaires include openended questions that allow the patients to describe their perceptions in each area surveyed (Schraub, Bransfield, Monpetit, & Fournier, 1987). The open-ended interview is the most thorough method by which to explore the patients' perceptions of their QOL. The interviewer questions the patient about the impact of the illness and treatment on various aspects of life. The interviewers can also use probes to obtain specific or more detailed answers. The interviewer can then organize, interpret, and code the information. This type of data collection can be influenced by the perceptions of the interviewer. Interviews are time-consuming and rarely attain sufficient levels of reliability. For these reasons, there is limited use of this technique in oncology settings (Moinpour et al., 1990).

Another universally accepted QOL methodology is to use measures with acceptable published psychometric properties. The QOL instruments should be cancer-specific so that the instrument can measure differences among diagnosed patient groups. All measurement instruments must have proven validity, reliability, and sensitivity. The instruments should also be sensitive across the range of clinical practice and designed to distinguish degrees of dysfunction between patients with varying extent of disease and intensity of therapeutic interventions (Waltz, Strickland, & Lenz, 1984). Another requisite is that the instrument be dependable and reliable and able to measure the trends of the patients' conditions over time (Waltz et al., 1984).

Applications of the Quality of Life Index

The Quality of Life Index-Cancer Version (QLI-CV) was used to evaluate sarcoma patients postchemotherapy. A convenience sample of 15 patients who had undergone limb-sparing surgery and a year of chemotherapy were surveyed to determine their QOL postchemotherapy (Arzouman, Dudas, Ferrans, & Holm, 1991). The overall scores were above the scale median score of 15, indicating a high level of QOL for the patients postchemotherapy. The highest QOL scores were in the family subscale, with two of the highest four satisfaction items being family health ($\underline{M} = 2.5$) and spouse ($\underline{M} = 5.5$). The patients' families were a source of physical and emotional support. The psychological/spiritual aspect of life was also high for this group. The item with the highest satisfaction was "faith in God" ($\underline{M} = 1.0$).

The health and functioning domain was significantly lower than the domain of family (Arzouman et al., 1991). The item with the lowest satisfaction and importance mean was sex life. This low score was explained by the patients' decreased physical functioning contributing to decreased sexual function. The socioeconomic domain was the lowest with two-thirds of the patients either being retired or unemployed. These findings emphasized the importance of the family to the cancer patients. In an attempt to explain the

high QOL scores, a patient was quoted, "Sure, I'm sorry it happened, but I don't let it get me down; I always see people who are worse off" (p. 892). No explanation for the use of this comparison was made by the authors.

In another report, Fazio and Glaspy (1991) applied the QLI-CV with neutropenic patients. Ten patients had absolute neutrophil counts less than 500/mm³ and had experienced an infection. Seven patients had severe congenital neutropenia, two had cyclic neutropenia, and one had idiopathic neutropenia. Subjects were administered the questionnaires at the beginning of therapy with recombinant methionyl human granulocyte colony-stimulating factor (r-met-GCSF) for the treatment of neutropenia, after 4 months, and at 10 months into treatment. The subjects ranged in age from 3 months to 32 years (M = 12.3 years). Parents completed the questionnaires for patients under age 6 years.

The total QOL scores from beginning of treatment to 10 months increased from 23.77 to 36.96. All four subscale scores showed an increase, with the greatest increase in the health and functioning (\underline{M} = 14.7 to 24.2) and socioeconomic (\underline{M} = 16.4 to 23.7) subscale scores. The family subscale was high at all administrations (\underline{M} = 21.4 to 27.1). The psychosocial/spiritual subscale was also stable with scores

varying from a beginning mean of 18.0 to a mean of 22.6 after 10 months. While Fazio and Glaspy (1991) documented an increase in the patients' total QOL and the subscale scores during treatment with r-met-GCSF, the small sample size and age of the participants restricted the findings to the population under study. It seemed inappropriate to use this questionnaire with a study sample with a mean age of 12.3 years. The authors suggested a QOL instrument be developed for pediatric patients. It also seems inappropriate to compare findings across an age range from 3 months to 32 years and to use the instrument developed and tested for cancer patients with noncancer patients.

Despite the limitations of the previous study, the QLI-Generic Version and the QLI-CV have been shown to be valuable in documenting the patients' QOL. However, no studies were reported in which the QLI-CV was used to document differences in perceptions between the cancer patient and the SKO. The QLI-CV allows the patient to rate both satisfaction and importance for the 34 items surveyed. Analyzed in subscales, these items allow for study of the areas of health recommended by the WHO (1958) definition. A study of QOL and the four subscale domains will enhance knowledge of the patients' potential use of coping

mechanisms that could alter goal attainment in multiple areas.

Quality of Life Research Studies

Spitzer et al. (1981) designed the Quality of Life

Index (QLI) as an objective measure for use by physicians
which operationalized QOL into five functional domains.

Activity, independence in daily living, perception of
health, social support, and outlook on life were categorized
into a 3-point scale. QOL ratings were calculated by
summing the six categorical ratings of 0 to 2 which would
result in a QOL score between a low of 0 and a high of 10.

Limitations of the scale include the use of a single item to
rate each domain and the weighting of all items as equal.

Although the scale has been self-administered by patients,
it was developed as an objective measure for physicians.

This scale has the advantages of measuring more than one
domain, taking less than one minute to complete, and being
easily scored.

Psychometric properties of the scale were assessed with 879 patients from Australia and Canada. The instrument was found to be sensitive and discriminated between chronic disease, cancer, and seriously ill patients. Health patients had mean QOL scores of 8.80 and 9.17, while cancer

patients had a mean score of 7.11 and seriously ill patients had a mean score of 3.31 (Spitzer et al., 1981).

Comparisons between physicians and patients who self-administered the Quality of Life Index showed a Spearman's \underline{r} = .61 (\underline{p} <.001) for the 161 Australian patients and \underline{r} = .69 (\underline{p} =<.001) for the 51 Canadian patients. The patients were found to systematically rate themselves 1 to 2 points higher (out of 10) than they were rated by physicians. Spitzer et al. (1981) concluded that patients with relatives willing to participate in a study seemed destined to score higher on the Quality of Life Index.

Padilla and Grant (1985) developed their Quality of Life Index (QLI) as a single instrument to measure QOL as a multidimensional concept. This multidimensional scale was developed for use by nurses in conjunction with applying the nursing process and impacting nursing care. The domains assessed included physical functioning, effective states, well-being, and support. Their QLI was a 14-item linear analoque self-assessment scale with a scale interval of 10 centimeters. The scale yielded continuous data that could be operationalized with parametric statistics. The scale was revised to 23 items for testing with 135 colostomy patients. Analysis of variance showed that psychological well-being was the most important dimension of quality of

life (\underline{F} = 29.30; \underline{p} <.001), followed by physical well-being (\underline{F} = 50.23; \underline{p} <.001). The factor analysis for psychological well-being included happiness, satisfaction, fun, general QOL, pleasure in eating, and sleep. Physical well-being was defined by strength, fatigue, ability to work, health, and perceived usefulness. The findings supported QOL as a multidimensional concept and, in applying the findings to clinical practice, demonstrated the importance of nurses influencing mediating variables that positively affect the patients' QOL.

Curtis and Fernsler (1989) reported on an application of the 14-item Quality of Life Index (Padilla & Grant, 1985) with 23 hospice patients and each one's family caregiver. Patients rated their overall mean QOL score at 44.8, which was lower than that reported earlier by Padilla et al. (1983) for hospitalized patients ($\underline{M} = 52$) or healthy nonpatients ($\underline{M} = 91$). Curtis and Fernsler's patient subjects rated as low their sexual satisfaction ($\underline{M} = 8.6$), ability to work ($\underline{M} = 10.3$), and amount of fun ($\underline{M} = 10.6$). Patients rated as high their QOL ($\underline{M} = 40.9$) and life satisfaction ($\underline{M} = 41.1$). Mean scores of patients' ratings were higher (better condition) than the means of family caregiver ratings on 7 of the 14 items. These items related to pain, nausea, vomiting, eating, sleep, usefulness, and

medical costs. While the patients rated their condition as better than did their caregivers, only pain was significant (2-tailed paired \underline{t} test = 2.37; \underline{p} = .027). No explanation was given for the differences in scores.

Holmes and Dickerson (1987) designed a single QOL instrument that included the 10 symptoms from the Symptom Distress Scale (McCorkle & Young, 1978) and 15 items related to the activities of daily living (ADL). A sample of 72 oncology inpatients was given a self-assessment scale that contained questions with either a linear analysis selfassessment scale (LASA) format, or a 5- or 6-point categorical scale. No statistical difference was found between the responses on the three types of instruments (\underline{n} = 20 per each form of the questionnaire). The LASA was the easiest for the patients to complete. Findings from the Symptom Distress section of the questionnaire connoted that patients with low SD scores (indicating higher symptom distress) also had low ADL scores (r = .88; p<.001). Symptoms causing major distress included appearance, fatique, and inability to concentrate. The development of this instrument allowed for patients to evaluate three scoring systems and to relate symptoms to 15 activities of daily living. While the score for the SD section of the instrument was reported as being significantly correlated to the score for the entire QOL measure, no data were given by the researchers to substantiate these findings. Adding symptom distress to QOL allows for the study of the effects of disease and treatment on the patients and enhances the study of areas that impact the patients' performance of activities of daily living and effect their performance of their usual roles.

Symptom Distress

A symptom has been defined as a subjective phenomenon that indicates a departure from normal function, sensation, or appearance (Rhodes & Watson, 1987). For example, as cancer progresses, most patients must adjust to the symptoms that result from the cancer and its treatment. How the patients perceive the effects of the symptoms has become known as symptom distress (Germino, 1987).

Studying symptom distress (SD) as a component of quality of life allows for the evaluation of the effects of the disease, such as cancer, and the treatment regime on the individual (Aaronson, 1990). By comparing the perceptions of the patient and the SKO on SD, it is possible to evaluate the human response to the disease and its treatment and understand how these perceptions affect the congruency between the dyad.

Measuring Symptom Distress

McCorkle and Young (1978) developed the seminal work on the study and measurement of symptom distress. These authors defined the concept as "the degree of discomfort from the specific symptom being experienced as perceived by the patient" (p. 374). The patients' responses to symptoms are subjective and, depending on the patients' perceptions and feeling states, produce varying degrees of physical and mental anguish which depend. A symptom is considered to be distressful to the person when its occurrence causes the patient to experience discomfort that is severe enough to necessitate interventions to alleviate the discomfort. If the stress of the symptoms is not alleviated, the distress will increase (Rhodes & Watson, 1987).

To deal effectively with symptoms, it is necessary to distinguish between the occurrence of the symptom and the amount of distress produced by the symptom. Symptom occurrence refers to the frequency, duration, severity, and intensity of the symptom. In contrast to the occurrence of a symptom, the perception of distress is the ability of the individual to perceive, or be cognizant of, and discern the amount of upset, strain, or physical or mental anguish produced by the symptom (Rhodes & Watson, 1987).

McCorkle and Young (1978) developed the Symptom Distress Scale (SDS) to measure the person's level of distress from a specific group of common symptoms. original symptom distress scale measured eight symptoms that were identified as being of major concern to cancer patients in a pilot study. The scale was expanded to 10 items that included nausea, mood, appetite, insomnia, pain, mobility, fatigue, bowel pattern, concentration, and appearance. symptoms were measured on a 5-point Likert-type scale with a score of 1 representing the least amount of distress for a given symptom and 5 the most distress. The intervals between 1 and 5 measure intermediate levels of distress. (The psychometric properties of the scale are discussed in the Instrument Section of Chapter 3.) The scale is selfadministered, and patients are asked to circle the number corresponding to their amount of distress for the moment or in a given day. The instrument takes 5 to 10 minutes to score; scores for each item are summed to produce an overall symptom distress scale score varying from 10 to 50. A score of 10 equates to no symptom distress, while a score of 50 indicates extreme distress (McCorkle, 1987).

Monitoring the patients' symptom distress allows nurses

(a) to assist patients in monitoring their level of health

distress and progress, (b) to determine the patients' needs

and problems, and (c) to determine the effectiveness of various interventions. Monitoring SD at systematic intervals allows nurses and patients to identify changes over time to adjust interventions accordingly. The goals of nursing interventions are to decrease symptom distress and decrease the number of symptom occurrences (McCorkle, 1987).

Managing the patients' symptom distress from a particular symptom acts as a positive mediating variable in improving the patients' overall quality of life (Germino, 1987). An example would be that an intervention targeted at pain will also relieve symptoms of insomnia, fatigue, and appearance. Alleviating pain improves sleep and decreases fatigue, and patients become more interested in their appearance. Improving these symptoms indirectly improves the patients' quality of life (McCorkle, 1987; Padilla & Grant, 1985). The Symptom Distress Scale (SDS) does not distinguish between symptoms of disease or treatment. goals of nursing interventions are to alleviate the occurrence and the distress of the symptoms, but even when this cannot be done, setting realistic expectations and helping the patient utilize effective coping strategies may improve the patients QOL (McCorkle, 1987).

Research Related to Symptom Distress

Defining symptom distress as the effects of disease and treatment is consistent with King's (1971, 1981) definition of health. Health in King's framework is the dynamic life experiences of human beings; it implies continued adjustment to stressors in the internal (disease) and external (treatment) environment through optimum use of one's resources to achieve maximum potential for daily living (King, 1981). Reviewing studies related to SD contributed to an understanding of the changes necessitated by illness.

Tishelman, Taube, and Sachs (1991), conducted a study in Sweden of SD and four categories of explanatory variables: demographic, medical/clinical, individual/ psychosocial, and patients' view of care provided by the health care system. The sample of 46 patients was chosen from a previous study sample and 29 significant others were chosen by the patients. Researchers conducted interviews composed of both open- and closed-ended questions. The original SD Scale was expanded to 15 symptoms, including nausea (frequency and intensity), appetite, insomnia, fatigue, pain (frequency and intensity), breathing, cough, mobility, bowel function, mood, concentration, appearance, and outlook. The SDS was studied as the dependent variable in the multiple regression in three ways as follows:

- 1. A summated rating of the 15 symptoms.
- 2. Five sub-indexes of symptoms grouped as pain, appetite and nausea, functional aspects, psychological aspects, and social aspects.
- 3. The 15 individual symptoms.

Multiple regression analysis done by Tishelman et al. (1991) indicated that the demographic variables accounted for 24% of the variance related to frequency and intensity of nausea and appetite. Symptom distress was significantly increased in women (& = 0.458; p<.01), in the unmarried (& = -0.492; p<.05) and in younger persons (& = 0.348; p<.05).

Medical/clinical variables such as type of treatment, pain, and psychological aspects accounted for 18% of the variance of the total SDS score on multiple regression analysis. Oncological treatment was significantly related to the total SDS score (& = 0.556; p<.01) and to the subscale of pain (& = 0.431; p<.05) and the sub-index of psychological aspects (& = 0.474; p<.05) (Tishelman et al., 1991).

When variables were combined, multiple regression analysis demonstrated that 67% of the variance in the total SDS index could be accounted for by six variables (\underline{n} = 45): widower/widow (\underline{B} = 0.591; \underline{p} <.0001), sense of coherence

(£ = -0.551; p<.0001), oncological treatment (£ = 0.482; p<0.001), support (£ = 0.466; p<.0001), gynecological diagnosis (£ = -0.275; p<=.0117), and no assessment of individual needs (£ = -0.69; p<.0001). The combining of six variables explained 72% of the variance related to psychological symptoms (n = 42). These variables included sense of coherence (£ = -0.69; p<.0001), support (£ = 0.388; p<.0001), oncological treatment (£ = 0.385; p<.0004), widow/widower (£ = 0.309; p<.0016), divorced/ separated (£ = -0.203; p<.0293), and number of physicians (£ = -0.03; p<.7584). While this study was a preliminary attempt to isolate variables related to total and subindexes of SD, findings indicated that SD is best studied as a multidimensional concept in relation to the patient and the patient's environment (Tishelman et al., 1991).

To explain how patients adjusted to the stressors of the internal and external environment, Holmes (1989) adapted the SDS to a 100 millimeter LASA scale with bi-polar anchors for each of the 11 symptoms. A total of 120 heterogeneous cancer patients were assessed. Reliability of the scale, determined with Cronbach's coefficient alpha, was .97, which indicated high internal consistency (Munro, Visintainer, & Page, 1986).

Multiple regression demonstrated that fatigue accounted for 63.5% of the variance in the SDS total score (p<.001). Significant distress was defined by an arbitrary cutoff point of 50 millimeters on the 100 millimeter scale. Significant distress was indicated for at least one symptom by 73% (88) of the 120 patients, 56% (67) had at least 2 or more distressing symptoms, and 28% (9) had 5 or more significant distressing symptoms (Holmes, 1989).

Multiple regression analysis indicated that tiredness accounted for the largest variance in the SD score and also correlated significantly with the total score (\underline{r} = .08; \underline{p} <.001). Holmes (1989) concluded that effective relief of other distress in symptoms may alleviate some of the fatigue experienced by the subjects. Two interesting findings of the study were that the 25% of patients with widespread disease did not differ significantly in the findings from the total sample. Also, no significant differences were found between male and female patients and between chemotherapy and radiotherapy patients.

In a second application of the revised SDS, Holmes (1991) reported on the symptoms experienced by patients undergoing treatment and how these symptoms affected the patient's ability to carry on activities of daily living. A total of 51 patients, 22 receiving chemotherapy (CT) and 29

receiving radiotherapy (RT), completed the SDS. Reliability of Cronbach's coefficient alpha for internal consistency was 0.94 (p<.0001) for the CT group and 0.91 (p<.0001) for the RT group. With CT patients, eight symptoms correlated significantly with the total score. These included nausea $(\underline{r} = 0.55; \, \underline{p} < .05)$, appetite change $(\underline{r} = .66; \, \underline{p} < .001)$, inability to sleep ($\underline{r} = .49$; $\underline{p} < .45$), mobility ($\underline{r} = .35$; \underline{p} <.05), tiredness (\underline{r} = .44; \underline{p} <.05), concentration $(\underline{r} = .65; \underline{p} < .05), \mod (\underline{r} = .62; \underline{p} < .05), \text{ and appearance}$ $(\underline{r} = .37; \underline{p} < .05)$. Consistently, fatigue was shown to be a cause of distress for both groups. Chemotherapy patients reported changes in concentration, mood, and appearance. Radiotherapy patients indicated appearance, pain, appetite, and constipation as the most distressing symptoms. Findings suggested that while the SDS is appropriate for use in evaluating groups of patients, it is of particular value in evaluating the needs and effects of interventions with individual patients. The total SDS score for CT patients varied from 472 to 1016 ($\underline{M} = 746.5 \pm 150.6$) compared with 427 to 1024 ($M = 710.4 \pm 152.8$) in RT patients. The range of scores indicated similarity in the amount of SD between the total groups, but yielded individual variations within the groups.

In a study that helped to explain the transaction process between the patient and their nurse caregivers, Holmes and Eburn (1989) reported on a third application of the revised SDS comparing the patients' and nurses' perceptions of the patients' symptoms. A total of 53 cancer patients and the nurses caring for them were compared on the 11-item LASA scale. Significant differences were found for 7 of the 11 items. Besides the total score ($\underline{t} = 5.224$; p>.001), other areas of significant differences included pain (t = 2.298; p>.05), nausea (t = 5.022; p>.001), appetite ($\underline{t} = 4.467$; $\underline{p} > .001$), sleep ($\underline{t} = 2.337$; $\underline{p} > .05$), concentration ($\underline{t} = 2.315$; $\underline{p} > .05$) and mood ($\underline{t} = 4.971$; p>.001). As projected by the social comparison theory, the nurses consistently overestimated the degree of distress when compared to the patient's assessment. The researchers recognized that there were significant differences in 7 of the 12 areas assessed, but stated that reasons for the differences were not easily explainable. They advocated the use of self-assessment by the patient and recognized that inaccurate perceptions by nurses may add to inadequate diagnosis and treatment of symptoms.

