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Fernsler, Jayne Irene

A COMPARISON OF PATIENT AND NURSE PERCEPTIONS OF PATIENTS' SELF-CARE DEFICITS ASSOCIATED WITH CANCER CHEMOTHERAPY

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A COMPARISON OF PATIENT AND NURSE PERCEPTIONS OF PATIENTS' SELF-CARE DEFICITS ASSOCIATED WITH CANCER CHEMOTHERAPY

by

JAYNE IRENE FERNSLER

A DISSERTATION

Submitted in partial fulfillment of the requirements for the degree of
Doctor of Science in Nursing in the School of Nursing
in The Graduate School, University of Alabama in Birmingham

BIRMINGHAM, ALABAMA

1983

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ABSTRACT OF DISSERTATION
GRADUATE SCHOOL, UNIVERSITY OF ALABAMA IN BIRMINGHAM

Degree Doctor of Science in Nursing Major Subject Nursing

Name of Candidate Jayne Irene Fernsler

Title A Comparison of Patient and Nurse Perceptions of Patients' Self-care Deficits Associated With Cancer Chemotherapy

Self-care concepts (Orem, 1980), perceptual theory of behavior (Combs & Snygg, 1959), and the assumptions of constructivist methodology (Magoon, 1977) were interrelated as a framework for this study to ascertain if there was a difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy. A comparative descriptive survey design was used to address the major problem and sub-problems that related to patient variables of gender, race, and age; medical variables of cancer site, number of chemotherapeutic agents, and number of chemotherapy treatments; and procedural variables of week of interview and interval between patient-nurse contact and nurse interview.

Using a convenience sample of 30 adult patients and 5 registered nurses in a hematology-oncology clinic, 30 paired open-ended interviews were conducted to elicit patients' and nurses' perceptions of patients' self-care deficits associated with cancer chemotherapy. Subjects' verbatim reports of self-care deficits were independently classified, by the investigator and three content experts, using the categories of universal self-care requisites. Null hypotheses regarding differences between patients' and nurses' perceptions were tested through use of the chi-square goodness-of-fit test.

Subjects reported 146 self-care deficits of which 122 were classified; 75 were from patients and 47 were from nurses. For overall number of classified responses, there was a significant difference between patient and nurse

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perceptions of patients' self-care deficits associated with cancer chemotherapy. Significant differences were also found for (a) the category of activity and rest, (b) female patients, (c) white patients, (d) patients who received two chemotherapeutic agents, (e) interviews conducted during the first week of the study, and (f) nurse interviews conducted within 1 hour of the patient-nurse contact.

The findings indicated that nurses did not perceive the extent to which patients required assistance to maintain a balance between activity and rest. For patients who received two drugs, the type of drugs in the regimen possibly contributed to the disparity between patients' and nurses' perceptions. Findings also indicated that nurses became sensitized to the research methodology.

Abstract Approved by:

Committee Chairman Mary Colette Smith, Ph.D.

Program Director

Dean of Graduate School

Date November 18, 1983

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CHAPTER I

INTRODUCTION

Cancer represents a significant problem for the health care system in America. In terms of numbers of individuals experiencing the disease, over five million Americans have a history of cancer and approximately 66 million Americans now living will eventually develop the disease. Of these 66 million people, approximately 855,000 will be diagnosed in 1983. In terms of deaths from cancer, approximately 440,000 Americans will die of the disease in 1983 (American Cancer Society, 1982). Cancer affects individuals of all ages, races, ethnic groups, and social strata (Vredevoe, Derdiarian, Sarna, Friel, & Shiplacoff, 1981).

Since the early 1900's cancer has evolved as a long-term chronic illness with acute exacerbations (Donovan & Pierce, 1976; Shehan, 1977). In the beginning of this century few cancer patients survived for 5 years after diagnosis. Now, because of advances in detection procedures and treatment modalities, 46% of patients with cancer will live for at least 5 years after diagnosis (American Cancer Society, 1982). Consequently, more cancer patients are in the health care system and undergoing procedures and treatments that have a profound effect on the patients themselves, the families, the community, and the health care system (Burkhalter & Donley, 1978; Donovan & Pierce, 1976; Kurtz & Owens, 1981; Vredevoe et al., 1981).

The human problems associated with cancer and its treatment are not adequately projected in statistical figures on prevalence, mortality, and survival.

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Both the disease and the treatment produce temporary and permanent biological, physiological, psychological and chemical changes in the human body which interfere with the individual's ability to function in society (Kurtz & Owens, 1981; Shehan, 1977). The negative feelings and meanings which society associates with cancer and the changes produced by the disease and its treatment are major factors contributing to individuals' feelings of fear, anxiety, loss of control, hopelessness, and loneliness (Hersh, 1982; Wortman & Dunkel-Schetter, 1979). Fear of loss is experienced by individuals in relation to life, body function, relationships with others, independence, physical attractiveness, and employment (Burkhalter & Donley, 1978; Donovan & Pierce, 1976; Hersh, 1982; Holland, 1980; Shehan, 1977; Vredevoe et al., 1981).

Although any one of the three major treatment modes for cancer—surgery, radiation therapy, and chemotherapy—represents a threat to individuals with cancer, chemotherapy presents a particular challenge for patients and families. Chemotherapy is the most recently developed and perhaps least understood of the three major treatment modalities. Research on systemic treatment of cancer with drugs was initiated immediately after World War II and rapidly accelerated in the form of clinical studies in the 1950's and 1960's (Burkhalter & Donley, 1978; Craytor, 1982; DeVita, 1982; Kurtz & Owens, 1981). Now approximately 50 drugs have been found effective against certain types of cancer (American Cancer Society, 1982), and between 200,000 and 400,000 patients a year are being treated with chemotherapy (DeVita, 1982) for one or more of the following purposes: to reduce tumor size before surgery, eliminate remaining cancer cells after surgery, treat tumors inaccessible to surgery, treat metastatic cancer, and treat localized cancer inadequately controlled by other treatment modalities (Burkhalter & Donley, 1978; DeVita, 1982; Vredevoe et al., 1981).

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The positive effects of chemotherapy, in terms of increased survival time and cure of certain types of cancer, are somewhat attenuated by the many stresses and demands which are imposed on patients and families by the treatment. Chemotherapy is frequently given over an extended period, and patients must have sustained motivation to continue the regimen, especially when the drugs produce side effects. Although the nature and intensity of side effects are a function of numerous factors, including the drug regimen, patient age and physical condition, the disease itself, and interaction with other treatments, common side effects are related to bone marrow suppression, immunosuppression, and gastrointestinal toxicity. Nearly every body organ or system may be affected by chemotherapy, including the kidneys, liver, heart, lungs, skin, genito-urinary system, and nervous system (Burkhalter & Donley, 1978; Vredevoe et al., 1981).

Stresses and demands experienced by patients undergoing cancer chemotherapy are not limited to physiological side effects. Whenever possible, treatment is provided on an outpatient basis; thus patients assume major responsibility for their own care. However, patients may not have adequate knowledge about chemotherapy to care appropriately for themselves (Dodd, 1981, 1982a, and Dodd & Mood, 1981). Clinic appointments may be viewed by patients as a continuous reminder of the disease. Also, patients who have no clinical evidence of disease may wonder if the therapy is necessary (Warren, 1979).

Nurses are responsible for administering chemotherapy, monitoring patients for side effects, teaching patients and families, and assisting patients to adjust their life styles as necessary during chemotherapy (Burkhalter & Donley, 1978; Vredevoe et al., 1981). To provide appropriate assistance, nurses need to assess patients' perceptions of the impact of chemotherapy on their lifestyles

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(Vredevoe et al., 1981). Patients' perceptions are influenced by patient conditioning factors (Orem, 1980), which include cultural background (Fitzgibbons, Cutler, & Cohen, 1971; Zola, 1966), age, personal characteristics, cancer site (Weisman & Worden, 1976), and values (Wagner & Bye, 1979). Consequently, patients undergoing cancer chemotherapy perceive a variety of physical, psychological, and social changes (Bean, Cooper, Alpert, & Kipnis, 1980; Cain & Henke, 1978; Davis, 1980; McCorkle & Young, 1978; Todres & Wojtiuk, 1979). Furthermore, patients perceive both positive and negative changes related to chemotherapy treatment (Cain & Henke, 1978; Todres & Wojtiuk, 1979).