Oberst, Hughes, Chang, and McCubbin (1991) used the Symptom Distress Scale to evaluate the self-care burden, stress appraisal, and mood among 72 (35 women, 37 men)

radiotherapy (RT) cancer patients. As reported in previous studies, fatigue was the most distressing symptom, followed by loss of strength and difficulty in sleeping. A multiple regression equation utilizing the SDS and Self-Care Burden Scale (SCB) indicated that the amount of symptom distress and dependency experienced by RT patients caused 48% of the variance in the total SCB score. Symptom distress and somatic mood were correlated ($\mathbf{r} = .71$; $\mathbf{p} < .05$). These findings indicated that symptom distress was responsible for the SCB score and that the patients appraised their situations as stressful. The two symptoms, somatic mood and fatigue, are both factors that might negate the patients' ability to enter into a relationship with the SKO that would lead to goal attainment.

In a subsequent reporting of chemotherapy (CT) patients, Munkres, Oberst, and Hughes (1992) studied 60 patients receiving chemotherapy in an outpatient setting on the same variables assessed in the previous study. Total symptom distress mean score was 36.65 (standard deviation = 16.89). Symptom distress mean score for the initial treatment group was 30.59 (standard deviation = 12.71), while patients with recurrent disease SD mean score was significantly greater at 42.49 (standard deviation = 18.51; p<.01).

In comparing their data to that from the previously studied 72 RT patients (Oberst et al., 1991), Munkres et al. (1992) reported 72 RT patients had a SD mean score of 30.49 (standard deviation = 17.72), while the 28 patients who were receiving initial chemotherapy had a comparable SDS score of 30.59 (standard deviation = 12.71). The chemotherapy group with recurrent disease (\underline{n} = 32) had a mean SD score of 42.49 (standard deviation = 18.51), which indicated substantially more symptom distress. Fatique remained the most distressing symptom for all three groups; loss of strength was the second most distressing symptom for the RT and recurrent CT group, while in the group with initial CT treatment, sleep disturbance was second. Sleep disturbance was the third most distressing symptom for the RT and recurrent CT group. Fatique, sleep disturbances, and loss of strength are all symptoms that affect the patients' ability to function in normal roles and have potential to affect the relationship with the SKO. Studying the patient's SD and QOL from the perspective of both the patient and the SKO will foster an understanding of any incongruencies that would impede goal attainment.

Summary

To understand how the use of the coping mechanism of downward shifting may alter the congruency of perceptions

between the patient and the SKO, a discussion of social comparison theory was presented. Social comparison theory (SCT) (Festinger, 1954; Wills, 1981) explains how individuals learn about themselves through comparison with others. Patients experiencing a threatening illness, such as cancer, use both upward and downward comparisons to learn more about their situations and self-enhance their condition. This change in the patients' perceptions has been responsible for patients assessing their conditions as better than the SKOs reported for them (Wills, 1981).

Since the use of social comparisons is a coping strategy and cannot be directly observed, quality of life and symptom distress were chosen as the means of evaluating whether there are differences in perceptions between the patient and the SKO. Quality of life was defined, and methodological issues were discussed. The concept was operationalized and allowed for a study of the WHO components of QOL. Using the QLI-CV (Ferrans, 1990a) and the SDS (McCorkle, 1987), the dimensions of health and functioning, socioeconomic, psychological/spiritual, and the family, as well as the effects of the cancer and its treatment, were discussed. Operationalizing social comparison theory may lead to a better understanding of how the coping mechanism of downward shifting potentially alters

the congruency of perceptions between the patient and the SKO. This congruency of perceptions is necessary if the dyad is to reach goal attainment during the cancer experience.

CHAPTER 3

PROCEDURE FOR THE COLLECTION AND TREATMENT OF DATA

A two-group, nonexperimental descriptive survey (Abdellah & Levine, 1986) was used to test the research questions regarding the congruence between the cancer patient's and the significant key other's (SKO) perceptions of the patient's quality of life (QOL) and symptom distress The study was designed to investigate the relationship between the independent variable of members of the dyad of patient and SKO and the dependent variables of QOL and SD. Quality of life and SD were operationalized by using the multiple dimensional instruments of the Quality of Life Index-Cancer Version (QLI-CV) (Ferrans, 1990a) and the Symptom Distress Scale (SDS) (McCorkle & Quint-Benoliel, 1983). The extraneous variable of medical diagnosis was controlled by selecting patients with solid malignant tumors and hematologic cancers. The patient's physical status was controlled by selecting patients with predetermined performance levels on the Performance Status scale (Karnofsky & Burchenal, 1949). A convenience quota sample of male and female patients that was representative of the national statistics for solid tumor and hematologic cancer

incidence by gender was used (Boring, Squires, Tong, & Montgomery, 1994). The SKO for each patient was chosen by the patient. Participants were asked not to discuss their answers with each other until all questionnaires were complete.

Setting

The setting for this study was a large city in the southwestern Gulf Coast area of the United States. The city contains a large medical center complex that serves the population of the area plus national and international referrals. Other than the major medical center, the city also includes multiple medical centers and outpatient oncology facilities. Due to the small target population in each facility, a multisite study was planned.

The medical center hospital chosen for the study was a university-affiliated teaching hospital with 482 beds in current use. Patients were treated in the oncology clinic by university-affiliated, board certified oncologists and staff residents. The registered nurse staff is specifically trained in administration of chemotherapy. The clinic carries a case load of approximately 80 patients. There are private examining rooms in the clinic and semiprivate rooms for administering chemotherapy. The hospital also has a 36-bed inpatient oncology unit with private rooms. Each room

includes an overbed table and a table and chairs. Clinic patients are admitted to the inpatient unit for treatment at physician discretion based on type and length of treatment. Clinic patients were administered questionnaires in private examining rooms or the chemotherapy administration area. Inpatients were administered questionnaires in their rooms.

The community-based setting for the study was a 365-bed for-profit medical center that serves the western portion of the city. The cancer program is accredited by the American College of Surgeons as a community hospital cancer center. The hospital provides both inpatient and outpatient services for adult cancer specialties. The treatment includes both Community Clinical Oncology Program Protocols and individual treatments. In the oncology program, approximately 340 patients were diagnosed during 1992. Approximately 98% of these patients are followed by the tumor registry at the medical center. The hospital serves as the inpatient facility for physician referrals from outpatient offices.

The inpatient unit contains 17 private rooms with overbed tables and table and chairs and 6 semiprivate rooms with overbed tables. The unit also has a waiting area with comfortable chairs and two offices with desks and chairs that could be used by the study participants. The Radiation Therapy Center, directed by a Board Certified Radiation

Therapy Physician and adjacent to the hospital, was also used for the study. The unit contains private offices and waiting areas, which were used for administering questionnaires.

The outpatient oncology settings were four private offices of Oncology Board Certified and Board Eligible Physicians. The first group practice has four physicians and approximately 50 patients in active treatment. Ouestionnaires were administered in two private treatment rooms or in the chair area with five recliners used for chemotherapy administration. The second oncology practice has two physicians and 40 patients in active treatment. Questionnaires were administered in the two chemotherapy chair areas with eight recliners, or in a private office or conference room with a large table and chairs. oncology office has three physicians and 30 patients in active treatment. Questionnaires were administered in private examining rooms or office. The fourth practice has one physician and 20 patients undergoing treatment. SKO's were administered the questionnaires in the same settings as the patients.

Population and Sample

The study population consisted of solid malignant tumor and hematologic cancer patients admitted to participating

agencies. Because of the small number of patients (210) available for study and the infrequency of most patient visits to the clinic or offices, all patients and SKOs who met the inclusion criteria and who agreed to participate constituted the study sample.

Based upon Beyer's (1966) probability tables, a minimum sample size of 134 (67 patients and 67 SKOs) was required to achieve a power of 0.80, a significance level of p = .05, and an effect size of \underline{r} = .35. Use of a medium effect size is appropriate since previous researchers have documented a measurable difference when patients' and SKOs' perceptions of patients' conditions are compared. However, the total sample size of 140 (70 patients and 70 SKOs) included a 5% increase over Beyer's original projected sample size to correct for use of the nonparametric Wilcoxon matched-pairs signed-ranks test which has a 95% power when compared to the t test for two related samples (Roscoe, 1975). A quota sample of 37 (52.3%) male and 33 (47.7%) female patients $(\underline{n} = 70)$ and the patients' SKOs $(\underline{n} = 70)$ was surveyed (N = 140), which was considered an acceptable sample size to diminish results due to chance and to a Type II error. percentages were representative of the national statistics for solid malignant tumors and hematologic cancers (Abdellah & Levine, 1986; Boring et al., 1994).

Patients who met the following study inclusion criteria were asked to participate:

- 1. Male and female patients.
- 2. Age 18 or older.
- 3. Diagnosis of solid tumor or hematologic cancer.
- 4. Awareness of the diagnosis of cancer as validated by the medical or nursing staff or in the medical record.
- 5. Performance status of 50 to 90 points on the Performance Status scale (Karnofsky & Burchenal, 1949).
- 6. Able to read and write English.
- 7. Absence of previous history of other malignancies.
- 8. Undergoing treatment with radiation therapy, chemotherapy, biological therapy, hyperthermia or a combination of these therapies.

Significant key others participating in the study met the following criteria:

- Male and female subjects.
- 2. Age 18 or older.
- 3. SKO status as documented by the patient.
- 4. Awareness of the patient's diagnosis of cancer as validated by the patient, medical, or nursing staff or documented in the medical record.
- 5. Able to read and write English.

Health professionals and employees or affiliates delivering care to the patient in participating agencies were excluded.

Protection of Human Subjects

The study was conducted in accordance with rules and regulations of the Human Subjects Review Committee

Guidelines of Texas Woman's University. Approval to conduct the study was obtained from the institutional review boards of Texas Woman's University (TWU) and the participating agencies (Appendix A). Subsequent to the agencies' approvals, the researcher verbally informed each patient's admitting physician of the institutional approval to conduct the study.

A short letter (Appendix B) introduced the study to the participants. The letter included the purpose of the study and explained that the patient and the designated SKO were asked to complete a demographic data sheet and two questionnaires. Use of this letter was a recommendation from the pilot study to ensure that patients fully understood the elements of informed consent.

Written informed consents individualized for the patient and SKO (Appendixes C and D) included the purpose of the study to determine differences in the perceptions of QOL and SD between the cancer patient and the SKOs.

Subjects were informed of the voluntary nature of

participation and that they could withdraw from the study at any time without penalty. Also, there was no penalty for nonparticipation. The subjects were informed that they would not receive any direct benefit from participating in the study. The risk of the study was also explained: because of the sensitive nature of some questions and possible disagreement between the dyad, the completion of the questionnaire may have produced anxiety. Patients and SKO's were instructed to omit any questions they found anxiety-producing. Each patient and SKO was assured that their responses would not be shared with the other member of the dyad unless they chose to share responses themselves. The consent also included a statement on confidentiality of information and a phone number to contact the investigator.

All instruments were coded to keep the pairs matched for statistical analysis. All instruments and codes were kept in a locked drawer and destroyed after data analysis was complete. All data were reported in summary form, and the subjects and institutions were not identified. A summary of the study results will be made available to each institution.

Instruments

The Performance Status scale (Karnofsky & Burchenal, 1949) (Appendix E) was completed by the nurse of the patient to determine if the patient met eligibility criteria (50 or above) for sample selection. If a current Performance Status was already in the medical record, that status was used.

The instruments in this study consisted of a set of Background Data Sheets, Quality of Life Index-Cancer Versions (Ferrans, 1990a), and Symptom Distress Scales (McCorkle & Quint-Benoliel, 1983) individualized for both the patient (Appendix F) and the SKO (Appendix G) groups. Permission to use the Quality of Life Index-Cancer Version and Symptom Distress Scale were obtained from the authors (Appendix H).

Background Data Sheets

The patient's background data sheet was divided into two parts to shorten the patient's response time. Part I included a list of demographic items for the patient to complete (Appendix F). Part II, completed by the investigator from the Medical Record, included the relevant items from the patient data that are tracked for each patient by the hospital tumor board (Appendix I).

The patient portion (Part I) of the data sheet included the patient's SKO and relationship to the SKO, sex, age, occupation, and income. The patients were asked to make selections to indicate ethnic group, religious preference, marital status, and level of education. These factors were deemed appropriate to report demographic data identified in the literature as impacting QOL and the patients' responses to symptom distress (McCorkle & Young, 1978; Strain, 1990). Patients were asked to list their occupation and their longest occupations; these factors related to the epidemiology of cancer (American Cancer Society, 1993). The patients were then instructed to designate their SKO, the person giving them emotional support during the illness, and to state this person's relationship to them.

Part II of the patient's background data sheet, coded by the investigator to indicate which of the seven medical setting sites where the patient received treatment, included type, site, and stage of cancer; performance status; initial diagnosis date; recurrence date; weight gain or loss; type of previous treatment; number of treatment cycles; and presence of other diseases.

The SKO background data sheet (Appendix G) included questions regarding relationship to the patient, gender, age, occupations, and person they consider their SKO. Also

included were questions regarding educational level, ethnic background, income level, religious preference, and marital status. The SKO's were also asked to specify the person giving them emotional support and to specify how long they had known this person.

Quality of Life Index-Cancer Version

The first form of the Quality of Life Index-Generic Version (Ferrans & Powers, 1985) was a 64-item Likert-type scale that measured multidimensional aspects of quality of life that were amenable to nursing interventions. The domains being surveyed included health and functioning, socioeconomic, psychological/spiritual, and family.

The scale was divided into two parts and had the feature of first measuring the subject's subjective satisfaction with the domains being surveyed and then allowing the subject to indicate the importance of each item. The 6-point Likert-type scale items are bi-polar and range from "very satisfied" to "very dissatisfied" on the satisfaction scale and "very important" to "very unimportant" for the importance items. Quality of life scores are then calculated by weighting satisfaction scores with importance scores to produce a measurement of the patient's satisfaction and evaluation of the value of the item to the individual.

A computer program was available to calculate and adjust scores to allow for the highest scores for items that indicate high satisfaction and high importance and lowest scores for high dissatisfaction and high importance responses. The item scores were compiled into subscale scores and overall Quality of Life scores ranging from 0 to 30. The instruments, first tested with female graduate students ($\underline{n} = 88$) and then dialysis patients ($\underline{n} = 37$), demonstrated sensitivity to both well and sick groups (Ferrans & Powers, 1992).

Content validity was determined by Ferrans and Powers (1985) from an extensive review of the literature and interviews with dialysis patients. Three questions specific to renal dialysis were added to the original instrument for dialysis patients. Criterion-related validity was determined by using one question with a 6-point rating scale to evaluate overall quality of life. Criterion-related validity between the Quality of Life Index and the life satisfaction item was $\underline{r} = .75$ for the graduate students and $\underline{r} = .65$ for the dialysis patients. These correlations indicated high and moderate concurrent validity between the two instruments (Munro, Visintainer, & Page, 1986).

Test/retest reliability of the Quality of Life Index to determine stability over time yielded correlations of

 \underline{r} = .87 for graduate students (\underline{n} = 69) after 2 weeks and \underline{r} = .81 for dialysis patients (\underline{n} = 20) after a 1-month interval. To test internal consistency of the instrument, Cronbach's alpha was \underline{r} = .93 for graduate students and \underline{r} = .90 for dialysis patients (Ferrans & Powers, 1985).

To study quality of life of cancer patients, the Ferrens and Power's Quality of Life Index-Generic Version was amended with three items after an extensive review of the oncology literature. The QLI-Cancer Version (QLI-CV) measured the same four domains for both satisfaction and importance. The QLI-CV was coded and scored the same as the original questionnaire (Ferrans, 1990a).

To determine validity and reliability of the QLI-CV, 111 female breast cancer patients from a tumor registry were surveyed. Content validity was assessed after an extensive review of the literature. Concurrent validity was assessed on the same single-item 6-point Likert-type scale which measured overall satisfaction (Campbell, Converse, & Rogers, 1976). A single-item scale is considered a subjective global type measure of quality of life (Guyatt & Jaeschke, 1990). Concurrent validity between the QLI-CV and the Assessment of Life Satisfaction measure was $\underline{r} = .80$. This correlation indicated a high correlation between the measures (Munro et al., 1986).

Construct validity was assessed using the Known Groups method. Questions related to pain, depression, and coping were selected from the Functional Living Index-Cancer (Schipper, Clinch, McMurray, & Levitt, 1984). Patients were placed into three groups depending on self-reported amounts of pain, depression, and success with coping. Ferrans (1990a) reported that the QLI-CV was sensitive and discriminated between lesser and greater amounts of these attributes as demonstrated by a paired test of the differences of the means between patients with greater and lesser amount of the pain, depression, and success in coping. Subjects who had less pain, less depression, and who were successfully coping with stress had significantly higher QOL scores than patients who had higher scores for depression.

Internal consistency reliability was determined with Cronbach's alpha. The entire instrument produced $\alpha=0.95$, while $\alpha=0.90$ for the subscale of health and functioning, $\alpha=0.84$ for the socioeconomic subscale, $\alpha=0.93$ for the psychological/spiritual subscale, and $\alpha=0.66$ for the family subscale. All alphas supported very high and high internal consistency except $\alpha=0.66$ for the family subscale. The family subscale indicated moderate correlation, which is acceptable for studying relationships

of human behaviors (Munro et al., 1986). An evaluation of the family subscale items demonstrated that subjects were generally satisfied with family members and family happiness, but less satisfied with the health of their families. The QLI-CV demonstrated adequate reliability and validity for use by cancer patients. No studies were found to ascertain where the QLI-CV was used by health care providers or caregivers to measure the patient's quality of life.

Symptom Distress Scale

The Symptom Distress Scale was developed to measure the degree of discomfort experienced by cancer patients in response to symptoms being experienced. The original scale measured variables that have been shown to be of concern to cancer patients and to produce distress in patients. These variables included nausea, mood, appetite, insomnia, pain, mobility, fatigue, bowel pattern, concentration, and appearance (McCorkle & Young, 1978). The scale was later expanded to include both the presence and intensity of nausea and pain, breathing, and cough. The symptom of mobility was eliminated (McCorkle & Quint-Benoliel, 1983). The distress score does not differentiate between symptoms caused by disease or by treatment. The items rank distress on a 5-point scale from a value of 1 (no distress) to a

value of 5 (extreme distress). A total score of 13 indicates no distress, while a score of 65 indicates extreme distress (McCorkle, 1987).

The original 10-item scale was pilot tested twice on 26 chemotherapy and radiation subjects and 45 cancer patients. The patients were asked to circle the number that most closely represented their distress for that moment or that day. High levels of distress were reported for at least one item by 28 (62.2%) of the respondents. Among the 28 patients who reported a high level of distress for one item, 13 (46%) indicated high distress for at least three items (McCorkle & Young, 1978).

Content validity and reliability were established in further testing of the instrument with 53 chronic illness patients. The reliability coefficient was $\alpha = 0.82$ (McCorkle & Young, 1978). In a study of breast cancer patients, the internal consistency score was $\underline{r} = 0.92$ (p=.05) (Coward, 1991).

In a study of 67 lung cancer patients at 1 and 2 months postdiagnosis, internal consistency reliability was 0.79 at first administration and 0.78 at second administration.

These findings indicated good internal consistency. With lung cancer patients, the mean score for item total was 26.67 at 1 month and 26.13 at 2 months. Analysis of

variance between lung cancer patients and myocardial infarction patients demonstrated that the cancer group reported significantly more symptom distress than the coronary group ($\underline{F} = 39.65$; $\underline{p} < .001$). Fatigue was considered the most distressing symptom for cancer patients at both administrations, with a distress score of 2.98 at the first month and 2.88 at the second month. Pain frequency was the second most distressing symptom, with a score of 2.64 at time 1 and 2.41 at time 2. Appetite was ranked third in distress, with mean scores of 2.48 and 2.29 at the two administrations (McCorkle & Quint-Benoliel, 1983).