Like patients, nurses perceive situations and events differently as a function of basic conditioning factors (Orem, 1980). Differences have been reported as a function of cultural background of the nurse, and age, diagnosis, and socioeconomic status of the patient (Davitz & Pendleton, 1969; Groszek, 1981; Larson, 1977). Also, differences between nurses' and patients' perceptions of cancer patients' affective states (Jennings & Muhlenkamp, 1981); physical, psychological, and psychosocial needs (Marecki, 1981); and educational needs (Lauer, Murphy, & Powers, 1982) have been reported.

If patients undergoing cancer chemotherapy and nurses who care for them perceive patients' needs differently, then nursing measures to assist patients in caring for themselves may be inappropriate and result in increased stress for patients during the treatment period. For instance, patients may perceive that they are incapable of performing the level of self-care that nurses expect of them in the clinic setting. Contrariwise, patients may perceive that they are capable of performing more self-care actions than nurses allow them to perform.

The concept of self-care with its inherent focus on perceptions and responsibilities of the individual appears frequently in the health-related

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literature (Freer, 1980; Green, 1979; Green, Werlin, Schauffler, & Avery, 1977; Knowles, 1977; Levin, 1977, 1978; Milio, 1977; Pratt, 1977). More specifically, the concept serves as a basis for organizing nursing practice, education, and research (Orem, 1979, 1980; Smith, 1977, 1979). Nursing is concerned with providing and managing health-related self-care. Nursing service is required by individuals who are unable to meet all of the requirements for health-related self-care (Orem, 1979, 1980).

Individuals receiving cancer chemotherapy on an outpatient basis are responsible for their own self-care. Moreover, chemotherapy produces bodily changes that alter individuals' requirements and abilities for self-care action. Nurses and patients may differ in their perceptions of patients' abilities in relation to the requirements for self-care action that arise during chemotherapy treatments.

Although nursing research has been done on the self-care of cancer patients, patients' perceptions of their needs associated with chemotherapy, and comparison of nurse and patient perceptions of cancer patients' educational needs, there are no published studies on the comparison of nurse and patient perceptions of patients' self-care deficits associated with cancer chemotherapy. Inasmuch as cancer constitutes a major health problem and chemotherapy is a common treatment mode that gives rise to self-care deficits that signal the need for nursing, a comparison of patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy would yield information of significance to nursing.

Statement of the Purpose

The purpose of this study was to ascertain if there is a difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy.

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Statement of the Problem

The problem statement developed for the study was: Is there a difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy?

Definition of Terms

Patient--refers to an adult outpatient with existing or potential self-care deficits arising during a course of cancer chemotherapy.

Nurse--refers to a registered nurse who provides care for outpatients receiving cancer chemotherapy in a hematology-oncology clinic on a selected day.

Perceptions--are defined as patients' and nurses' verbal expressions of their personal views during interview in a hematology-oncology clinic on a selected day.

Self-care deficits--refer to nurses' and patients' verbal responses to an open-ended interview question regarding the requirements for self-care actions, arising from the event of undergoing cancer chemotherapy, which patients are unable to meet adequately.

Cancer chemotherapy--refers to drug treatment regimens prescribed for outpatients with neoplastic disease in a selected hematology-oncology clinic.

Conceptual Framework

The conceptual framework for this study was derived from Orem's (1980) model of nursing, perceptual theory of behavior (Allport, 1955; Combs & Snygg, 1959), and constructivist methodology (Magoon, 1977). Self-care concepts, perceptions, and the assumptions of constructivist methodology are interrelated as a foundation for the study.

Orem's Self-care Model of Nursing

Orem's (1980) model was first published in 1958. Since that time it has been refined and further developed by Orem and a committee of her colleagues

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known as the Nursing Development Conference Group. The model is based on the premise that all persons require self-care in order to maintain health and life. When individuals are unable to meet all of the requirements for health-related self-care, nursing service is required. Nursing's concern, according to Orem (1980) is "the individual's need for self-care action and the provision and management of it on a continuous basis in order to sustain life and health, recover from disease or injury, and cope with their effects" (p. 6). The model further proposes a three-step nursing process for assessing the patient's need for nursing care, designing the nursing system, and implementing and controlling nursing actions.

The major constructs in Orem's model are self-care, self-care agency, self-care requisites, therapeutic self-care demand, self-care deficit, and nursing agency. The concepts are defined and their interrelatedness is presented in the following discussion.

Self-care. "Self-care is the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health, and well-being" (Orem, 1980, p. 35). Self-care is performed freely by individuals, is purposeful, and is the individual's contribution to his or her own existence and well-being. Self-care practices may be culturally or scientifically derived and are directed to the self or to conditions in the environment (Orem, 1979).

Self-care agency. Self-care agency is the ability of the individual to engage in the operations required for self-care. In estimative operations the individual investigates the situation and determines what actions should be taken. In productive operations the individual performs the actions necessary to bring about a change or to maintain a certain state.

The self-care agency of an individual can be described in terms of development, operability, and adequacy. The degree of development and

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operability depend upon basic conditioning factors including age, developmental state, health state, life experiences, culture, and genetic and constitutional factors, all of which influence the individual's knowledge, motivation, and skills. Adequacy of self-care agency depends upon the ability of the individual to engage in operations and the nature of the demand for self-care (Orem, 1980).

Self-care requisites. Orem (1980) defines self-care requisites as the purposes that are to be attained by individuals when they engage in self-care actions. She divides self-care requisites into three types—universal, developmental, and health deviation. As the name implies, the universal requisites are common to all human beings and are associated with life processes and maintenance of human integrity. Developmental requisites are associated with processes and events that occur during a particular life cycle. Health-deviation requisites are associated with genetic defects, illness, disease, injury, or other abnormal variations in human functioning (Orem, 1980).

Universal self-care requisites are purposive self-care actions that are required by all human beings to meet their basic needs. When universal self-care requisites are met by individuals, or by others, life processes are supported and human structure and functioning are maintained. Orem (1980) identifies the universal self-care requisites as:

1. Maintenance of sufficient intake of air;
2. Maintenance of sufficient intake of water;
3. Maintenance of sufficient intake of food;
4. Provision of care related to elimination and excrements;
5. Maintenance of balance between activity and rest;
6. Maintenance of balance between solitude and social interaction;
7. Prevention of hazards to human life, functioning, and well-being;
8. Promotion of human normalcy.

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The need for an individual to take action in regard to a requisite may manifest itself in a variety of ways. Dyspnea, hypoxia, shortness of breath, or alterations in the structure and/or function of the respiratory system may signal the need to attend to the intake of oxygen. Thirst, sweating, deprivation of water, and alterations in fluid and electrolyte balance signal the need to attend to water intake. Hunger, changes in appetite, changes in weight, or alterations in the structure and functioning of the gastrointestinal tract indicate a need to attend to food intake. General actions for meeting the requirements for air, food, and water include consuming a sufficient amount of each, preserving the anatomy and physiology of associated body parts, and enjoying the experiences of eating, drinking, and breathing.

In the category of elimination, alterations in structure and function of excretory organs, urges to eliminate and the substances eliminated produce the need for care. Urine, sweat, respiratory tract excretions, feces, menstrual flow in women, and seminal fluid of men are normal excrements (Orem, 1971). Actions which meet the requisite for elimination are (a) regulating internal and external conditions that influence elimination, (b) disposing of excrements, (c) protecting the structure and function of the excretory organs, (d) providing hygienic care to the body, and (e) maintaining sanitary conditions in the environment (Orem, 1980).

Demands on the balance between activity and rest may originate from both internal and external sources and may be physiological or psychological in nature. Changes requiring action to restore a balance between activity and rest include intense, prolonged emotional states, fatigue, weakness, and insomnia. General actions for restoring the balance are (a) selecting activities that maintain physical movement, affective responses, intellectual effort, and social interaction; (b) recognizing and acting on needs for activity and rest; and

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(c) developing a pattern of rest and activity that is personally and culturally appropriate.

Both solitude and social interaction are required for normal human development. Loneliness, excessive social stimuli, noisy and crowded environments, and problems in forming and maintaining interpersonal relationships signal the need for action to meet the requisite for solitude and social interaction. General actions for meeting the requisite are (a) developing and maintaining autonomy and social relationships; (b) fostering love, affection, and friendship while respecting the integrity of others; and (c) providing for social warmth and closeness.