In a 4-year longitudinal study of 53 inoperable lung cancer patients, symptom distress was found to be the most important predictor of survival, indicating that amount of distress at diagnosis may indicate length of survival (Kukull, McCorkle, & Driever, 1986). The SDS has been used with multiple cancer groups and has indicated sensitivity in distinguishing between cancer patients with varying amounts of symptom distress.

Performance Status Scale

The Performance Status Scale, commonly known as the Karnofsky Performance Scale (KPS) (Karnofsky & Burchenal, 1949) (Appendix E), is a single categorical measure that yields a numerical figure to describe the patient's ability

to carry out a variety of activities that are normal for most people (Aaronson, 1988). This measure was originally developed for use as one of four measures to evaluate the effectiveness of chemotherapeutic agents in clinical trials. The authors proposed that besides evaluating subjective measures of well-being, objective physical parameters, and length of survival and tumor response, it was also necessary to determine the effect of the disease and chemotherapy treatments on the patients' activities of daily living or functional performance status (FPS).

The scale, which has historically been completed by physicians, has become the most universally acceptable measure to evaluate patients' activity level. It has also been widely used as a global quality of life measure, but this application gives a skewed result since it measures only one domain (Grieco & Long, 1984). The Performance Status Scale is an 11-point rating scale with values ranging from normal functioning (100) to dead (0). The rater assesses the patient's ability to carry out activities of daily living, and this score places the patient in one of three categories that classifies the patient's ability to work and the need for physical care. Percentage scores of 100 to 80, normal with no complaints to normal activity with effort -- some signs and symptoms of disease, place the

patient in a normal category with no special care needs. Percentage scores of 70 to 50, self-care but unable to actively work to requiring considerable medical care, equates the patient to a category which includes the inability to work and the patient's requirements for varying degrees of assistance. Scores of 40 to 10, disabled requires assistance to moribund, categorizes the patient as requiring the equivalent of institutional or hospital care. The scale also has a 0-point equated with death (Fallowfield, 1990; Jones, Fayers, & Simons, 1987).

Because of the percentage ratings of 0% to 100% and the presence of a zero point or complete lack of performance ability, the scale is often considered continuous and the scores treated as ratio level data. In fact, the scale measures discrete unequal categories, and while relationships have been correlated between the KPS and levels of activity for statistical purposes, the scale is considered an ordinal scale (Verger, Salamero, & Conill, 1992).

The KPS has been widely employed in various oncology settings. The scale scores have been used as a selection criteria for patient inclusion in oncology clinical trials because they clearly define the physical status and medical requirements of patients (Conill, Verger, & Salamero, 1990).

The KPS is the main objective measure used to evaluate the impact and progression of the disease and chemotherapy and radiotherapy treatment with individual patients and in clinical trials (Schag, Heinrich, & Ganz, 1984). The KPS has also been shown to have predictive value in determining length of survival (Ganz et al., 1993).

While the scale had been used for years without adequate psychomotor evaluation, researchers have now determined adequate validity and reliability for the measure with oncology patients (Grieco & Long, 1984; Schag et al., 1984). Grieco and Long conducted psychometric studies on the reliability of the KPS. The researchers studied 30 subjects from five different nononcology services at a Veterans Administration Medical Center (VAMC). Two raters used three standard procedures for obtaining data: (a) medical record chart reviews, (b) patient interviews, and (c) structured interviews with people who knew the When the raters then completed the KPS, the patients. interrater reliability between the two raters was found to be a Spearman rank correlation of 0.86. This interrater reliability indicated a high correlation and was acceptable for raters using the same clinical information (Munro et al., 1986).

Yates, Chalmer, and McKegney (1980) evaluated the test/retest reliability of the KPS by examining 52 cancer patient scores at a week's interval. Pearson correlation scores were $\underline{r}=0.69$ (p<.001) between the two administrations. This lower score was attributed to the poor condition of the original group. These patients had initial KPS ratings of 70 or less at the first administration, and the patients' scores in this category were expected to deteriorate over a week's time.

Mor, Laliberte, Morris, and Wiemann (1984) assessed the reliability and validity of the instrument to determine the appropriateness of the instrument's use in the National Hospice Study. The intent of this project was to evaluate the impact of hospice care on the QOL of 685 terminally ill patients. The KPS was routinely measured on all patients entering the study. Raters were trained in the use of the scale and conducted thorough interviews with the patients. After 4 months of working with the scale, 47 interviewers were asked to rate 17 scenarios. Cronbach's coefficient alpha for the total scenarios was 0.97 (p<.001) which indicated support for reliability (Munro et al., 1986).

In this same study, construct validity of the KPS was determined by comparison with the categories of activities of daily living (ADL) as specified in the Katz ADL Index.

Interviewers correlated the findings on the KPS items of 10% to 50% with the seven categories and three levels of variables measured by the Katz ADL Index. The chi-square test for all 21 categories indicated that the differences in performance levels on the KPS were significant (p<.001). Since hospice patients are disabled on admission, the validity score only pertained to the bottom portion of the scale.

The content validity of the KPS as a measurement of functional performance status has been universally accepted (Aaronson, 1988). To determine construct validity, the KPS scores were correlated with the Eastern Cooperative Oncology Group Scoring Scale (ECOG) (Conill et al., 1990). is a 6-point functional performance measure that rates the patients from a 0 (normal) to 5 (death). The ECOG has the same indications for use as the KPS, and a review of the literature demonstrated that of 227 studies using functional performance scales, 114 (50%) used the KPS and 113 (50%) used the ECOG scale. A total of 100 oncology patients receiving radiation were assessed twice by two oncologists on the same day using the above two scales. Kendall's correlation between the physicians was 0.76 (p<.001) for the KPS and 0.75 (p<.001) for the ECOG. These correlations were significant and indicated high construct validity (Munro

et al., 1986). A second report of the same study (Verger et al., 1992) indicated that although overall scores on the KPS and ECOG correlated significantly, it was impossible to compare individual scale items between the two instruments. While scores for KPS 100 and 90 and ECOG 0 and 1 have excellent correlations, to convert a lesser score on the KPS to an ECOG score with 95% confidence, a wide interval of three ECOG values to one KPS interval must be used. This conversion would invalidate use of the scale. Conill et al. recommended that one scale be chosen rather than trying to compare values from the two scales with different interval levels. They also cautioned about comparing functional performance status of patients in studies that use different scales.

Aaronson (1988) recommended the KPS as the instrument of choice for measuring FPS and stated that when raters were sufficiently oriented to use of the scale and had clear operational definitions of each scale level and sufficient patient knowledge, the KPS would be valid and would yield appropriate interrater reliability. Since the physicians and nurses involved with the present study are oncology specialists adept at scoring the KPS and thoroughly familiar with the patients' conditions, they met the criteria for

adequately determining if the patients were included in the five categories chosen for inclusion in the study.

Pilot Study

A pilot study was conducted to test methodology and instruments to be used in the dissertation study. The purpose of the study was to test differences in perceptions of the patient's condition between bronchogenic lung cancer patients and their spouses at the beginning of a chemotherapy treatment cycle. Permission was obtained from the supervising TWU professor to change from spouses to SKOs because many patients did not have spouses available.

A convenience sample of 10 patients and 8 SKOs was recruited from the university- and community-affiliated medical centers. Patients and SKO groups were unequal since two SKOs did not complete questionnaires. The small sample used for the pilot study prevented generalization beyond the sample group. However, the procedures and instruments were revised based on the pilot study experience and findings.

Protection of Human Subjects

The pilot study was conducted according to the Texas Woman's University Human Subjects Review Committee
Guidelines. The Human Subjects Review Board in the
university-affiliated medical center hospital approved the

study, as did the representatives of the other agencies. A written informed consent was obtained from each subject.

Instruments

A cover letter introduced the study to the patient and the SKO. This introduction was considered important, since many of the older patients were skeptical of interacting with a stranger. The informed consent was given to each subject. Only one patient read the paper. The other patients and SKOs asked the investigator to read them the information. The investigator read a summary of each section to the subjects.

Demographic Data Sheet

The demographic data sheet used was two pages long and included sex, age, ethnic group, religion, present marital status, highest level of education, and approximate household income. There were also six questions related to diagnosis, onset of symptoms, start of treatment, type of treatment, occupation, and ability to continue in one's occupation.

Symptom Distress Scale

The Symptom Distress Scale (McCorkle & Quint-Benoliel, 1983) was a 13-item Likert-type scale selected to measure the amount of distress produced by the symptoms the patient

experienced. This scale was described previously in the Instrument section of this chapter.

Quality of Life Index

The Quality of Life Index (Spitzer et al., 1981) is a 3-point, Likert-type scale that assesses the patient's levels of activity, independence in daily living, health, support, and outlook. The scale was developed and tested extensively with cancer patients. Convergent and discriminant validity was determined with chronic illness and cancer patients and normal subjects. Cronbach's alpha to determine reliability for the 5-item scale was reported at 0.78 and indicated adequate internal consistency. Interrater reliability between two sets of physicians on three groups produced Spearman rank order correlations of 0.74 (p<.005) and 0.84 (p<.001).

Data Collection

The pilot study allowed for testing the methodology of data collection and obtaining feedback regarding instruments used. The nurse managers in each agency identified the patients and asked if they would talk to the investigator regarding the study. Data were collected only at the beginning of a chemotherapy treatment cycle.

The nursing staffs had good rapport with the patients and balanced their needs with the requirements of the investigator. The nurses explained the study to the patients prior to introducing the investigator and assured the patients that they would have everything explained prior to signing the informed consent. The nurses accepted the rights of one patient and two spouses to refuse participation.

The setting for the study was adequate in each agency. The patient had a private area in which to talk to the investigator and fill out forms. In the clinic area, there was adequate time between the drawing of blood work and medication administrator to allow for instrument administration. Patients were not rushed or delayed in beginning treatment. Spouses were not always with the patient at the time of treatment, and data were collected at different times, causing a threat to the internal validity of the study.

The inpatient setting at each agency was also adequate for instrument administration; a time when both subject and spouse could be surveyed together was arranged. Since all patients did not have spouses, it was deemed appropriate by the investigator and the faculty advisor to collect data on the person designated as the SKO by the patient.

Analysis of the Instruments

Reliability and validity were assessed on the Symptom Distress Scale. The measure of reliability established for this instrument was internal consistency as measured by Cronbach's alpha coefficient. Cronbach's alpha coefficient for the Symptom Distress Scale was 0.8296 (ps.05). This score indicated good internal consistency and was the same reliability score (Cronbach's alpha coefficient 0.82) reported by McCorkle and Quint-Benoliel (1983) in a study with chemotherapy and radiation patients.

Content validity for the Symptom Distress Scale and the Quality Life Index was determined by a panel of three oncology experts. Content validity was established by evaluating the objectives and the two questionnaires to determine if they adequately represented the content. Construct validity was determined for the Symptom Distress Scale. Point-biserials were analyzed to determine the item correlation to total test scores. Of the 13 items, 11 had point-biserials correlations of $\underline{r}_{bi} = \langle 0.3 \ (p \leq .05) \rangle$. The factor analysis for determining construct validity identified four factors that explained more than 3% of the explained variance. The criterion selected for factor loading was .50. The test items with point-biserial values

greater than .3 were analyzed in relation to factor loadings.

Factor 1 contained four items with factor loadings greater than .5. These questions related to objective findings regarding physical symptoms. Item 12 had a point-biserial of .2315 but a factor loading of .768 under Factor 1.

Factor 2 contained five items with factor loadings greater than .5. These questions related to subjective findings regarding symptoms. Factor 3 contained one item with factor loading greater than .5. This item related to nausea. Item 2 under Factor 3 had a point-biserial of .2737 but a factor loading of .783. Both items related to Factor 4 had one item with factor loading greater than .5. This item related to concentration. One item is not enough to determine a trend.

An analysis of the instrument revealed that 11 of the 13 items correlated significantly with the total test score and related significantly to the previously identified four factors. The Symptom Distress Scale was retained for the dissertation study.

The Quality of Life Index (Spitzer et al., 1981) is a 5-item scale that measured the areas of activity, daily living, health, support, and outlook. Each area is assessed

on a 3-point Likert-type scale. This Index was one of the original health questionnaires developed for evaluating the patient's QOL. Since its development, the concept of QOL has been expanded to include a broader range of domains and the patient's satisfaction with each area. The Quality of Life Index was deemed inadequate to fully measure quality of life in its evolving form. The QLI-CV (Ferrans, 1990a) was deemed a more adequate measure of the concept as it is presently defined.

Analysis of Pilot Data

The sample consisted of 10 adult bronchogenic lung cancer patients at the beginning of a chemotherapy treatment cycle and eight spouses or SKOs. The patient sample was evenly divided between five male (50%) and five female (50%) patients. The spouse SKO group consisted of seven females (87.5%) and one male (12.5%). Five of the relative group were spouses, two were daughters, and one was a sister of the patient.

Demographic data were analyzed on all 18 respondents. The combined sample was 15 (83%) caucasian and 3 (17%) black with no other ethnic groups surveyed. Three (17%) subjects reported being Catholic, 11 (61%) Protestant, and 4 (22%) other denominations. The educational level of the 18 subjects was widely distributed with 4 (25%) reporting less

than a high school education, 4 (25%) with high school diplomas, 7 (44%) with a college education, and 1 (6%) with a graduate education. Of the 18 participants, 3 (19%) had incomes of less than \$10,000, 3 (19%) had incomes in the \$25,000 to \$50,000 range, and 3 (19%) had incomes above \$50,000. The other 9 subjects did not respond to the question.

Data from the 8 dyads that responded were used to analyze the following measures. The Symptom Distress Scale (SDS) and the Quality of Life Index (QLI) were used to measure the dependent variables of symptom distress and quality of life. The SDS has a possible range of 65 points. The mean SDS score for this sample was 27.25 and included a minimum score of 16 to a maximum score of 48. The standard deviation was 9.706. The QLI had a possible range of 15 points. The mean QLI score was 7.688 and varied from a minimum score of 6 to a maximum score of 9. The standard deviation was 1.302.

Correlations were analyzed between the two scales and the demographic variables of the sample. The Spearman rank correlation coefficient was used to analyze the variables of sex, ethnic background, religion, marital status, educational level, and level of income with the ordinal scales SDS and the QLI. The highest correlations were

between the SDS and religion (\underline{r} = .5345; \underline{p} = .016) and the QLI and the variable of education (\underline{r} = .32; \underline{p} = .113). The Pearson product moment correlation coefficients between the SDS and the QLI and age were not significant. It was projected that these relationships will become more pronounced with a larger sample size.

The Mann-Whitney \underline{U} test was utilized to test research Questions 1 and 2 in the pilot study. Research Question 1 asked: What is the difference in the perceptions of the lung cancer patient's condition between the patient and the spouse? The Mann-Whitney \underline{U} test showed no significant differences between the patient's and the SKO's perceptions of the patient's condition measured by the SDS and the QLI. The spouses perceived more symptom distress than the patients, but the difference was not significant. On the QLI, the Mann-Whitney \underline{U} test also revealed no significant differences (\underline{u} = 25; \underline{p} = .43 corrected for ties). A higher score indicating a more normal condition was noted for the patient group. Spouses perceived patients as having less function than the patient group perceived for themselves.

Recommendations

Administering questionnaires to the patient group went according to the proposal. Administering questionnaires to the spouse group was problematic. Half of the 10 patients

did not have available spouses. It was recommended that in the dissertation study, the patients designate their primary social support persons or significant key others while undergoing treatment. This expansion of spouse to SKO allowed for a more realistic picture of the support system for this group.

The sample size of the dissertation study was enlarged to allow for adequate significance level, power, and effect size (Cohen, 1988; Woods & Catanzaro, 1988). To decrease the possibility of a threat to the internal validity of the study through maturation, the patients were interviewed at the same time as the SKO group. If the SKO was unavailable at the time of initial contact, the patient was asked to specify a convenient time when the patient and SKO could be surveyed at the same time.

To familiarize the patient and SKO group with the study and decrease the anxiety of dealing with a stranger, notification of the study in the form of a flyer (Appendix J) was placed on the bulletin board with similar announcements about support groups and programs for patients. The cover letter and informed consent forms were revised for clarity.

Limiting the subjects to the use of a group of lung cancer patients was questioned by the nurses in the

agencies. The office nurses stated that lung cancer patients were a small percentage of their practice and limiting the study to lung cancer patients was not reflective of the cancer population being treated. This comment was evaluated, and the study criterion was changed from bronchogenic lung cancer patients to patients with solid tumor or hematologic cancers.

Using the beginning of a treatment cycle as a study inclusion criterion was not practical, since many patients were asymptomatic at the beginning of a treatment cycle. The functional performance status of the patients was used to determine sample selection criteria. While administering the pilot study questionnaires, it became apparent that concentration was a problem. It was recommended that the collection of demographic data be kept to a minimum, thus the patient background data sheet was divided into two parts. Patients were asked to complete only the necessary questions. These questions included specifying the SKO, sex, age, educational level, religion, marital status, ethnic background, income, and occupation. The second form with the other demographic items was collected by the investigator from the medical record information. demographic data items were revised to conform to the

appropriate standardized items collected by the tumor boards in each institution.

The Symptom Distress Scale (McCorkle & Quint-Benoliel, 1983) was readily understood and was kept for the dissertation study. The Quality of Life Index (Spitzer et al., 1981) used in the pilot study measures the physical performance of the patient and was replaced. The QLI-CV (Ferrans, 1990a) measures QOL as a multidimensional concept and assesses areas of the patient's life that can be impacted by nursing practice. The revised consent forms, demographic data forms, and SDS and QLI-CV were retested at the beginning of the dissertation study with the first 20 subjects and SKOs.

Data Collection

The patients included in the study were identified by nurses in the physicians' offices and nurse managers of the oncology clinic and inpatient unit. Medical records of the patients being considered for the study were reviewed by the investigator to determine eligibility according to study criteria before the patients were contacted. The Performance Status Scale (Karnofsky & Burchenal, 1949) was completed by the nurse responsible for the patient if there was not a current point scale on the medical record.

The outpatient and office patients were contacted by the investigator at their regularly scheduled appointments. Hospitalized patients were contacted in their rooms at a time recommended by the nurse of the patient or nurse managers of the units.

Upon determining eligibility, the nurses responsible for the patients or the nurse managers asked the patients if they were willing to talk to the investigator. A letter introducing the study and stating the purpose of the study was given to interested patients. Completion time for the consent process was 10 minutes; for the demographic and two study questionnaires, it was less than 30 minutes. After the informed consent was signed by the patients, patients were asked to designate their SKOs. The SKOs were contacted at the same time as the patients if they were available, or a letter introducing the study was left with the patient. If the patient or SKO was unable to complete the form at the time of study introduction, or if the SKO was unavailable, the patient was asked to specify a convenient time when the patient and SKO could be surveyed at the same time.

At the time of study participation, the patient and SKO were each given a packet containing the informed consent form, the patient or SKO background data sheet, and the two questionnaires (QLI-CV and SDS). Part II of the patient

background data sheet was completed from the patient's medical records by the investigator after the informed consent form was signed. The investigator assigned a code for each patient to indicate one of the seven medical setting sites where the patient was receiving treatment.

Patients were instructed to complete the forms in the available areas. Patients and SKOs were instructed to place the completed forms in the envelopes provided, seal the envelopes, and return them to the investigator or nurse. The nurse placed the envelopes in a locked drawer in the nurse manager's office for the investigator to pick up. The patient and SKO were instructed to complete their questionnaires at the same time and not to discuss their responses with each other until after the questionnaires were completed and returned. If the patient and SKO were unable to return the instruments at the initial interview, they were instructed to obtain a stamped envelope from the investigator or nurse, seal the envelope, and return to the nurse at the next appointment or mail at their earliest convenience.

Patients were instructed to complete the forms according to how they perceived the questions at the present time. SKOs were instructed to complete their background data sheet with their personal information and to complete

the QLI-CV and the SDS according to how they perceived the patient's QOL and SD.

Treatment of Data

Descriptive statistics were used to describe and summarize demographic data for the patient and the SKO groups and for the total sample. Demographic data for the patient and the SKO groups were reported separately.