Hazards to life and well-being include accidents, natural disasters, extremes in climate, substance abuse, overcrowded living conditions, scarce resources, and problems arising from faulty interpersonal relations. To prevent hazards, individuals need to be aware of what constitutes a threat to their lives and well-being and take action to prevent and control hazardous situations (Orem, 1971, 1980).

Demands related to normalcy arise from physical, psychological, and social situations. Changes in a person's usual height, weight, physical ability, mental ability, emotional state, and general pattern of structure and functioning signal the need to attend to the requirement for normalcy. Actions which meet this requisite are (a) developing and maintaining a realistic self-concept as well as human structure and functioning, (b) fostering human developments, and (c) recognizing and attending to deviations from one's normal structure and function (Orem, 1971, 1980).

The eight universal self-care requisites are interrelated. Requisites vary in nature and quantity from one individual to another depending upon age, sex,

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developmental state, health state, sociocultural orientation, and resources (Orem, 1980).

Therapeutic self-care demand. Therapeutic self-care demand is a collective term for the totality of actions to be taken or work to be done in order to meet the requirements for self-care. Individuals may be able to calculate their own therapeutic self-care demands. The experiencing of a therapeutic self-care demand by an individual activates the self-care agency (Orem, 1979).

Self-care deficit. Self-care deficit is a function of self-care agency and therapeutic self-care demand. A self-care deficit exists when self-care agency is qualitatively or quantitatively inadequate to meet the therapeutic self-care demand (Orem, 1979).

Nursing agency. Nursing agency is the specialized ability, acquired through educational preparation and experience, to provide assistance to other individuals in meeting their self-care demands. Methods of assisting may consist of one or all of the following: (a) acting or doing for, (b) teaching, (c) guiding, (d) supporting, (e) providing a developmental environment.

The end product of nursing agency is a nursing system which may be identified as either wholly compensatory, partly compensatory, or supportive-educative. A wholly compensatory system is required by the individual who is unable to engage in any self-care actions. The partly compensatory system allows both nurse and patient to perform care, the distribution of responsibility depending upon the patient's limitations. In the supportive-educative system the patient can, with assistance, meet the demand for self-care.

Interrelatedness of the constructs. The six major constructs in Orem's model interrelate to provide focus and boundaries for nursing. Self-care provides the basis for the model and thus partially defines each of the other five

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constructs. Therapeutic self-care demands activate self-care agency and self-care requisites provide purpose for the exercise of self-care agency. When self-care agency is inadequate to meet the therapeutic self-care demand, a self-care deficit exists. A self-care deficit signals the need to activate nursing agency. Nursing agency in turn assists with the achievement of self-care by decreasing therapeutic self-care demands and increasing self-care agency. When self-care agency is sufficient to meet self-care demands, nursing agency is no longer required by the individual. Basic conditioning factors may change the self-care requirement, bring new requirements for self-care, or influence the value of self-care agency.

Perceptual Theory of Behavior

Perceptual theory of behavior focuses on individuals and how they behave in response to the meanings they attach to situations and events. The perceptual approach is referred to as the phenomenological method and is used to describe experiences from the perspective of the perceiver. Individuals' perceptions of situations rather than the objective situations themselves determine behavior (Allport, 1955; Combs & Snygg, 1959). Perceptions then are "the personal meanings which govern behavior" (Combs & Snygg, 1959, p. 18).

The entire organization of an individual's perceptions constitute the perceptual field. More specifically, perceptual field means "the entire universe, including himself, as it is experienced by the individual at the instant of action" (Combs & Snygg, 1959, p. 20). The perceptual field then is the unique reality of the individual. The basic postulate of perceptual theory is that "all behavior, without exception, is completely determined by, and pertinent to, the perceptual field of the behaving organism" (Combs & Snygg, 1959, p. 20).

Characteristics of the perceptual field are fluidity, stability, directionality, and intensity (Combs & Snygg, 1979). Fluidity refers to continual

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change in response to new and different situations. It is the character of fluidity in the perceptual field that enables individuals to learn, reason, forget, remember, and create. Despite its changeability, the perceptual field is stable, or organized, and has direction, or constancy of organization and meaning. Organization and meaning are a function of the individual's need and the activity which one engages in to satisfy the need. Intensity of the perceptual field is a function of differentiation and levels of awareness. Differentiation is the process whereby phenomena emerge in the perceptual field and thus change perceptions.