Nominal level variables for the patient group included the medical setting site where treatment was received, gender, ethnic group, religious preference, marital status, relationship to the SKO, occupation, type of cancer, and type of treatment. The frequency, percentages, and modes were reported for these data. For the SKO group, the nominal level demographic variables of gender, ethnic group, religious preference, marital status, relationship to the patient, and occupation were reported using frequencies, percentages, and modes.

For the patient group, ordinal level demographic data of stage of disease, educational status, and functional performance status were grouped and reported as frequencies, percentages, modes, medians, and ranges. Educational level ordinal data from the SKO group were also reported as frequencies, percentages, modes, medians, and ranges. The ratio level data for the patient, including age, weight gain

or loss, years knowing the SKO, and income, were reported as frequencies, percentages, modes, medians, means, variances and standard deviations (Roscoe, 1975). For the SKO group, the ratio level data of age, years knowing the patient, and income were reported using the same statistics as for the patient group.

Correlations between appropriate demographic variables and differences between the patient and SKO Symptom Distress Scale total scores were reported. The relationship between the ratio level demographic variables of age, weight gain or loss, and income and the ordinal level SDS difference scores were analyzed using the Spearman rank correlation coefficient test. The Spearman rank correlation coefficient test was used to test the relationship between the ordinal level variables of stage of disease, functional performance status, and educational status and the ordinal level SDS difference scores. The relationship between the nominal level variables of gender, ethnic group, religious preference, and marital status and the ordinal level SDS difference scores was analyzed using the Chi square test (Roscoe, 1975; Woods & Catanzaro, 1988).

Data from the QLI-CV subscale scores and the SDS total scores yielded ordinal level data. Frequencies, percentages, modes, medians, and ranges were reported for

both groups on the QLI-CV total scores and the subscale scores of the domains for health and functioning, socioeconomic, psychological/spiritual, and family. The total scores on the SDS were reported for each group.

Research questions 1 and 2 related to the differences in perception between the cancer patients' and their SKOs' perception of the patients' QOL and symptom distress. The QLI-CV total scores and subscale scores and the SDS scores were analyzed using the Wilcoxon matched-pairs signed-ranks test with alpha set at .05. This nonparametric alternative to the test for two related samples was used to test the significance of the differences between the means of the two groups (Woods & Catanzaro, 1988).

Summary

A two-group nonexperimental, descriptive survey of 140 cancer patients and their SKOs was conducted to determine differences between the cancer patient's and the significant key other's perceptions of the patient's quality of life and symptom distress. A quota convenience sample of 37 (52.3%) male and 33 (47.7%) female cancer patients (\underline{n} = 70), chosen to represent the national statistics for solid tumor and hematologic cancers by gender (American Cancer Society, 1993), and their SKOs (\underline{n} = 70) was used.

The patient's QOL and SD were operationalized using the QLI-CV total and subscale scores (Ferrans, 1990a) and the SDS scores (McCorkle & Quint-Benoliel, 1983). The Wilcoxon matched-pairs signed-ranks test was used to test the means of differences between the SKO and the patient groups. Demographic information was consistent with the 20 items collected on each cancer patient by the tumor boards of the participating agencies and analyzed by the National Cancer Institute. The extraneous variable of medical diagnosis was controlled by selecting patients with solid malignant tumors and hematological cancers undergoing treatment, and physical status was controlled by selecting patients with predetermined levels on the Performance Status Scale (Karnofsky & Burchenal, 1949).

CHAPTER 4

ANALYSIS OF DATA

A two-group, nonexperimental descriptive survey was conducted to determine the differences between the cancer patients' and their significant key others' (SKOs') perceptions of the patients' quality of life (QOL) and symptom distress (SD). Questionnaires used in the study included a two-part background data sheet, the Quality of Life Index-Cancer Version (QLI-CV) (Ferrans, 1990a), and the Symptom Distress Scale (SDS) (McCorkle & Quint-Benoliel, 1983). A description of the sample is presented, and findings from data analysis are reported. Additional findings that emerged from the data analysis are also presented. A summary of findings completes this chapter.

Description of the Sample

The sample, recruited from seven sites, was originally composed of 154 subjects divided evenly between the patient and SKO groups; however, seven dyads were eliminated from the study. In the patient group, one patient's functional performance status declined and the patient was unable to complete the questionnaires. In the SKO group, three SKOs did not complete their QLI-CV questionnaires and the scores

of the dyad were eliminated. Two SKOs returned their questionnaires over 4 weeks after the patients did and the scores were not tabulated. Questionnaires were returned by 142 patients and SKOs who met the study criteria, but the last dyad from the agency with the largest number of study participants was eliminated. The total tabulated sample numbered 140 participants, evenly divided, 70 in the patient and 70 in the SKO group. The SKOs were chosen by the patients.

Data were collected at seven cancer treatment sites. The inpatient settings included a cancer clinic and inpatient unit located in a university-affiliated hospital within a large medical center complex (Site 1) and a cancer treatment unit that is part of a private medical center hospital located in a community setting (Site 2). A radiotherapy outpatient unit affiliated with the community medical center was also utilized (Site 3). The other four settings were private offices of oncologists in private practice (Sites 4, 5, 6, 7). The private practice physicians were affiliated with the cancer program at the community medical center through active, provisional or courtesy privileges. Almost half (34; 48.6%) of the cancer patients received their treatment in the hospital setting

(Sites 1 and 2) (Table 1). The mode for site was university-affiliated hospital.

Table 1

Frequencies and Percentages of Medical Setting Site for Treatment of 70 Cancer Patients

Medical Setting Site	<u>n</u>	%
University-affiliated Hospital (Site 1) Private Medical Center Hospital (Site 2) Radiotherapy Center (Site 3) Private Office 1 (Site 4) Private Office 2 (Site 5) Private Office 3 (Site 6) Private Office 4 (Site 7)	22 12 12 9 8 5	31.5 17.1 17.1 12.9 11.4 7.1 2.9
Total	70	100.0

Demographic Data Reported by Subjects

The patient sample consisted of 37 (52.9%) male patients and 33 (47.1%) female patients. This quota sample represented the national occurrence by gender for solid malignant tumors and hematologic cancers. The SKO group selected by the patients consisted of 20 (28.6%) males and 50 (71.4%) females.

Ages of the patient group varied from a minimum of 32 years to a maximum of 84 years. The mean age for the sample was 60.7 years (standard deviation = 13.57). The median age was 63 years. For the SKO group, ages varied from a minimum of 20 years to a maximum of 83 years. The median age was

55.5 years. The mean age for the SKO sample was 53.8 years (standard deviation = 14.2).

Ethnic backgrounds of the patient group and the SKO group were similar. The groups were composed of Anglo-Americans, Black Americans, Mexican-Americans, and Asian/Asian-Americans. Anglo-Americans comprised the majority of the sample for both the patient (53; 75.7%) and the SKO (51; 72.9%) groups (Table 2).

Religious preference of the sample included Protestants, Catholics, Jewish, other, and no preference. The patient and SKO groups were also similar in religious preference. The mode was Protestant in both the patient (49; 70.0%) and SKO (48; 68.6%) groups (Table 2).

Marital status for the sample included single, married, separated, divorced, and widow/widower. The majority of both patient (50; 71.4%) and SKO (59; 84.3%) groups were married (Table 2).

Educational levels of sample varied from elementary level through graduate school. The mode for educational level was some college for the patient (26; 37.1%) group (Table 3). However, educational level was bimodal with high school graduate and some college (20; 28.6% each) for the SKO subjects.

Table 2
Frequencies and Percentages of Ethnic Backgrounds,
Religious Preference, and Marital Status
of 70 Cancer Patients and 70 SKOs

Patients		ients	SKOs		
Variable	n	%	n	%	
Ethnic Background					
Anglo-American Black American Mexican-American Asian/Asian-American	53 13 2 _2	75.7 18.5 2.9 2.9	51 13 4 _2	72.9 18.5 5.7 2.9	
Total	70	100.0	70	100.0	
Religious Preference					
Protestant Catholic Jewish Other No Preference Missing Data	49 15 1 3 2 0	70.0 21.4 1.4 4.3 2.9 0.0	48 17 1 2 1	68.6 24.3 1.4 2.9 1.4 1.4	
Total	70	100.0	70	100.0	
Marital Status					
Single Married Separated Divorced Widow/Widower	3 50 0 9 <u>8</u>	4.3 71.4 0.0 12.9 11.4	6 59 1 3 <u>1</u>	8.6 84.3 1.4 4.3 1.4	
Total	70	100.0	70	100.0	

Household income for the patient group ranged from \$1,700 to \$120,000 per year. The mean income was \$41,713 and the median income was \$40,000. Data were missing on 25 (35.7%) patients. For the SKO group, household income ranged from \$6,000 to \$300,000. The mean income of the SKO group was \$49,034, and the median income \$45,000. In the SKO group only 5 subjects reported incomes less than \$10,000.

Occupations of subjects were divided into 5 categories: professional, trade, retired/houseperson, medical/clerk-administration, and education. Professional was the most frequent category for both the patient (21; 30%) and SKO (18; 25.7%) groups (Table 3).

Relationships of the sample included the categories of spouse, parent, sibling, child, in-law, and friend/neighbor. The mode was spouse for both the patient (42; 60%) and SKO (41; 58.6%) groups (Table 3).

Years the patient group knew the SKOs varied from 4 to 63 years, with a median of 37 years and a mean 35.75 years. Data were missing on 5 patients. Years the SKO group knew the patients varied from 4 to 61 years, with a median of 35 years and a mean of 34.6 years.

Table 3

Frequencies and Percentages of Educational Level,
Occupation and Relationship of 70 Cancer
Patients and 70 SKOs

	Pat	ients	SKOs		
Variable	<u>n</u>	%	<u>n</u>	왕	
Educational Level					
Elementary School Some High School/	2	2.9	0	0.0	
High School Graduate	29	41.4	30	42.8	
Some College College Graduate/ Some Graduate	26	37.1	20	28.6	
Education	13	18.6	18	25.7	
Missing Data	_0	0.0	_2	2.9	
Total	70	100.0	70	100.0	
Occupation					
Professional	21	30.0	18	25.7	
Trade	16	22.9	9	12.9	
Retired/Houseperson	13	20.0	14	20.0	
Medical/Clerk- Administration	9	12.9	21	30.0	
Education	0	0.0	5	7.1	
Missing Data	_5	7.1	3	4.3	
MISSING Data		<u></u>		4.3	
Total	70	100.0	70	100.0	
Relationship					
Spouse	42	60.0	41	58.6	
Parent	7	10.0	3	4.3	
Sibling	3	4.3	5	7.1	
Child	4	5.7	10	14.3	
In-Law	1	1.4	2	2.9	
Friend/Neighbor	6	8.6	6	8.5	
Missing Data	_7	10.0	_3	4.3	
Total	70	100.0	70	100.0	

Medical Record Information

Information regarding the type and stage of cancer treatment modality and physical status were obtained from the patient's medical record. These findings were used to describe the sample and correlate demographic data with the findings from the research questions.

Cancer Diagnosis

A total of 18 different cancer diagnoses occurred in the patient group. Lung cancer was the mode for the patient group. Lung cancer was the most frequent diagnosis with 16 (22.9%) cases (Table 4). Breast cancer was the second most frequent diagnosis with 12 (17.1%) patients. Sixteen other diagnoses accounted for the 42 (60%) other cancer diagnoses.

Stage of Disease

Of the patient group, 7 (10%) had Stage I cancer, 2 (2.9%) had Stage II cancer, and 16 (22.9%) had Stage III cancer. Stage IV cancer was the largest frequency with 43 (61.4%) patients. Two patients had documented cancer diagnosed but staging was not available.

Functional Performance Status

Functional performance status was taken from the medical record where available or determined in collaboration with physicians or nurses of the patients and

Table 4
Frequencies and Percentages of Type of Cancer of 70 Cancer Patients

Type of Cancer	n	%
Breast Lung Colon Leukemia Ovarian	12 16 6 2 2	17.1 22.9 8.6 2.9 2.9
Esophageal Adenocarcinoma Unknown Primary Rectal Pancreas Lymphomanon-Hodgkin	3 2 3 4 5	4.3 2.9 4.3 5.7 7.1
Head and Neck Prostate Cervical Hodgkin Lymphoma Bladder	1 6 1 1 3	1.4 8.6 1.4 1.4
Liver Multiple Myeloma Gastric	1 1 _1	$ \begin{array}{r} 1.4 \\ 1.4 \\ \hline 1.4 \end{array} $
Total	70	100.0

the investigator. For this group of patients, functional performance values varied from 50 to 90. The mean of functional performance status was a value of 76 (standard deviation = 12.18) and the median was a value of 80. The majority (40; 57.2%) of the patient group had values from 80 to 90 which indicated that their functioning was normal with no complaints to normal activity with effort, but some signs

and symptoms of disease (Table 5). Only 1 (1.4%) patient had a value of 50 which indicated the inability to work and needing varying degrees of assistance.

Table 5

Frequencies and Percentages of Functional Performance
Status Values of 70 Cancer Patients

Value	<u>n</u>	%
50 60 70 80 90	1 17 12 17 23	1.4 24.3 17.1 24.3 32.9
Total	70	100.0

Weight Gain or Loss

Changes in weight varied from a maximum loss of 55 pounds to a maximum gain of 44 pounds. The mode of weight loss was zero weight change with 12 (17.1%) patients. The mean weight change was -1.14 pounds and the median was .0000 pounds. Weight loss was experienced by 32 (47.1%) patients. No weight change occurred in 12 (17.1%) of patients, and weight gain occurred in 24 (34.7%) patients.

Type of Treatment

Treatment modalities for the 18 types of cancer diagnoses included both single and combination agents.

Chemotherapy alone was the mode with 23 (32.9%) subjects. A majority (43; 61.4%) of the patients had some type of combination therapy (Table 6).

Table 6
Frequencies and Percentages of Type of Treatment of 70 Cancer Patients

Type of Treatment	n	%
Surgery Surgery and Chemotherapy Surgery-Chemotherapy-Radiation Chemotherapy Alone Radiation Alone Non-Determinable Radiation-Chemotherapy Surgery-Radiation	1 17 13 23 2 1 5 8	1.4 24.3 18.6 32.9 2.9 1.4 7.1 11.4
Total	70	100.0

Findings

Two questionnaires, the Quality of Life Index-Cancer Version (QLI-CV) and the Symptom Distress Scale (SDS), were used to determine if there were differences in perceptions of two variables, quality of life and symptom distress, between the patient and SKO groups. Although the two sets of questionnaires were similar, they were individualized for the patient and SKO groups.

The QLI-CV measures total quality of life of cancer patients as well as four other areas (subscales): health

and functioning, socioeconomic, psychological-spiritual, and family. The SDS measures the degree of discomfort cancer patients experience in response to symptoms. The SDS contains 13 items to describe degree of distress for nausea (presence and intensity), appetite, insomnia, pain (presence and intensity), fatigue, bowel, concentration, appearance, breathing, outlook, and cough.

Research Ouestion 1

The first research question for the study was: Do cancer patients have a different perception of their quality of life than their significant key others perceive for the patients as measured by Quality of Life Index-Cancer Version total and subscale scores?

Differences between the patient and the SKO groups were calculated using the Wilcoxon matched-pairs signed-ranks test for total scores and the 4 subscale scores. The acceptable level of significance was $p \le .05$. When adjusted, the total QLI-CV and subscale scores had a potential range of 0 = low quality of life to 30 = high quality of life. The QLI-CV scores of the patient group varied from 6.4559 to 29.7778, with a mean QLI-CV total score of 21.4460 (standard deviation = 4.6231). The SKO group's QLI-CV total scores varied from 9.0967 to 29.0152, with a mean QLI-CV total score of 21.7348 (standard deviation = 4.5623). The QLI-CV

median total score for the patient group was 21.5684; for the SKO group, it was 22.7129. The Wilcoxon matched-pairs signed-ranks test was used to analyze the QLI-CV total and subscale scores (Table 7). Difference in mean rank scores of patient and SKO groups' QLI-CV total and subscale scores were not statistically significant. These findings did not document a difference in perception between the patient and SKO groups. The SKO and patient groups perceived the patients' QOL in a similar manner.

Table 7
Wilcoxon Matched-Pairs Signed Ranks Test for Differences in Quality of Life Index-Cancer Version Total and Subscale Scores Between Patient and SKO Groups

Scale	Z Score	2-Tailed p
Total QLI-CV	8398	.4010
Subscales		
Health and Functioning Socioeconomic Psychological-Spiritual Family	-1.0505 -1.3901 -0.6548 -1.0473	.2935 .1645 .5126 .2950

The Wilcoxon matched-pairs signed-ranks test also computed differences in perceptions between the dyads expressed as the number of positive and negative ranks and the number of ties for the QLI-CV total and subscale scores.

For the QLI-CV total scores, the negative ranks were 30, the positive ranks were 40, and 0 cases were tied (Table 8). While differences between the groups were not significant, no complete congruency of perceptions emerged as evidenced by the small number of tied scores. The direction of the rankings indicated that the SKOs ranked the patients QOL as better than the patients rated themselves.

Table 8

Wilcoxon Matched-Pairs Signed Ranks Test for Rankings in Quality of Life Index-Cancer Version Total and Subscale Scores Between Patient and SKO Groups

Scale	Negative Ranks	Number of Positive Ranks	Cases Tied	Total
Total QLI-CV	30	40	0	70
<u>Subscales</u>				
Health and Functioning Socioeconomic Psychological-Spiritual Family	31 24 1 32 32	39 44 34 23	0 2 4 15	70 70 70 70

Research Ouestion 2

The second research question for the study was: Do cancer patients have a different perception of symptom distress than their significant key others perceive for the patients as measured by total scores on the Symptom Distress

Scale? The difference between the patients and the SKOs groups' perceptions were analyzed using the Wilcoxon matched-pairs signed-ranks test. The significance level was set at $p \le .05$. Responses to eight items were missing from either the patients' or SKOs' SDS questionnaires. The matching item was eliminated from the dyad's scores and the total scores were calculated. This procedure did not change the direction of the scores.

The 13-item SDS total score had a possible range of scores from a minimum of 13, little symptom distress, to a maximum of 65, high symptom distress. Scores of the patient group varied from a low of 14 to a high of 47. The mean score for the patient group was 28.36 (standard deviation = 7.52), and the median score was 28.50. The SKO's symptom distress scale total scores varied from a low of 16 to a high of 48. The mean score of the SKO group was 30.86 (standard deviation = 7.55), and the median score was 32.5. A comparison of the range of scores between the groups indicated that although there is little variation between the perceptions of the groups there is considerable variation within the groups. The mean and median scores showed that both groups perceived the patients as experiencing mild to moderate symptom distress.

The Wilcoxon matched-pairs signed-ranks test for the SDS total scores yielded \underline{Z} = -2.76 (\underline{p} = .0058). A significant difference occurred between cancer patients' and their SKOs' perceptions of patients' symptom distress. The Wilcoxon matched-pairs signed-ranks test also was used to compute difference in perceptions on the SDS total scores between the dyad and to calculate the number of positive and negative ranks and number of ties. The number of positive ranks was 42, the number of negative ranks was 22, and the number of ties was 6. When comparing the two groups, the SKOs overestimated the degree of distress experienced by the patients.

A difference score was calculated by subtracting the SDS total score of the SKO group from the patient group. The difference scores varied from a minimum of -29 to a maximum of +14. The mean difference between the two groups was -2.5 (standard deviation = 7.13), with a median of -1.5. The average amount by which the SKO group overestimated the patients distress score was 2.5 points.

Additional Findings

Correlations were calculated between demographic variables and the difference scores that were computed by subtracting the Symptom Distress Scale total score for the SKO group from the SDS total score for the patient group.

The relationship between the patients' and SKOs' nominal level variables of gender, ethic group, marital status, and religion scores and the difference scores were analyzed using the chi-square test. The relationships for gender, ethnic group, and marital status were not statistically significant. For the religion score, the chi-square yielded $\underline{X}^2 = 158.7$ ($\underline{p} = .0001$) for the patient group and $\underline{X}^2 = 129.18$ ($\underline{p} = .014$) for the SKO group. There was a statistically significant relationship between religion and the SDS difference score. Protestants in both the patient and SKO groups perceived a greater difference in symptom distress than did subjects with other religious beliefs.

The Spearman rank order correlation coefficient was used to test the relationships between the ordinal level variables of educational level, patient's stage of disease, and patient's functional performance status and the SDS difference scores. The patient's stage of disease and functional performance status were not significant. The educational level score for the patient was rho = -.2768 (p = .010) and for the SKO group rho = -.3025 (p = .006). There was a significant negative relationship between the education levels of both groups and the difference scores. For both groups the subjects with less education perceived greater differences in symptom distress.

The Spearman rank correlation coefficient between the ratio level variables of patient's and SKO's age and income and the patient's weight change scores and the difference scores were calculated. No significant difference emerged between the patient's and SKO's age and the patient's weight change. There was a significant negative relationship between patient's income (rho = -.4550, p = .001) and the SKO's income (rho = -.2834, p = .027) and the SDS difference score. The negative relationship indicated that for both groups subjects with lower incomes perceived the largest differences between patients' and SKOs' symptom distress.

Additional findings of the study related to the differences between the SDS individual item scores for the patient and SKO groups. In an effort to control for type I errors, the results of the Wilcoxon matched-pairs signed-ranks test between the 13 individual items of the SDS were reported as incidental findings only (Table 9). With the designated power and fixed sample size, using these additional multiple comparisons increases the likelihood that significant results were due simply to chance (Kirk, 1982; Woods & Catanzaro, 1988). The calculations indicated that intensity of nausea, presence and intensity of pain, outlook, and cough were symptoms responsible for the SKOs overestimating the amount of SD experienced by the patients.

Table 9
Wilcoxon Matched-Pairs Signed Ranks Test for Symptom Distress Individual Item Scores of Patient and SKO Groups

Symptom	Z Score	2-Tailed p
Nausea (Presence) Nausea (Intensity) Appetite Insomnia	-1.4858 -2.7482 -0.7516 -1.1843	.1373 .0060* .4523 .2363
Pain (Presence) Pain (Intensity) Fatigue Bowel Pattern	-2.2995 -2.3614 -1.7037 -0.2073	.0215* .0182* .0884 .8357
Concentration Appearance Breathing Outlook	-0.4914 -0.3139 -1.7792 -2.9817	.6232 .7536 .0752 .0029*
Cough	-2.4790	.0132*

^{*}p≤.05.

Summary of Findings

A two-group, nonexperimental descriptive survey was conducted to determine the differences between the cancer patients' and their significant key others' (SKOs') perceptions of the patients' quality of life (QOL) and symptom distress (SD). The patient group consisted of 37 (52.9%) males and 33 (47.1%) females (\underline{n} = 70); each patient had an SKO (\underline{n} = 70). Median age was 63 years for the patient group and 55.5 years for the SKO group.

Anglo-Americans comprised the largest ethnic background with 53 (75.7%) patients and 51 (72.9%) SKOs.

In the patient group, the mode was Protestant with a frequency of 49 (70%) subjects. The mode for educational level was some college with 26 (37.1%) subjects. Household income for the patient group was high with a mean income of \$41,713 and a median income of \$40,000. The demographic data in the SKO group was similar.

The Wilcoxon matched-pairs signed-ranks test was used to test differences between the patient and SKO groups' QLI-CV total and subscale scores. No significant differences were found. The Wilcoxon matched-pairs signed-ranks test between the patient and SKO groups' SDS total scores were significant (\underline{Z} = -2.76, \underline{p} = .0058). A significant difference was found between cancer patients' and their SKOs' perceptions of the patients' symptom distress. The SKOs overestimated the degree of distress experienced by the patient.

CHAPTER 5

SUMMARY OF THE STUDY

A two-group, nonexperimental descriptive survey was conducted to determine if there was congruency of perceptions between cancer patients' and their significant key others' (SKOs') perceptions of patients' quality of life (QOL) and symptom distress (SD). The incongruency of perceptions has been attributed to the patients self-enhancing their conditions through the use of the coping mechanism of downward shifting (Wills, 1981). King's (1981; personal communication, February, 1994) model of human transaction postulates that the use of a coping mechanism has the potential to restrict the cues one allows to enter the perceptual field and affect the congruency of perceptions between the patients and SKOs. This congruency of perceptions is necessary for goal attainment.

A summary of the study is presented, and findings are discussed by comparing and contrasting with previous research. Additionally, study results are related to King's model of transaction. Conclusions and implications are offered, and recommendations for future study are presented.

Summary

Data were collected at seven cancer treatment centers located in a large city in the Southwestern Gulf Coast area. The sample consisted of 140 participants divided equally between the patient and SKO groups. Patients were interviewed at their regularly scheduled outpatient appointment times or during inpatient hospitalization.

Patients were asked to complete the informed consent and then to designate the person who was their SKO, the person giving them social support while undergoing treatment. Patients and SKOs were asked to complete the background data sheet, the Quality of Life Index-Cancer Version (QLI-CV) and the Symptom Distress Scale (SDS) at the same time and not to compare answers until questionnaires were returned. The researcher completed the Patient Background Data Sheet-Part II from the patients' medical records.

The patient group included 37 (52.9%) males and 33 (47.1%) females (\underline{n} = 70); each patient had an SKO (\underline{n} = 70). Median age was 63 years for the patient group and 55.5 years for the SKO group. Anglo-Americans comprised the largest ethnic background, with 53 (75.7%) patients and 51 (72.9%) SKOs. In the patient group the mode was Protestant with a frequency of 49 (70%) subjects. The mode for educational

level was some college, with 26 (37.1%) subjects. Household income for the patient group was high with a mean income of \$41,713 and a median income of \$40,000. Demographic data in the SKO group was similar.

The research questions relating to the congruency of perceptions between the patient and SKO groups on the QLI-CV total and subscale scores and SDS total scores were analyzed using the Wilcoxon matched-pairs signed-ranks test.

Correlations were analyzed with appropriate demographic data and the results of the difference scores. The difference scores were determined by subtracting the SKO's SDS total score from the patient's SDS total score.

Discussion of Findings

Research questions in this study examined whether patients undergoing cancer treatment rated their quality of life (QOL) and amount of symptom distress (SD) as better than their SKO's rated for them. Research question 1 related to the congruency of perceptions of QOL between the patients and SKOs as measured by QLI-CV total and 4 subscale scores. The patients' QLI-CV total scores varied from a low of 6.4559 to a high of 29.7778. The QLI-CV total score for the SKOs ranged from a low of 9.0967 to a high of 29.0152. The mean QLI-CV total scores were 21.4460 for the patient group and 21.7348 for the SKO group. Wilcoxon matched-pairs

signed-ranks test for the QLI-CV total scores and 4 subscale scores between the patient and SKOs groups were not significant. No difference was found in perception of cancer patients and significant key others of patients' total quality of life or on the 4 subscales of health and functioning, socioeconomic, psychological-spiritual, and family.

One interesting result of the Wilcoxon matched-pairs signed-ranks test was the congruency of the rankings. For the total and 4 subscale scores of the 70 dyads, the socioeconomic subscale produced 2 ties, the psychological/spiritual subscale 4 ties, and the family subscale 15 ties. There were no ties for the health and functioning domain or for the QLI-CV total scores. While there were no statistical differences in the QOL total and subscale scores, the small number of tied scores indicated that the patients and SKOs lack the congruency of perceptions necessary for goal attainment.

When the patient's subscale scores were ranked, the family subscale had the highest mean score at 26.0500. The socioeconomic subscale mean score was the next highest with a score of 22.8493. The psychological/spiritual subscale was similar at 22.6306. The health and functioning subscale had the lowest mean score at 18.7126. These scores were all

above the scale median of 15 indicating a high level of QOL for the patient group.

One explanation is offered for the nonsignificant findings on research question 1. Although the QLI-CV subscale items included opinion type questions, asked how satisfied the subjects were with each of 34 questions, and then asked the importance of each question, the areas covered still had an objective basis for response. The patient and SKO groups were composed of mainly spouses 42 (60%), parents 7 (10%), and siblings 3 (4.3%). The group had known each other a minimum of 4 and a maximum of 63 years. Even though questions were phrased in a subjective or opinion style, the material covered was well known to each member of the dyad. Therefore, the SKOs were familiar with the patients' perceptions of QOL for the areas surveyed in the questionnaires.

In social comparison theory, Festinger (1954)
hypothesized that individuals first attempt to evaluate
their opinions and attributes through objective nonsocial
means. When objective means are not available, people then
gain information to evaluate their opinions and abilities
through comparison with others.

The study findings regarding the high quality of life scores is consistent with other quality of life studies

(Breetvelt & van Dam, 1991). Patients rate their own quality of life high despite experiencing physical complaints. The QLI-CV total mean score of the patients in this study was 21.4460, while the health and functioning subscale score, although still above the median scale score, was the lowest subscale score at 18.7126.

The high overall QOL score may be due in part to the design of the questionnaire. The first section asks about satisfaction and the second with the importance of each area. Many subjects marked very important for every area which helped to elevate the total QOL score. Also, it was common for patients to separate their cancer experience from their general health. The first question asked, "How satisfied are you with your health?" Patients would comment, "My health has been fine, it's the cancer that is a problem."

An application of the QLI-CV with sarcoma patients postchemotherapy (Arzouman, Dudas, Ferrans, & Holm, 1991) showed similar rankings for 3 of the 4 subscale scores. The total and subscale scores were also above the scale median of 15. The family subscale had the highest score followed by the psychological/spiritual subscale which was also high. The health and functioning domain was significantly lower than the family subscale. Unlike the present study, in the

sarcoma study the socioeconomic subscale had the lowest score since two-thirds of the patients were either retired or unemployed.

Padilla and Grant (1985) used an application of the Quality of Life Index, a 23-item questionnaire the authors developed, to study 135 colostomy patients. Analysis of variance indicated that psychological well-being was the most important dimension of quality of life (\underline{F} = 29.30; \underline{p} <.001). This dimension was followed by physical well-being (\underline{F} = 50.23; \underline{p} <.001). While findings from both the present study and the application of the scale with sarcoma patients (Arzouman, et al., 1991) showed the family subscale as the highest scores, this domain was not assessed in the Padilla and Grant studies.

Comparing the findings of this study to other research, Curtis and Fernsler (1989) conducted a study with 23 hospice patients' and the family caregivers' perceptions on the Quality of Life Index (Padilla & Grant, 1985). The hospice patients were not undergoing active treatment and were generally considered to have functional performance status scores of below 50. In the hospice study, no significant difference was reported between the patient and SKO groups. A significant difference on the pain score was found, which indicated patients rated themselves having significantly

less pain than the family caregivers reported for them. In the present study, pain questions were not analyzed individually, but the health and functioning subscale had the lowest score.

Spitzer et al. (1981) developed the Quality of Life Index as a means for physicians to measure patients' QOL. Activity, independence in daily living, perception of health, social support, and outlook were each rated by a single item. Comparisons between physicians' and patients' ratings showed a Spearman's $\underline{r} = .61 (\underline{p} < .001)$ for the 161 Australian patients and \underline{r} = .69 (\underline{p} <.001) for the 51 Canadian patients. Patients were found to systematically rate themselves one to two points higher (out of 10) than rated by the physicians. Spitzer et al. concluded that patients with relatives willing to participate in a study seemed destined to score higher on the Quality of Life Index. While the present study did not document these same differences for the QLI-CV total or subscale scores, using one question to evaluate each domain may give a more subjective evaluation of each area. Social comparison theory postulates that when patients become threatened and objective means are not available, they compare themselves to other patients and rate themselves better than others rate them. Using only one question per domain with

subjective type questions may give a more accurate difference in perception than was possible with the QLI-CV in the present study.

Research question 2 related to the congruency of perceptions of symptom distress between the patient and SKO groups as measured by the SDS total scores. The SDS total scores for the patient group varied from a low of 14 to a high of 47. The range of SDS total scores for the SKO group was comparable at a low score of 16 to a high score of 48. The mean SDS total scores for the patient group were 28.357 and 30.857 for the SKO group. The Wilcoxon matched-pairs signed-ranks test for the SDS total scores was $\underline{Z} = 2.76$ ($\underline{p} = .0058$). A significant difference was found between the scores of the two groups. The SKOs overestimated the amount of symptom distress experienced by the patients.

The Wilcoxon matched-pairs signed-ranks test produced 42 positive ranks, 22 negative ranks, and 6 ties. The percentage of SKOs who rated the patients SD greater than the patients was 60%. The mean SDS difference score calculated between the SKO and patient group was -2.5. The SKOs perceived 2.5 points more distress for the patient than the patients did for themselves. While the group was similar on the QOL section of the study, 60% of the SKOs significantly overestimated the patients' degree of SD by

2.5 points. The lack of tied scores indicates that the congruency of perceptions necessary for goal attainment is not present in this area.

When the patients' SDS total scores from this study were compared with findings from previous oncology studies, the patients in this study had more symptom distress. study of 60 cancer patients receiving chemotherapy, Murkres, Oberst, and Hughes (1992) calculated the total SDS mean score calibrated on a linear analysis self-assessment scale (LASA) of 0 to 100 mm. The LASA score of 36.65 out of 100 is proportionately less than the present patient SDS score of 28.357 out of 65. In a report of the use of the SDS with 72 radiotherapy patients, Oberst, Hughes, Chang, and McCublin (1991) reported the LASA scores on the 0 to 100 mm scale produced a total mean SDS score of 30.49. finding also indicated proportionately less symptom distress than experienced by the patients in this study, 28.357 on the total 65 point scale.

In the original application of the 10-item SDS,

McCorkle and Young (1978) reported on comparisons made

between 5 patients and their family members. The percentage

of family members who rated more symptom distress than the

patients rated for themselves was 60%, the same percentage

as the SKOs and patients in the present study. The family

members in the original study perceived approximately onethird greater SD or a 7 to 12 point difference, while in the present study, the SKOs and patients SD mean difference was only -2.5 points.

In an application of the SDS 11-item LASA version, Holmes and Eburn (1989) compared differences in perceptions of SD between 53 cancer patients and the nurses caring for them. Results of these comparisons were similar to the present study. Holmes and Eburn found a significant difference between the patient and nurse caregiver group (t = 5.224; p>.001) on the SDS. Analysis of the ranking of the scores indicated 40 (75.5%) of the nurses overestimated the amount of total SD compared to 42 (60%) of the SKOs in the present study. The number of nurses underestimating the amount of SD was 13 (24.5%) compared with 22 (31.5%) of the SKOs in the present study. Holmes and Eburn found no ties between the nurses and patients in contrast to findings of the present study of 6 tie rankings.

Holmes and Eburn (1989) attributed their difference in perception to the fact that the symptoms of malignancy experienced by the patient were not readily "visible" and "immediately apparent" to the nurse or close family member. The authors hypothesized that since the symptoms were

subjective, nurses should underestimate the amount of symptom distress experienced by the patients.

The findings of overestimation of symptoms in the Holmes and Eburn (1989) study, as well as the present study, are understandable and explained through the patients' use of the coping mechanism of downward shifting. When evaluating the presence and distress produced by symptoms, and when objective measures are not available for comparison, patients threatened by the diagnosis and treatment of cancer possess a motivational drive to evaluate their conditions through comparisons with real or hypothetical less fortunate others (Taylor, Buunk, & Aspin, 1990). Through these comparisons, patients rate themselves as better than others rate them. This type of emotional-focused coping does not eliminate the threatening situation, but allows the person to decrease the anxiety associated with the threat (Lazarus & Folkman, 1984).

A deeper understanding of the findings of this study can occur when discussed in the context of the conceptual framework. King's (1981; personal communication February, 1994) process of human transaction explains both nonverbal and verbal portions of the interactive process that occurs between the patient and their SKO. The outcomes of the theory are for the patient and SKO to identify goals and the

means to achieve these goals. Findings from the present study help explain how coping mechanisms such as downward shifting affect the nonverbal portion of the interaction. In the present study, patients and SKOs rated the subjective SD experienced by patients. The SKOs rated the patients an average of 2.5 points higher than the patients rated themselves, which indicated the SKO group perceived more SD for the patients than the patients perceived for themselves. Calculations of the Wilcoxon matched-pairs signed-ranks test indicated this difference was significant. The rankings of the scores produced only 6 ties scores for the 70 dyads on the SDS total scores.

An analysis of the QLI-CV documented that although there was not a significant difference in the scores of the patients and SKOs on this more objective measure, there were few tie ranking. The QLI-CV total score produced no tie scores, the subscale scores of the family 15 ties, the psychological/spiritual 4 ties, the socioeconomic 2 ties, and the health and functioning 0 ties. If the cancer patient and SKO are to attain goals for the patient during treatment, it is imperative that the dyads be taught that the stress of the situation may cause incongruities in perceptions. Before patients and SKOs can plan and attain

goals, they must verify their perceptions with each other to attain congruency of understanding.

Conclusions

Based on the findings of this study, the following conclusions were drawn:

- Patients' quality of life is perceived similarly by cancer patients and their SKOs who have close relationships with them.
- 2. Patients' symptom distress is perceived differently by cancer patients and their SKOs who are closely related to them. The SKOs perceive more symptom distress than the patients do, which may be attributed to patients' use of the coping mechanism of downward shifting.
- 3. Incongruencies do exist between cancer patients' and their SKOs' perceptions of individual symptom distress, such as intensity of nausea, presence and intensity of pain, outlook, and cough.
- 4. Demographically, religion, education, and income may contribute to differences in cancer patients' and their SKOs' perceptions of patients' subjective symptom distress.

Implications

Implications of the study relate to the diagnosis and treatment of cancer patients in a changing health care environment. To meet the goals of reducing costs while maintaining or improving patient outcomes, families are assuming more responsibility for patient care. To help SKOs and patients meet this challenge it is imperative to teach them as much as possible about what to expect during the cancer experience.

Dealing with the patients use of the coping mechanism of downward shifting will be easier if the patients and SKOs are aware of the phenomenon and the differences in perceptions that result from its use. The SKOs can better understand the patients need to increase their self-esteem and interact with the patients in ways that positively affect their relationship.

Trying to be objective in dealings with patients and decreasing subjectivity would be beneficial to increase understanding. Using pain scales to document the amount and intensity of pain, counting the actual number of hours slept or the amount of calories eaten might make the perceptions of both members of the dyad more congruent.

Before making judgements about the patient in areas that are not as easily quantified, the SKOs should not just

project their own ideas but ask patients how they feel. The dyads should then compare their perceptions. When there is disagreement nurses should help the SKOs and patients acknowledge and understand the differences in perceptions and not allow conflict and stress to result.

The patients and SKOs should particularly evaluate symptoms in the areas shown to cause incongruency. Pain, nausea, and cough should be specifically treated and the patients and SKOs should determine a mutually acceptable level of distress. The dyad should also be taught to understand the importance of mediating variables in enhancing the patients self-image. By getting pain and nausea at an acceptable level the patient may be able to sleep better and then feel more like eating or dressing.

Besides the teachings of health professionals, the patients and SKOs rely on publications of the National Cancer Institute and American Cancer Society for information on what to expect while undergoing treatment. While these publications encourage supportive behavior, the information on how to be supportive is often very general. To be helpful, these sources must be realistic and specific. Including specific information about downward shifting and including information on the differences of perceptions and

measures to increase congruency may give the patients and SKOs insight into their behaviors.

To reinforce the necessary support to deal with the stress of treatment patients and SKOs are encouraged to attend group support sessions. The stress reducing benefits of affiliation may help the patients and SKOs cope better during this stressful time. Additionally, nurses should help the SKOs to understand that all interactions with cancer patients should enhance the patient's self-esteem and help the patient feel supported.

Recommendations for Future Study

As a result of this study, several recommendations were made:

- This study should be replicated with a more heterogenous patient population of low-income and minority patients to increase the generalizability of the findings beyond the study sample.
- 2. A replication of this study should be undertaken with a broader sample of patients experiencing acute and chronic diseases, especially Acquired Immune Deficiency Syndrome, to increase the generalizability of the findings beyond the study sample.
- 3. This study also should be replicated with other groups in addition to SKOs who interact with the patients,

- such as physicians, nurses, relatives and other members of the patient's support system.
- 4. A long-term study should be conducted to determine the patients' use of downward shifting over the course of the cancer diagnosis and treatment.
- 5. A qualitative study should be conducted to determine how the difference in perceptions affects the relational dynamics between the dyad.
- 6. The effect of downward shifting on goal attainment should be studied to determine if understanding downward shifting increases goal attainment.
- 7. A study is recommended to determine the influence of teaching the patients and SKOs about downward shifting through programs such as the American Cancer Society's program "I Can Cope."
- 8. A study should be undertaken to determine whether an understanding of downward shifting will decrease the length of hospital stay and allow the patients to remain at home for longer periods of time during therapy.
- 9. Control group interventional studies should be conducted to determine how downward shifting affects the internal validity of research studies.

REFERENCES

- Aaronson, N. K. (1988). The assessment of subjective response in prostatic cancer clinical research. <u>American Journal of Clinical Oncology</u>, <u>11</u>(Suppl. 2), 543-547.
- Aaronson, N. K. (1990). Quality of life research in cancer clinical trials: A need for common rules and language.

 Oncology, 4(5), 59-66.
- Aaronson, N. K., Bakker, W., Stewart, A. L., van Dam, F., van Zankdwijk, N., Yarnold, J. R., & Kirkpatrick, A. (1987). Multidimensional approach to the measurement of quality of life in lung cancer clinical trials. In N. K. Aaronson & J. Beckmann (Eds.), The quality of life of cancer patients (pp. 63-82). New York: Raven Press.
- Abdellah, F. G., & Levine, E. (1986). <u>Better patient care</u> <u>through nursing research</u> (3rd ed.). New York: Macmillan Publishing Company, Inc.
- Affleck, G., & Tennen, H. (1991). Social comparison and coping with major medical problems. In G. Suls & T. A. Wills (Eds.), <u>Social comparison--contemporary theory and research</u> (pp. 369-393). Hillsdale, NJ: Lawrence Erlbaum Associates.
- Affleck, G., Tennen, H., Pfeiffer, C., & Fifield, J. (1988). Social comparisons in rheumatoid arthritis: Accuracy and adaptational significance. <u>Journal of Social and Clinical Psychology</u>, 6, 219-234.
- Affleck, G., Tennen, H., Pfeiffer, C., Fifield, J., & Rowe, J. (1987). Downward comparison and coping with serious medical problems. <u>American Journal of Orthopsychiatry</u>, <u>57</u>, 570-578.
- American Cancer Society. (1993). <u>Cancer facts and figures-1993</u>. Atlanta, GA: Author.
- American Nurses' Association and Oncology Nursing Society (1987). Standards of oncology nursing practice. Kansas City: American Nurses' Association.

- Anderson, K. H., & Tomlinson, P. S. (1992). The family health system as an emerging paradigmatic view for nursing. Image: Journal of Nursing Scholarship, 24(1), 57-63.
- Arzouman, J. M., Dudas, S., Ferrans, C. E., & Holm, K. (1991). Quality of life of patients with sarcoma postchemotherapy. Oncology Nursing Forum, 18, 889-894.
- Baird, S. B. (1987, September). The changing economics of cancer care: Challenges and opportunities. Paper presented at the meeting of the Fifth National Conference on Cancer Nursing, American Cancer Society.
- Baird, S. B., & Mortenson, L. E. (1990). Economic concerns in the changing health care delivery system. <u>Cancer</u>, 65, 766-769.
- Beyer, W. H. (Ed.). (1966). <u>CRC handbook of tables for probability and statistics</u>. Cleveland, OH: The Chemical Rubber Company.
- Blalock, S. J., deVellis, B. M., deVellis, R. F., & van H. Sauter, S. (1988). Self-evaluation processes and adjustment to rheumatoid arthritis. <u>Arthritis & Rheumatism</u>, 31, 1245-1251.
- Boring, C. C., Squires, T. S., Tong, T., & Montgomery, J. (1994). Cancer statistics, 1994. <u>CA: A Cancer Journal For Clinicians</u>, 44(1), 7-26.
- Bowling, A. (1991). <u>Measuring health: A review of quality of life measurement scales</u>. Philadelphia: Open University Press.
- Breetvelt, I. S., & van Dam, F. S. (1991). Underreporting by cancer patients: The case of response-shift. <u>Social</u> <u>Science Medicine</u>, <u>32</u>, 981-987.
- Calman, K. C. (1984). Quality of life in cancer patients-an hypothesis. <u>Journal of Medical Ethics</u>, <u>10</u>(3), 124-127.
- Campbell, A., Converse, P. E., & Rogers, W. L. (1976).

 The quality of American life: Perceptions, evaluations, and satisfactions. New York: Russell Sage Foundation.

- Cella, D. F., & Tulsky, D. S. (1993). Quality of life in cancer: Definition, purpose and method of measurement. Cancer Investigation, 11, 327-336.
- Cherner, L. L. (Ed.). (1993). <u>The universal healthcare almanac</u>. Phoenix, AZ: Silver & Cherner.
- Clark, A., & Fallowfield, L. J. (1986). Quality of life measurements in patients with malignant disease: A review. <u>Journal of the Royal Society of Medicine</u>, <u>79</u>(3), 165-169.
- Clipp, E. C., & George, L, K. (1992). Patients with cancer and their spouse caregivers. <u>Cancer</u>, <u>69</u>, 1074-1079.
- Cohen, J. (1988). <u>Statistical power analysis for the behavioral sciences</u> (2nd ed.). Hillsdale, New Jersey: Lawrence Erlbaum Associates.
- Conill, C., Verger, E., & Salamero, M. (1990). Performance status assessment in cancer patients. <u>Cancer</u>, <u>65</u>, 1864-1866.
- Coward, D. D. (1991). Self-transcendence and emotional well-being in women with advanced breast cancer.

 <u>Oncology Nursing Forum</u>, <u>18</u>, 857-863.
- Curtis, A. E., & Fernsler, J. F. (1989). Quality of life of oncology hospice patients: A comparison of patient and primary caregiver reports. Oncology Nursing Forum, 16, 49-53.
- deHaes, J. C., & van Knippenberg, F. C. (1985). The quality
 of life of cancer patients: A review of the literature.
 <u>Social Science Medicine</u>, <u>20</u>, 809-817.
- Fallowfield, L. (1990). <u>The quality of life: The missing measurement in health care</u>. London: Souvenir Press Ltd.
- Fawcett, J. (1984). <u>Analysis and evaluation of conceptual models of nursing</u>. Philadelphia: F. A. Davis Company.
- Fazio, M. T., & Glaspy, J. A. (1991). The impact of granulocyte colony-stimulating factor on quality of life in patients with several chronic neutropenia. Oncology Nursing Forum, 18, 1411-1414.

- Felder, L. (1990). When a loved one is ill: How to take better care of your loved one, your family, and yourself. New York: Penguin Group.
- Ferrans, C. E. (1990a). Development of a quality of life index for patients with cancer. <u>Oncology Nursing Forum</u>, <u>17</u>(3 Supplement), 15-21.
- Ferrans, C. E. (1990b). Quality of life: Conceptual issues. Seminars In Oncology Nursing, 6, 248-254.
- Ferrans, C. E., & Powers, M. J. (1985). Quality of life index: Development and psychometric properties.

 <u>Advances in Nursing Science</u>, 8(1), 15-24.
- Ferrans, C. E., & Powers, M. J. (1992). Psychometric assessment of the quality of life index. Research in Nursing & Health, 15(1), 29-38.
- Festinger, L. (1950). Informal social communication. <u>Psychological Review</u>, <u>57</u>, 271-282.
- Festinger, L. (1954). A theory of social comparison processes. <u>Human Relations</u>, 7, 117-140.
- Festinger, L., Torrey, J., & Willerman, J. (1954). Self-evaluation as a function of attraction to the group. Human Relations, 7, 161-174.
- Fletcher, A. E. (1988). Measurement of quality of life in clinical trials of therapy. In H. Scheuler, R. Kay, & M. Baum (Eds.), <u>Recent results in cancer research:</u>
 Volume 111 (pp. 216-230). Berlin: Springer-Verlag.
- Frank-Stromborg, M. (1988). Single instruments for measuring quality of life. In. M. Frank-Stromborg (Ed.),

 <u>Instruments for clinical nursing research</u> (pp. 79-95).

 Norwalk, CT: Appleton & Lange.
- Ganz, P. A., Hirji, K., Sim, M. S., Schag, C. C., Fred, C., & Polinsky, M. L. (1993). Predicting psychosocial risk in patients with breast cancer. <u>Medical Care</u>, <u>31</u>, 419-431.
- Germino, B. (1987). Symptom distress and quality of life. Seminars in Oncology Nursing, 3, 299-302.

- Gibbons, F. X., & Gerrard, M. (1991). Downward comparison and coping with threat. In J. Suls & T. A. Wills (Eds.). Social comparison—contemporary theory and research (pp. 317-345). Hillsdale, NJ: Lawrence Erlbaum Associates.
- Grant, M., Padilla, G. V., Ferrell, B. R., & Rhiner, M. (1990). Assessment of quality of life with a single instrument. <u>Seminars In Oncology Nursing</u>, 6, 260-270.
- Grieco, A., & Long, C. J. (1984). Investigation of the Karnofsky Performance Status as a measure of quality of life. <u>Health Psychology</u>, <u>3</u>(2), 129-142.
- Gruder, C. L. (1977). Choice of comparison persons in evaluating oneself. In J. M. Suls & R. L. Miller (Eds.), Social comparison processes (pp. 21-41). Washington, DC: Hemisphere Publishing Corporation.
- Guyatt, G. H., & Jaeschke, R. (1990). Measurements in clinical trials: Choosing the appropriate approach. In B. Spilker (Ed.), <u>Quality of life in clinical trials</u> (pp. 37-46). New York: Raven Press.
- Hagopian, G. A. (1993). Cognitive strategies used in adapting to a cancer diagnosis. <u>Oncology Nursing Forum</u>, <u>20</u>, 759-763.
- Hinds, P. S., & Martin, J. (1988). Hopefulness and the self-sustaining process in adolescents with cancer. Nursing Research, 37, 336-340.
- Hoffman, P. J., Festinger, L., & Lawrence, D. H. (1954). Tendencies toward group comparability in competitive bargaining. <u>Human Relations</u>, 7, 141-159.
- Holmes, S. (1989). Use of a modified symptom distress scale in assessment of the cancer patient. <u>International</u> <u>Journal of Nursing Studies</u>, <u>26</u>(1), 69-79.
- Holmes, S. (1991). Preliminary investigation of symptom distress in two cancer patient population's evaluation of a measurement instrument. <u>Journal of Advanced Nursing</u>, 16, 439-446.

- Holmes, S., & Dickerson, J. (1987). The quality of life: Design and evaluation of a self-assessment instrument for use with cancer patients. <u>International Journal of</u> <u>Nursing Studies</u>, <u>24</u>(1), 15-24.
- Holmes, S., & Eburn, E. (1989). Patients' and nurses' perceptions of symptom distress in cancer. <u>Journal of Advanced Nursing</u>, <u>14</u>, 840-846.
- Joint Commission on Accreditation of Healthcare Organizations. (1992). <u>Accreditation manual for hospitals</u>, 1993. Oakbrook Terrace, IL: Joint Commission on Accreditation of Healthcare Organizations.
- Johnson, J. R., & Temple, R. (1985). Food and Drug
 Administration requirements for approval of new
 anticancer drugs. <u>Cancer Treatment Reports</u>, <u>69</u>,
 1155-1157.
- Jones, D. R., Fayers, P. M., & Simons, J. (1987).

 Measuring and analyzing quality of life in cancer clinical trials. In N. K. Aaronson & J. Beckmann (Eds.). The quality of life of cancer patients.

 New York: Raven Press.
- Karnofsky, D. A., & Burchenal, J. H. (1949). The clinical evaluation of chemotherapeutic agents in cancer. In C. M. MacLeod (Ed.), <u>Evaluation of chemotherapeutic</u> agents (pp.191-205). New York: Columbia University Press.
- Kerr, M. E., & Bowen, M. (1988). Family evaluation: An approach based on Bowen theory. New York: W. W. Norton & Company.
- King, I. M. (1971). <u>Toward a theory for nursing</u>. New York: John Wiley & Sons.
- King, I. M. (1981). <u>A theory for nursing: Systems, concepts, process</u>. New York: John Wiley & Sons.
- King, I. M. (1992). King's theory of goal attainment.
 Nursing Science Ouarterly, 5(1), 19-26.
- Kirk, R. E. (1982). <u>Experimental design: Procedures for the behavioral sciences</u> (2nd ed.). Belmont, CA: Brooks/Cole Publishing Co.

- Kleinpell, R. M. (1991). Concept analysis of quality of life. Dimensions of Critical Care Nursing, 10, 223-229.
- Kukull, W. A., McCorkle, R., & Driever, M. (1986). Symptom distress, psychosocial variables, and survival from lung cancer. <u>Journal of Psychosocial Oncology</u>, <u>4</u>(1/2), 91-104.
- Larson, P., Viele, C., Coleman, S., Dibble, S., & Cebulski, C. (1993). Comparison of perceived symptoms of patients undergoing bone marrow transplant and the nurses caring for them. <u>Oncology Nursing Forum</u>, <u>20</u>, 81-88.
- Lazarus, R. S., & Folkman, S. (1984). <u>Stress, appraisal and coping</u>. New York: Springer Publishing.
- Maisto, S. A., O'Farrell, T. J., McKay, J. R., Connors, G. J., & Pelcovits, M. (1988). Alcoholic and spouse concordance on attributions about relapse to drinking. <u>Journal of Substance Abuse Treatment</u>, 5(1), 179-181.
- Maxwell, M. (1990). General principles of therapy. In S. Groenwald, M. Frogge, M. Goodman, & C. Yarbro (Eds.), Cancer nursing principles and practice (2nd ed.; pp. 177-188). Boston: Jones & Bartlett Publishers.
- McCorkle, R. (1987). The measurement of symptom distress. Seminars in Oncology Nursing, 3, 248-256.
- McCorkle, R., & Quint-Benoliel, J. (1983). Symptom distress, current concerns and mood disturbance after diagnosis of life-threatening disease. <u>Social Science Medicine</u>, <u>17</u>, 431-438.
- McCorkle, R., & Young, K. (1978). Development of a symptom distress scale, <u>Cancer Nursing</u>, <u>1</u>, 373-378.
- Miettinen, O. S. (1987). Quality of life from the epidemiologic perspective. <u>Journal of Chronic Diseases</u>, 40, 641-643.
- Moinpour, C. M., Hayden, K. A., Thompson, J. M., Feigl, P., & Metch, B. (1990). Quality of life assessment in Southwest Oncology Group trials. Oncology, 4(5), 79-84.

- Molleman, E., Pruyn, J., & van Knippenberg, A. (1986). Social comparison processes among cancer patients. British Journal of Social Psychology, 25 (Part 1), 1-13.
- Mooney, K. H., Ferrell, B. R., Nail, L. M., Benedict, S. C., & Haberman, M. R. (1991). 1991 Oncology Nursing Society research priorities survey. Oncology Nursing Forum, 18, 1381-1388.
- Mor, V., Laliberte, L., Morris, J. N., & Wiemann, M. (1984). The Karnofsky Performance Status Scale: An examination of its reliability and validity in a research setting. Cancer, 53, 2002-2007.
- Munkres, A., Oberst, M. T., & Hughes, S. H. (1992).
 Appraisal of illness, symptom distress, self-care burden, and mood states in patients receiving chemotherapy for initial and recurrent cancer. Oncology Nursing Forum, 19, 1201-1209.
- Munro, B. H., Visintainer, M. A., & Page, E. B. (1986). Statistical methods for health care research. Philadelphia: J. B. Lippincott Company.
- Nightingale, F. (1946). <u>Notes on nursing: What it is,</u> <u>and what it is not</u>. Philadelphia: Edward Stern & Company, Inc. (Original work published 1859).
- Oberst, M. T., Hughes, S. H., Chang, A. S., & McCubbin, M. A. (1991). Self-care burden, stress appraisal, and mood among persons receiving radiotherapy. <u>Cancer Nursing</u>, 14(2), 71-78.
- Osoba, D. (1991). <u>Effect of cancer on quality of life</u>. Boca Raton, FL: CRC Press.
- Padilla, G. V., & Grant, M. M. (1985). Quality of life as a cancer nursing outcome variable. <u>Advances in Nursing Science</u>, <u>8</u>(1), 45-60.
- Padilla, G. V., Presant, C., Grant, M. M., Metter, G., Lipsett, J., & Heide, F. (1983). Quality of life index for patients with cancer. Research in Nursing & Health, 6(3), 117-126.
- Papero. A. V. (1990). <u>Bowen family systems theory</u>. Boston: Allyn and Bacon.

- Peteet, J. R. (1982). A closer look at the concept of support: Some applications to the care of patients with cancer. General Hospital Psychiatry, 4(1), 19-23.
- Rhodes, V. A., & Watson, P. M. (1987). Symptom distress—the concept: past and present. <u>Seminars In Oncology</u>
 <u>Nursing</u>, 3, 242-247.
- Roscoe, J. T. (1975). <u>Fundamental research statistics for the behavioral sciences</u>. New York: Holt, Rinehart and Winston.
- Sandrik, K. (1990). Oncology: Who's managing outpatient programs? Hospitals, 64(3), 32-37.
- Schachter, S. (1959). <u>The psychology of affiliation</u>. Stanford, CA: Stanford University Press.
- Schag, C. C., Heinrich, R. L., & Ganz, P. A. (1984). Karnofsky Performance Status revisited: Reliability, validity and guidelines. <u>Journal of Clinical Oncology</u>, 2(3), 187-193.
- Schipper, H. (1990). Guidelines and caveats for quality of life measurement in clinical practice and research.

 Oncology, 4(5), 51-57.
- Schipper, H., Clinch, J., McMurray, A., & Levitt, M. (1984). Measuring the quality of life of cancer patients: The Functional Living Index-Cancer: Development and validation. <u>Journal of Clinical Oncology</u>, 2, 472-483.
- Schraub, S., Bransfield, D. D., Monpetit, E., & Fournier, J. (1987). Comparison of three methods to measure quality of life. In N. K. Aaronson & J. H. Beckmann (Eds.), The quality of life of cancer patients (pp. 83-92). New York: Raven Press.
- Selby, P., & Robertson, B. (1987). Measurement of quality of life in patients with cancer. <u>Cancer Surveys</u>, <u>6</u>, 521-532.
- Shaw, A. (1977). Defining the quality of life. <u>The Hastings</u> <u>Center Report</u>, <u>7</u>(5), 11.
- Shaw, A. (1988). Quality of life revisited. <u>The Hastings</u> <u>Center Report</u>, <u>18</u>(2), 10-12.

- Spilker, B. (Ed.). (1990). <u>Quality of life assessments in clinical trials</u>. New York: Raven Press.
- Spitzer, W. O., Dobson, A. J., Hall, J., Chesterman, E., Levi, J., Shepherd, R., Battista, R. N., & Catchlove, B. R. (1981). Measuring the quality of life of cancer patients. <u>Journal of Chronic Diseases</u>, <u>34</u>, 585-597.
- Strain, J. J. (1990). The evolution of quality of life evaluations in cancer therapy. Oncology, 4(5), 22-26.
- Strong, M. (1988). <u>Mainstay: For the well spouse of the chronically ill</u>. New York: Penguin Group.
- Suls, J. (1977). Social comparison theory and research.
 In J. M. Suls & R. L. Miller (Eds.), Social comparison
 process (pp. 1-19). Washington, DC: Hemisphere
 Publishing.
- Taylor, S. E., & Lobel, M. (1989). Social comparison activity under threat: Downward evaluation and upward contacts. <u>Psychological Review</u>, <u>96</u>, 569-575.
- Taylor, S. E., Buunk, B. P. & Aspinwall, L. G. (1990).

 Social comparison, stress and coping. <u>Personality and Social Psychology Bulletin</u>, <u>16</u>(1), 74-89.
- Tchekmedyian, N. S., & Cella, D. F. (1990). Foreward. Oncology 4(5), 21.
- Tishelman, C., Taube, A., & Sachs, L. (1991). Self-reported symptom distress in cancer patients: Reflections of disease, illness or sickness? <u>Social Science Medicine</u>, 33, 1229-1240.
- Verger, E., Salamero, M., & Conill, C. (1992). Can Karnofsky Performance Status be transformed to the Eastern Cooperative Oncology Group Scouring Scale and vice versa? <u>European Journal Cancer</u>, <u>28A</u>, 1328-1330.
- Volker, D. L. (1992). Standards of oncology education:
 Patient, family, and public. In J. C. Clark & R. F. McGee
 (Eds.), Core curriculum for oncology nursing (2nd ed.;
 pp. 18-24). Philadelphia: W. B. Saunders Company.
- Waltz, C. F., Strickland, O. L., & Lenz, E. R. (1984).

 <u>Measurement in nursing research</u>. Philadelphia:
 F. A. Davis.

- Wheeler, L. (1991). A brief history of social comparison theory. In J. Suls & T. A. Wills (Eds.), <u>Social</u> comparison: Contemporary theory and research (pp. 3-21). Hillsdale, NJ: Lawrence Erlbaum Associates.
- Wills, T. A. (1981). Downward comparison principles in social psychology. <u>American Psychological Bulletin</u>. 90, 245-271.
- Wood, J. V., & Taylor, K. L. (1991). Serving self-relevant goals through social comparison. In J. Suls & T. A. Wills (Eds.), <u>Social comparison: Contemporary theory and research</u> (pp. 23-49). Hillsdale, NJ: Lawrence Erlbaum Associates.
- Wood, J. V., Taylor, S. E., & Lichtman, R. R. (1985). Social comparison in adjustment to breast cancer. <u>Journal of Personality and Social Psychology</u>, <u>49</u>, 1169-1184.
- Woods, N. F., & Catanzaro, M. (1988). <u>Nursing research</u>, theory and practice. St. Louis: C.V. Mosby Co.
- World Health Organization (1958). The first ten years of the World Health Organization. Geneva: Author.
- Yates, W., Chalmer, B., & McKegney, F. P. (1980). Evaluation of patients with advanced cancer using the Karnofsky Performance Status. <u>Cancer</u>, <u>45</u>, 2220-2224.

APPENDIX A AGENCY APPROVALS

TEXAS WOMAN'S UNIVERSITY DENTON DALLAS HOUSTON HUMAN SUBJECTS REVIEW COMMITTEE - HOUSTON CENTER

HSRC APPROVAL FOR	M
Name of Investigator(s): Hilda E. Porter	
Social Security Number(s):075-36-6653	
Name of Research Advisor(s): Anne Young, Ed.D., Assoc	iate Professor
Address: 5810 Braesheather Drive, Houston, Te	
Dear:	
Your study entitled: A Comparison Of Perceptions Of	Cancer Patients And
Significant Key Others Of Patients' Quality O	
(The applicant must complete the top portion of this form)	
has been reviewed by the Human Subjects Review Committee - Ho requirements in regard to protection of the individual's rights.	ouston Center and it appears to meet our
Please be reminded that both the University and the Department of typically require that signatures indicating informed consent be of study. These are to be filed with the Human Subjects Review C this requirement is noted below. Furthermore, according to HHHSRC is required if your project changes or if it exidate of approval.	otained from all human subjects in your ommittee Chairman. Any exception to IS regulations, another review by the
Any special provisions pertaining to your study are noted below:	
Add to informed consent form: "I understand that constitutes my informed consent to act as a subjection."	the return of my questionnaire ct in this research.
The filing of signatures of subjects with the Hurr required.	nan Subjects Review Committee is not
Other: see attached sheet.	
No special provisions apply.	
Sino	erely,
<u> </u>	ous E. Wylet
	is E. Wright, Ph.D. Uipperson, HSRC - Houston Center
	Lest 14 1694



C.P.H.S. Number: HSC-0-94-013

Notification of C.P.H.S. Approval: 9/20/94

"A Comparison of Perceptions of Cancer Patients and Significant Key Others of Patients' Quality of Life and Symptom Distress" Title:

P.I.: Hilda Porter, PhD Candidate

Thank you for choosing Hermann Hospital to participate in this research project. Approval is hereby granted by Hermann Hospital Administration to initiate this research project involving Hermann Hospital patients. staff or facilities.

This approval is subject to the investigator's acceptance of the following stipulations:

Changes to a study, including change of principal investigator, changes in services involved, or changes in budget or funding will require a new Hermann Hospital approval. Changes

The ${\rm P.I.}$ will provide inservice education to all personnel affected by the research study. Education

All in-patients on any research protocol will have in their hospital Records

medical record a copy of the signed informed consent document.

The P.I. will register all Hermann Hospital patients in this study with Special Billing, 704-6262. Information required is the patient's name, patient account #, study number and enrollment date. Patient Enrollment

There are no research related charges attached to this study. However, the Investigator agrees to forward a copy of the study results to the Hermann **Billing**

Research Office.

Please sign and return a copy of this letter to Special Billing. Hermann Administrative Annex (or FAX #704-4257), to indicate your acceptance of our terms and policies.

If you have any questions, or need additional information, please contact the Hermann Hospital Research Office at 704-4255

Hermann Hospital

Approval:

P.I. Acceptance:

copy: Special Billing CPHS

Hermann Hespital Texas Medical Center 6411 Fannin Hoiston, Texas 770 O 1501 713,797,4011

Applicated with the University of Term Mode it Short in Houseon



The Committee for the Protection of Human Subjects

NOTICE OF APPROVAL TO BEGIN RESEARCH

September 16, 1994

<u>HSC-O-94-013</u> - "A Comparison of Perceptions of Cancer Patients and Significant Key Others of Patients' Quality of Life and Symptom Disease" P.I.: Hilda Porter, RN, Ph.D. Candidate

PROVISIONS: Unless otherwise noted, this approval relates to the research to be conducted under the above referenced title and/or to any associated materials considered at this meeting, e.g. study documents, informed consent, etc.

APPROVED: At a Convened Meeting

APPROVAL DATE: September 16, 1994 EXPIRATION DATE: September 30, 1995

CHAIRPERSON: Alan C. Swann, M/Dist

Subject to any provisions noted above, you may now begin this research.

<u>CHANGES</u> - The P.I. must receive approval from the CPHS before initiating any changes, including those required by the sponsor, which would affect human subjects, e.g. changes in methods or procedures, numbers or kinds of human subjects, or revisions to the informed consent document or procedures. The addition of co-investigators must also receive approval from the CPHS. ALL PROTOCOL REVISIONS MUST BE SUBMITTED TO THE SPONSOR OF THE RESEARCH.

INFORMED CONSENT - Informed consent must be obtained by the P.I. or designee using the format and procedures approved by the CPHS. The P.I. must instruct the designee in the methods approved by the CPHS for the consent process. The individual obtaining informed consent must also sign the consent document.

<u>UNANTICIPATED RISK OR HARM, OR ADVERSE DRUG REACTIONS</u> - The P.I. will immediately inform the CPHS of any unanticipated problems involving risks to subjects or others, of any serious harm to subjects, and of any adverse drug reactions.

<u>RECORDS</u> - The P.I. will maintain adequate records, including signed consent documents if required, in a manner which ensures confidentiality.

cc: Hermann Hospital

SPRING BRANCH MEDICAL CENTER

8850 Long Point Houston, Texas 77055

An Affiliate of Columbia/HCA Healthcare Corporation

(713) 467-6555 Fax (713) 722-3780 **January 20, 1995**

Misty Porter, R.N. 5810 Braesheather Dr. Houston, Texas 77096-3906

> RE: A Comparison of Perceptions of Cancer Patients and Significant Key Others of Patients' Quality of Life and Symptom Distress: Principal Investigator: Misty Porter, R.N.

Dear Ms. Porter.

The Institutional Review Board of Spring Branch Medical Center, at the annual meeting on January 20, 1995, considered the above referenced protocol and consent form for which you are Principal Investigator. The protocol was reviewed and your request for approval of the study was granted for ten (10) months.

If you have any questions, please do not hesitate to contact me at 722-3723.

Sincerely,

William E. Luper, M.D.

Chairman

Institutional Review Board

WEL/ad

AGENCY PERMISSION FOR CONDUCTING STUDY*

THE	Dr. Philip Cimo
a stude	STQ <u>Hilda E. Porter</u> Int enrolled in a program of nursing leading to a Ph.D. in nursing at Texas Woman's ity, the privilege of its facilities in order to study the following problem:
	A Comparison of Perceptions of Cancer Patients and Significant Key Others of Patients' Quality of Life and Symptom Distress.
The con	ditions 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.	The agency is (willing) (unwilling) to allow the completed report to be circulated through interlibrary loan.
5.	Other
Date:	1/10/95 /CCm
Le	Signature of Agency Personnel
	Signature of Student Signature of Faculty Advisor
Fill out a	and sign three copies to be distributed as follows: Original-Student; First copy - Second copy - TWU College of Nursing.

DR:lt 1/13/92

AGENCY PERMISSION FOR CONDUCTING STUDY.

THE_	Lemahologyy Oncology Sercials					
GRANT	STO Lieda & Mas.					
a stude	a student enrolled in a program of nursing leading to a Ph.D. In nursing at Texas Woman's University, the privilege of its facilities in order to study the following problem:					
A C	omparison of Cancer Patients' and Significant					
Кеу	Others' Perceptions of Patients' Quality of Life					
and	Symptom Distress.					
The con	ditions 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.	The agency is (willing) (unwilling) to allow the completed report to be circulated through interlibrary loan.					
5.	Other					
	June John R. Bremer En					
Date:a	Signature of Agency Personnel					
Wild	(a) buter					
	Signature of Student Signature of Faculty Advisor					
	and sign three copies to be distributed as follows: Original-Student; First copy - Second copy - TWU College of Nursing.					

DR:It 1/13/92

AGENCY PERMISSION FOR CONDUCTING STUDY

I HE	HOUSTON CANCER CENTER
	STO HILDA E. PORTER
a stude Univers	ent enrolled in a program of nursing leading to a Ph.D. In nursing at Texas Woman's sity, the privilege of its facilities in order to study the following problem:
Si	Comparison of Perceptions of Cancer Patients and gnificant Key Others of Patients Quality of Life and mptom Distress.
The cor	nditions 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.	The agency is (willing) (unwilling) to allow the completed report to be circulated through interlibrary loan.
5.	Other
Date:	
She	Signature of Agency Personnel
	Signature of Student Signature of Faculty Advisor
*Fill out agency;	and sign three copies to be distributed as follows: Original-Student; First copy - Second copy - TWU College of Nursing.

DR:lt 1/13/92

AGENCY PERMISSION FOR CONDUCTING STUDY

THE Oncology Consultants, PA				
a student enrolled in a program of nursing leading to a Ph.D. in nursing at Texas Woman's University, the privilege of its facilities in order to study the following problem:				
A Comparison of Perceptions of Cancer Patients				
and Significant Key Others of Patients' Quality of				
Life and Symptom Distress.				
The conditions mutually agreed upon are as follows:				
1. The agency (may) (may not) be identified in the final report.				
 The names of consultative or administrative personnel in the agency (may) (may not) be identified in the final report. 				
 The agency (wants) (does not want) a conference with the student when the report is completed. 				
through interlibrary loan.				
5. Other				
2 1				
Date: 2-1-95 Signature of Agency Personnel				
the 10 forth L				
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.				

DR:lt 1/13/92

APPENDIX B LETTER OF INTRODUCTION



COLLEGE OF NURSING Houston Center 1130 M.D. Anderson Blvd. Houston, TX 77030-2897 Phone: 713/794-2100

LETTER OF INTRODUCTION

Dear Participant:

My name is Misty Porter, and I am a doctoral nursing student at Texas Woman's University, Houston Center. I am conducting a research study comparing the perceptions of cancer patients and significant key others of patients' quality of life and symptom distress. I am requesting your assistance in the completion of three questionnaires which will take approximately 30 minutes. You will not be compensated for your participation.

There are no specific benefits for participating in the study. Potential risks include dealing with sensitive issues that might be anxiety producing. Your participation in this research study is completely voluntary, and there is no penalty for not participating. The information of the questionnaires will be kept confidential. The questionnaires will be kept in a locked drawer and destroyed after data analysis. The data will not be connected with your name. If you have any questions or concerns about the study or the questionnaire, please contact Misty Porter at 713-704-3961. Thank you for considering participation.

Mixty Better
Misty Porter, R.N., M.S.

APPENDIX C INFORMED CONSENT--PATIENT FORM



COLLEGE OF NURSING Houston Center 1130 M.D. Anderson Blvd. Houston, TX 77030-2897 Phone: 713/794-2100

> A Comparison Of Perceptions Of Cancer Patients And Significant Key Others Of Patients' Quality Of Life And Symptom Distress

INFORMED CONSENT PATIENT FORM

Page 1 of 2

1. Purpose of Study

I am being asked by Misty Porter, a doctoral nursing student at Texas Woman's University, Houston Center, to participate in a research study entitled "A Comparison Of Perceptions Of Cancer Patients And Significant Key Others Of Patients' Quality Of Life And Symptom Distress". The purpose of this study is to compare the cancer patients' and the significant key others' perceptions of the patients' quality of life and symptom distress. Both I and my significant key other will be asked to rate the quality of life and symptom distress experienced by the patient. If I choose to take part in the study, I will be asked to complete a data sheet and two questionnaires. The medical record will be used to obtain data concerning my illness and treatment. The questionnaires will take approximately 30 minutes to complete and can be done during the scheduled appointment time or hospital stay.

2. Voluntary Nature of Participation

My participation in this study is completely voluntary and I may refuse to participate or to continue in the study at any time. There will be no penalty for not participating or for withdrawing from the study.

3. Benefits

There are no direct benefits to participating in this study.

4. Reimbursement for Expenses

I will not be paid for taking part in the study. There are no financial costs associated with my participation.

5. Risks

Page 2 of 2

Potential risks include the loss of confidentiality and dealing with sensitive issues that might be anxiety producing. I may leave out any questions that I find anxiety producing.

6. Confidentiality

To insure confidentiality, all questionnaires will be marked with a number, not my name, and the questionnaires and Informed Consent will be kept in a locked file cabinet. Only the investigator and research assistants will have access to the questionnaires and Informed Consent. The information will be destroyed when reports of the study are completed. All data will be reported as group data and my identity will not be disclosed.

7. Investigator's Statement

I will return the completed forms to the investigator or return in the enclosed envelope.

IF I HAVE ANY QUESTIONS OR CONCERNS ABOUT THE STUDY OR THE QUESTIONNAIRES, I WILL CONTACT:

Misty Porter at 713-704-3961 (Office) or Dr. Anne Young at Texas Woman's University 713-794-2100.

8. Subject's Statement

The study described above has been explained to me, and I voluntarily consent to participate in this activity. By signing below I am agreeing to participate in this research study. If I have any questions as to my rights as a research subject, I may call the Committee for the Protection of Human Subjects (CPHS) at 713-984-3651. I have had an opportunity to ask questions and understand that future questions I may have about the research will be answered by the investigator listed above. If I decide to participate in this research study, a copy of this document will be given to me.

Signature of Subject	Date
Witness	Date

The study has been approved by the Committee for the Protection of Human Subjects of the Spring Branch Medical Center as SBMC-00-94.

APPENDIX D

INFORMED CONSENT--SIGNIFICANT KEY OTHER



COLLEGE OF NURSING Houston Center 1130 M.D. Anderson Blvd. Houston, TX 77030-2897 Phone: 713/794-2100

> A Comparison Of Perceptions Of Cancer Patients And Significant Key Others Of Patients' Quality Of Life And Symptom Distress

INFORMED CONSENT SIGNIFICANT KEY OTHER FORM

Page 1 of 2

1. Purpose of Study

I am being asked by Misty Porter, a doctoral nursing student at Texas Woman's University, Houston Center, to participate in a research study entitled "A Comparison Of Perceptions Of Cancer Patients And Significant Key Others Of Patients' Quality Of Life And Symptom Distress". The purpose of this study is to compare the cancer patients' and the significant key others' perceptions of the patients' quality of life and symptom distress. Both I and the patient will be asked to rate the quality of life and symptom distress experienced by the patient. If I choose to take part in the study, I will be asked to complete a data sheet and two questionnaires. The questionnaires will take approximately 30 minutes to complete and can be done during the patient's scheduled appointment time or hospital stay.

2. Voluntary Nature of Participation

My participation in this study is completely voluntary and I may refuse to participate or to continue in the study at any time. There will be no penalty for not participating or for withdrawing from the study.

3. Benefits

There are no direct benefits to participating in this study.

4. Reimbursement for Expenses

I will not be paid for taking part in the study. There are no financial costs associated with my participation.

5. Risks

Page 2 of 2

Potential risks include the loss of confidentiality and dealing with sensitive issues that might be anxiety producing. I may leave out any questions that I find anxiety producing.

6. Confidentiality

To insure confidentiality, all questionnaires will be marked with a number, not my name, and the questionnaires and Informed Consent will be kept in a locked file cabinet. Only the investigator and research assistants will have access to the questionnaires and Informed Consent. The information will be destroyed when reports of the study are completed. All data will be reported as group data and my identity will not be disclosed.

7. Investigator's Statement

I will return the completed forms to the investigator or return in the enclosed envelope.

IF I HAVE ANY QUESTIONS OR CONCERNS ABOUT THE STUDY OR THE QUESTIONNAIRES, I WILL CONTACT:

Misty Porter at 713-704-3961 (Office) or Dr. Anne Young at Texas Woman's University 713-794-2100.

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The study described above has been explained to me, and I voluntarily consent to participate in this activity. By signing below I am agreeing to participate in this research study. If I have any questions as to my rights as a research subject, I may call the Committee for the Protection of Human Subjects (CPHS) at 713-984-3651. I have had an opportunity to ask questions and understand that future questions I may have about the research will be answered by the investigator listed above. If I decide to participate in this research study, a copy of this document will be given to me.

Signature of Subject	Date
Witness	Date

The study has been approved by the Committee for the Protection of Human Subjects of the Spring Branch Medical Center as SBMC-00-94.

APPENDIX E PERFORMANCE STATUS SCALE

PERFORMANCE STATUS

Condition	Percent-	Comments
A: Able to carry on normal activity and to work. No special care is needed.	<i>age</i> 100	Normal, no complaints, no evidence of disease.
necucu.	90	Able to carry on normal activity, minor signs or symptoms of disease.
	80	Normal activity with effort, some signs or symptoms of disease.
B: Unable to work. Able to live at home, care for most personal needs. A varying degree of assistance is needed.	70	Cares for self. Unable to carry on normal activity or to do active work.
	60	Requires occasional assistance, but is able to care for most of his needs.
	50	Requires considerable assistance and frequent medical care.
C: Unable to care for self. Requires equivalent of institutional or hospital care. Disease may be progressing rapidly.	40	Disabled, requires special care and assistance.
	30	Severely disabled, hospitalization is indicated although death not imminent.
	20	Hospitalization necessary, very sick, active supportive treatment necessary.
	10	Moribund, fatal processes progressing rapidly.
	0	Dead.

Karnofsky, D. A., Burchenal, J. H. (1949). The clinical evaluation of chemotherapeutic agents in cancer. In C. M. MacLeod (Ed.), <u>Evaluation of chemotherapeutic agents</u> (pp. 191-205). New York: Columbia University Press.

APPENDIX F PATIENT QUESTIONNAIRE PACKET

A COMPARISON OF PERCEPTIONS OF CANCER PATIENTS AND SIGNIFICANT KEY OTHERS OF PATIENTS' QUALITY OF LIFE AND SYMPTOM DISTRESS

		Subject ID No Interview No
	PATIENT BACKGROUND DATA	SHEET
que	order for the researcher to evalua stionnaires, please complete the ormation:	
l.	What is your sex? Male Female_	
2.	What is your age?	
3.	To which ethnic group do you belong?	
	a. Anglo-American b. Black-American c. Mexican-American d. Asian or Asian-American e. Other (specify)	
1.	What is your religious preference?	
	a. Catholic b. Jewish c. Protestant d. Other (specify) e. No particular preference	
5.	What is your present marital status?	
	a. Single b. Married c. Separated d. Divorced e. Widow or widower	

6.	What is your level of education?
	a. Elementary school b. Some High School c. High School Graduate d. Some College e. College Graduate f. Graduate Education
7.	What is the approximate income of your household?
8.	What is/was your occupation?
9.	What was your longest occupation?
10.	Who is your designated significant key other?
11.	Who is the most significant person giving you emotional support during this illness?
12.	What is this person's relationship to you?
13.	How many years have you known this person?

Date	
Subje	ct I.D. No
Interv	icw No.

Ferrans and Powers QUALITY OF LIFE INDEX CANCER VERSION PATIENT FORM

<u>Part I.</u> For each of the following, please choose the answer that best describes how satisfied you are with the area of your life. Please mark your answer by circling the number. There are no right or wrong answers.

HOW SATISFIED ARE YOU WITH:	Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
1. Your health?	1	2	3	4	5	6
2. The health care you are receiving?	1	2	3	4	5	6
3. The amount of pain that you have?	1	2	3	4	5	6
4. The amount of energy you have for everyday activities?	1	2	3 .	4	5	6
5. Your physical independence?	1	2	3	4	5	6
6. The amount of control you have over your life?	1	2	3	4	5	6
7. Your potential to live a long time?	1	2	3	4	5	6
8. Your family's health?	1	2	3	4	5	6
9. Your children?	1	2	3	4	5	6
10. Your family's happiness?	1	2	3	4	5	6
11. Your relationship with your spouse/significant other?	1	2	3	4	5	6
12. Your level of intimacy?	1	2	3	4	5	6
13. Your friends?	1	2	3	4	5	o i
14. The emotional support you get from others?	1	2	3	4	5	6
15. Your ability to meet family responsibilities?	1	2	3	4	5	6
16. Your usefulness to others?	1	2	3	4	5	6

HOW SATISFIED ARE YOU WITH:	Vcry Dissausfied	Moderately Dissauisfied	Slightly Dissausfied	Slightly Satisfied	Moderately Satisfied	Very Sausfied
17. The amount of stress or worries in your life?	1	2	3	4	5	6
18. Your home?	1	2	3	4	5	6
19. Your neighborhood?	1	2	3	4	5	6
20. Your standard of living?	1	2	3	· 4	5	6
21. Your job?	1	2	3	4	5	6
22. Not having a job?	1	2	3	4	5	6
23. Your education?	1	2	3	4	5	6
24. Your financial independence?	1	2	3	4	5	6
25. Your leisure time activities?	1	2	3	4	5	6
26. Your ability to travel on vacations?	1	2	3	4	5	6
27. Your potential for a happy old age/retirement?	1	2	3	4	5	6
28. Your peace of mind?	1	2	3	4	5	6
29. Your personal faith in God?	1	2	3	4	5	6
30. Your achievement of personal goals?	1	2	3	4	5	6
31. Your happiness in general?	1	2	3	4	5	6
32. Your life in general?	1	2	3	4	5	6
33. Your personal appearance?	1	2	3	4	5	6
34. Yourself in general?	1	2	3	4	5	6

<u>Part II.</u> For each of the following, please choose the answer that best describes how important that area of life is to you. Please mark your answer by circling the number. There are no right or wrong answers.

но	OW IMPORTANT TO YOU IS:	Very Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Important	
1.	Your health?	1	2	3	4	5	6	
2.	Health care?	1	2	3	4	5	6	
3.	Being completely free of pain?	1	2	3	4	5	6	_
4.	Having enough energy for everyday activities?	1	2	3	4	5	6	_
5.	Your physical independence?	1	2	3.	4	5	6	_
6.	Having control over your life?	1	2	3	4	5	6	
7.	Living a long time?	1	2	3	4	5	6	
8.	Your family's health?	1	2	3	4	5	6	
9.	Your children?	1	2	3	4	5	6	
10.	Your family's happiness?	1	2	3	4	5	6	
11.	Your relationship with your spouse/significant other?	1	2	3	4	5	6	
12.	Your level of intimacy?	1	2	3	4	5	6	
13.	Your friends?	1	2	3	4	5	6	
14.	The emotional support you get from others?	1	2	3	4	5	6	
15.	Meeting family responsibilities?	1	2	3	4	5	6	
16.	Being useful to others?	1	2	3	4	5	6	
17.	Having a reasonable amount of stress or worries?	1	2	3	4	5	6	
18.	Your home?	1	2	.3	4	5	6	

HOW IMPORTANT TO YOU IS:	Very Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very limportant	
19. Your neighborhood?	1	2	3	4	5	6	
20. A good standard of living?	1	2	3	4	5	6	_
21. Your job?	1	2	3	4	5	6	
22. To have a job?	1	2	3	4	5	6	
23. Your education?	1	2	3	4	5	6	
24. Your financial independence?	1	2	3	4	5	6	
25. Leisure time activities?	1	2	3	4	5	6	
26. The ability to travel on vacations?	1	2	3	4	5	6	
27. Having a happy old age/retirement?	1	2	3	4	5	6	
28. Peace of mind?	1	2	3	4	5	6	
29. Your personal faith in God?	1	2	3	4	5	6	
30. Achieving your personal goals?	1	2	3	4	5	6	
31. Your happiness in general?	1	2	3	4	5	6	
32. Being satisfied with life?	1	2	3	4	5	6	
33. Your personal appearance?	1	2	3	4	5	6	
34. Are you to yourself?	1	2	3 .	. 4	5	6	_

SYMPTOM DISTRESS SCALE - PATIENT

Date			
Subject	ID	No.	
Intervie	w l	٠. ol	

SYMPTOMS - PATIENT

Each of the following cards lists 5 different numbered statements. Think about what each statement says, then place a circle around the one statement on each card that most closely indicates how you have been feeling lately. The statements on each card are ranked from 1 to 5, where Number One indicates no problems and Number Five indicates the maximum amount of problems. Numbers Two through Four indicate you feel somewhere in between these two extremes. Please circle one number on each card.

SYMPTOM DISTRESS SCALE - PATIENT

SYMPTOMS	DEGREE OF DISRESS		
Nausea (1)	I seldom feel any nausea at all	1 2 3 4 5	I suffer from nausea almost continually
Nausea (2)	When I do have nausea, it is very mild	1 2 3 4 5	When I have nausea, I am as sick as I could possibly be
Appetite	I have my normal appetite	1 2 3 4 5	I cannot stand the thought of food
Insomnia	I sleep as well as I always have	1 2 3 4 5	It is almost impossible for me to get a decent night's sleep
Pain (1)	I almost never have pain	1 2 3 4 5	I am in some degree of pain almost constantly
Pain (2)	When I do have pain, it is very mild	1 2 3 4 5	The pain I have is almost unbearable
Fatigue	I am usually not tired at all	1 2 3 4 5	Most of the time, I feel exhausted
Bowel	I have my normal bowel pattern	1 2 3 4 5	My present bowel pattern has changed drastically from what was normal for me
Concentration	I have my normal ability to concentrate	1 2 3 4 5	I just can't seem to concentrate at all
Appearance	My appearance has basically not changed	1 2 3 4 5	My appearance has changed drastically from what it was
Breathing	I usually breathe normally	1 2 3 4 5	I almost always have severe trouble with my breathing
Outlook	I am not fearful or worried	1 2 3 4 5	I am worried and scared about things
Cough	I seldom cough	1 2 3 4 5	I often have persistent and severe coughing spells

McCorkle, R. (1987). The measurement of symptom distress. Seminars in Oncology Nursing. 3(4), 248-256.

APPENDIX G SIGNIFICANT KEY OTHER QUESTIONNAIRE PACKET

A COMPARISON OF PERCEPTIONS OF CANCER PATIENTS AND SIGNIFICANT KEY OTHERS OF PATIENTS' QUALITY OF LIFE AND SYMPTOM DISTRESS

Date:_____

	Subject ID No Interview No
	SIGNIFICANT KEY OTHER BACKGROUND DATA SHEET
que	order for the researcher to evaluate the answers to the stionnaires, please complete the following background ormation:
1.	What is your sex? Male Female
2.	What is your age?
3.	To which ethnic group do you belong?
	a. Anglo-American b. Black-American c. Mexican-American d. Asian or Asian-American e. Other (specify)
4.	What is your religious preference?
•	a. Catholic b. Jewish c. Protestant d. Other (specify) e. No particular preference
5.	What is your present marital status?
	a. Single b. Married c. Separated d. Divorced e. Widow or widower

6.	What is your level of education?
	a. Elementary school b. Some High School c. High School Graduate d. Some College e. College Graduate f. Graduate Education
7.	What is the approximate income of your household?
8.	What is/was your occupation?
9.	What was your longest occupation?
10.	What is your relationship to the patient?
11.	Who is the most significant person giving <u>you</u> emotional support during this illness?
12.	What is this person's relationship to you?
	How long have you known this person?

Date		
Subje	ct I.D. No.	
Interv	icw No.	

Ferrans and Powers QUALITY OF LIFE INDEX CANCER VERSION SIGNIFICANT KEY OTHER FORM

<u>Part 1</u>. These questions are for you to evaluate the patient's quality of life. For each of the following, please choose the answer that best describes how satisfied you are with the area of the patient's life. Please mark your answer by circling the number. There are no right or wrong answers.

нс	OW SATISFIED ARE YOU WITH:	Very Dissausfied	Moderately Dissativfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Sausfied
1.	The patient's health?	1	2	3	4	5	6
2.	The health care the patient is receiving?	1	2	3	4	5	6
3.	The amount of pain that the patient has?	1	2	3	4	5	6
4.	The amount of energy the patient has for everyday activities?	1	2	3	4	5	6
5.	The patient's physical independence?	1	2	3	4	5	6
6.	The amount of control the patient has over life?	1	2	3	4	5	6
7.	The potential of the patient to live a long time?	1	2	3	4	5	6
8.	The health of the patient's family?	1	2	3	4	5	6
9.	The patient's children?	1	2	3	4	5	6
10.	The happiness of the patient's family?	1	2	3	4	5	6
11.	The patient's relationship with the spouse/significant other?	1	2	3	4	5	6
12.	The patient's level of intimacy?	1	2	3	4	5	6
13.	The patient's friends?	1	2	3	4	5	6
14.	The emotional support the patient gets from others?	1	2	3	4	5	6
15.	The patient's ability to meet family responsibilities?	1	2	3	4	5	6
16.	The patient's usefulness to others?	1	2	3	4	5	6

HOW SATISFIED ARE YOU WITH:	Very Dissalisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
17. The amount of stress or worries in the patient's life?	1	2	3	4	5	6
18. The patient's home?	1	2	3	4	5	6
19. The patient's neighborhood?	1	2	3	4	5	6
20. The patient's standard of living?	1	2	3	4	5	6
21. The patient's job?	1	2	3	4	5	6
22. The patient's not having a job?	1	2	3	4	5	6
23. The patient's education?	1	2	3	4	5	6
24. The patient's financial independence?	1	· 2	3	4	5	6
25. The patient's leisure time activities?	1	2	3	4	5	6
26. The patient's ability to travel on vacations?	1	2	3	4	5	6
27. The patient's potential for a happy old age/retirement?	1	2	3	4	5	6
28. The patient's peace of mind?	1	2	3	4	5	6
29. The patient's personal faith in God?	1	2	3	4	5	6
30. The patient's achievement of personal goals?	1	2	3	4	5	6
31. The patient's happiness in general?	1	2	3	4	5	6
32. The patient's life in general?	1	2	3	4	5	6
33. The patient's personal appearance?	1	2	3	4	5	6
34. The patient in general?	1	2	3	4	5	6

<u>Part II.</u> These questions are for you to evaluate the patient's quality of life. For each of the following, please choose the answer that best describes how important that area of the patient's life is to you. Please mark your answer by circling the number. There are no right or wrong answers.

HOW IMPORTANT TO YOU IS:	Vcry Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Important
1. The patient's health?	1	2	3	4	5	6
2. The health care the patient is receiving?	1	2	3	4	5	6
3. The patient being free of pain?	1	2	3	4.	5	6
4. The amount of energy the patient has for everyday activities?	1	2	3	4	5	6
5. The patient's physical independence?	1	2	3	4	5	6
6. The amount of control the patient has over life?	1	2	3	4	5	6
7. The potential of the patient to live a long time?	1	2	3	4	5	6
8. The health of the patient's family?	1	2	3	4	5	6
9. The patient's children?	1	2 .	3	4	5	6
10. The happiness of the patient's family?	1	2	3	4	5	6
11. The patient's relationship with the spouse/significant other?	1	2	3	4	5	6
12. The patient's level of intimacy?	1	2	3	4	5	6
13. The patient's friends?	1	2	3	4	5	6
14. The emotional support the patient gets from others?	1	2	3	4	5	6
15. The patient's ability to meeting family responsibilities?	1	2	3	4	5	6
16. The patient's usefulness to others?	1	2	3	4	5	6
17. The amount of stress or worries in the patient's life?	1	2	3	4	5	6
18. The patient's home?	1	2	3	4	5	6

HOW IMPORTANT TO YOU IS:	Very Unimportant	· Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Inportant
19. The patient's neighborhood?	1	2	3	4	5	6
20. The patient's standard of living?	1	2	3,	4	5	6
21. The patient's job?	1	2	3	4	5	6
22. The patient's not having a job?	1	2	3	4	5	6
23. The patient's education?	1	2	3	4	5	6
24. The patient's financial independence?	1	2	3	4	5	6
25. The patient's leisure time activities?	1	2	3	4	5	6
26. The patient's ability to travel on vacations?	1	2	3	4	5	6
27. The patient's potential for a happy old age/retirement?	1	2	3	4	5	6
28. The patient's peace of mind?	1	2	3	4	5	6
29. The patient's personal faith in God?	1	2	3	4	5	6
30. The patient's achievement of personal goals?	1	2	3	4	5	6
31. The patient's happiness in general?	1	2	3	4	5	6
32. The patient's life in general?	1	2	3	4	5	6
33. The patient's personal appearance?	1	2	3	4	5	6
34. The patient's sense of self-worth?	1	2	3	4	5	6

SYMPTOM DISTRESS SCALE - SIGNIFICANT KEY OTHER

Date			
Subject	ID	No.	
Intervie			

SYMPTOMS - SIGNIFICANT KEY OTHER

Each of the following cards list 5 different numbered statements. Think about what each statement says, then place a circle around the one statement on each card that most closely indicates how you feel the patient has been feeling lately. The statements on each card are ranked from 1 to 5, where Number One indicates no problems and Number Five indicates the maximum amount of problems. Numbers Two through Four indicate you feel somewhere in between these two extremes. Please circle one number on each card.

SYMPTOM DISTRESS SCALE - SIGNIFICANT KEY OTHER

SYMPTOMS	DEGREE OF DISTRESS		
Nausca (1)	The patient seldom feels any nausea at all	1 2 3 4 5	The patient suffers from nausea continually
Nausea (2)	When the patient has nausea, it is very mild	1 2 3 4 5	When the patient has nausea, the patient is as sick as could possibly be
Appetite	The patient has normal appetite	1 2 3 4 5	The patient cannot stand the thought of food
Insomnia	The patient sleeps as well as always	12345	It is almost impossible for the patient to get a decent night's sleep
Pain (1)	The patient almost never has pain	1 2 3 4 5	The patient is in some degree of pain almost constantly
Pain (2)	When the patient has pain, it is very mild	1 2 3 4 5	When the patient has pain, it is almost unbearable
Fatigue	The patient is usually not tired at all	1 2 3 4 5	Most of the time, the patient is exhausted
Bowel	The patient has a normal bowel pattern	1 2 3 4 5	The bowel pattern of the patient has changed drastically from normal
Concentration	The patient has normal ability to concentrate	1 2 3 4 5	The patient just can't seem to concentrate at all
Appearance	The appearance of the patient has basically not changed	1 2 3 4 5	The appearance of the patient has charged drastically from what it was
Breathing	The patient breathes normally	1 2 3 4 5	The patient always has severe trouble with breathing
Outlook	The patient is not fearful or worried	1 2 3 4 5	The patient is worried and scared about things
Cough	The patient seldom coughs	1 2 3 4 5	The patient has persistent and severe coughing spells

Adapted with permission: McCorkle, R. (1987). The measurement of symptom distress. <u>Seminars in Oncology Nursing</u>. <u>3</u>(4), 248-256.

APPENDIX H INSTRUMENT USE PERMISSION LETTERS

UIC

The University of Illinois at Chicago

Department of Medical-Surgical Nursing (M/C 802) College of Nursing 845 South Damen Avenue, 7th Floor Chicago, Illinois 60612 (312) 996-7900

March 19, 1991

Ms. Misty Porter 5810 Braesheather Houston, TX 77096

Dear Ms. Porter:

Thank you for your interest in the Quality of Life Index (QLI). I have enclosed the cancer version of the QLI and the computer program for calculating scores. I also have included a list of the weighted items that are used for each of four subscales: health and functioning, socioeconomic, psychological/spiritual, and family, as well as the computer commands used to calculate the subscale scores. The same steps are used to calculate subscale scores and overall scores.

There is no charge for use of the QLI. You have my permission to use the QLI for your study. In return, if you do use the QLI for your research and publish an article(s) reporting the findings, I would appreciate it very much if you would send me a copy. Such reports are extremely important to me.

If I can be of further assistance, please do not hesitate to contact me. I wish you much success with your research.

Sincerely,

Carol Estwing Ferrans, PhD, RN

Assistant Professor

UNIVERSITY of PENNSYLVANIA

School of Nursing Nursing Education Building Philadelphia, PA 19104-6096 215-898-8281

July 28, 1988

Misty Porter, RN., M.S. 5810 Braesheather Houston, TX 77096

Dear Ms. Porter:

You have my permission to use the Symptom Distress Scale for your research on lung cancer patients. I've enclosed a copy of the scale we are using in our present study and also another article you may not have.

Please don't hesitate to call me if you have further questions, 215/898-9134 (0) or 215/635-3384 (H). I'm sorry for the mix-up on the time of our call. The reference I think you should look at for gender differences is Marshall & Funch, Women & Health, 1986, 1(3/4), 67-82. Good Luck.

Sincerely,

Ruth McCorkle, Ph.D., F.A.A.N.

Ruth McCale

Professor

RM/kr Enclosure

APPENDIX I PATIENT BACKGROUND DATA SHEET--PART II

A COMPARISON OF PERCEPTIONS OF CANCER PATIENTS AND SIGNIFICANT KEY OTHERS OF PATIENTS' QUALITY OF LIFE AND SYMPTOM DISTRESS

Date:		
Subject	ID	No
Intervie	W N	10. <u> </u>

PART II PATIENT BACKGROUND DATA SHEET MEDICAL RECORD INFORMATION

1.	Type of Cancer:
2.	Site of Cancer:
3.	Stage of Cancer: (T, N, M)
4.	Performance Status: KPS points
	Credentials of Evaluator:
5.	Weight: Loss or Gain:
6.	Type of treatment A: Type of treatment B: Type of treatment C:
7.	Number of Treatment Cycles: A: B: C:
8.	Recurrence Date:
9.	Residual tumor:
10.	Initial Diagnosis Date:
11.	First Treatment Date:
12	Presence of other diseases:

APPENDIX J NOTIFICATION OF STUDY

Quality of Life and Symptom Distress Study

Texas Woman's University
Doctoral Candidate
Misty Porter, R. N. will be
conducting a nursing research
study with cancer patients
and their main support persons.

Participants will be asked to complete three sets of questions.

If interested in participating or to obtain more information please contact

the nurses of 4 West Cullen - 704-2270 the nurses of 4 East Cullen - 704-3300

Hematology/Oncology Clinic - 704-3961

Misty Porter at 704-3961

Thank You