Although the perceptual field of each individual is unique, commonalities in two or more individuals' perceptual fields may exist. The existence of perceptual commonalities, particularly within nations and cultures, makes communication possible. Through communication, individuals acquire understanding of each others' perceptual fields (Combs & Snygg, 1959).

Perceptions are a function of a number of variables within the individual and the setting (Combs & Snygg, 1959). The basic human need for adequacy and the individual's continuous effort to maintain the physical body and the perceived self in order to become more adequate determine what is meaningful to the individual. The physical organism, as the vehicle of perception, influences what can be perceived by an individual. More specifically, the organism requires sensory organs, an intact nervous system, and temporal and spatial awareness to perceive objects and events. Also, perceptions may be affected by physical characteristics such as height, weight, skin color, sex, and strength.

Time and opportunity influence perceptions in that length of time of exposure to an event and previous perceptions determine what is perceived by human beings. Individuals need opportunities to perceive and thus allow differentiations to emerge in the field. Goals and values also affect perceptions

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through influence on the meanings individuals ascribe to phenomena (Combs & Snygg, 1959).

Other variables of perception are the development of the phenomenal self and the effect of self. The phenomenal self consists of everything experienced by the individual as me, at a given instant. "It provides the central core around which all other perceptions are organized" (Combs & Snygg, 1959, p. 122). The phenomenal self accounts for the qualities of continuity and consistency in one's personality. Perceptions one holds about oneself are determined by the meanings one attaches to experiences. Because the meaning of the experience governs behavior, experiences which are perceived to be more closely related to the phenomenal self affect behavior more than do experiences which are not perceived to be closely related to the self. Threats to the phenomenal self may narrow the perceptual field and impair the efficiency of behavior.

An additional variable of perception is the availability of perceptions in the field. Because perceptions determine behavior, the repertoire of behaviors available to an individual is a function of the scope of the perceptual field. Restrictions on the perceptual field reduce the individual's ability to deal efficiently, effectively, and appropriately with life situations (Combs & Snygg, 1959).

In essence, according to the perceptual view, individuals are growing, changing, creative beings who have a basic need for adequacy and continually seek to become more adequate. People are purposive agents who engage in a continuous process of becoming.

Constructivist Approach

The constructivist approach is a descriptive data gathering method that focuses on how individuals construct and interpret their situations. Magoon (1977) documents the philosophical and historical bases of the approach and its

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use in sociological, psychological, anthropological, and educational research. Magoon suggests that the approach be used, instead of the traditional experimental approach, to study situations in which multiple interrelated factors influence outcomes.

A basic assumption of the constructivist approach is that subjects being studied are knowing beings whose knowledge and attendant referents and meanings must be considered by the researcher when interpreting behavior. Another assumption is that the locus of control over intelligent behavior resides within subjects themselves, although free and independent action is frequently limited by circumstances such as adherence to social norms. Because behavior is purposive, it can best be understood by studying the meanings and purposes constructed by subjects themselves. An additional assumption is that human beings have the capacity to develop knowledge, attend to meanings of complex communications, and assume and restructure complex social roles (Magoon, 1977).

Data obtained through the constructivist approach are used to describe precisely and validate patterns of interrelationships or behaviors. Construct validation is obtained from subjects' accounts of the meanings they attach to situations and events.

Interrelatedness of Orem's Model, Perceptual Theory, and Constructivist Methodology

Orem's self-care model, perceptual theory, and constructivist methodology are philosophically congruent. All three view persons as thinking, knowing, purposive agents who have the capacity for developing knowledge and dealing with complexity. In addition, all three approaches focus on individuals and their behaviors as a function of perceptions.

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Patients' and nurses' perceptions are influenced by the basic conditioning factors and the variables of perception. Therefore, both patients and nurses have unique perceptual fields. Within a nursing system, commonalities between patients' and nurses' perceptual fields make communication possible. Through continued communication, patients and nurses acquire an understanding of each others' perceptions.

Illness and its treatment may be perceived as a threat to the phenomenal self of both the patient and nurse and result in a narrowing of their perceptual fields. Thus the patient and nurse may not share a common perceptual field and may perceive the patient's self-care deficit differently. A constructivist approach is appropriate for studying patients' and nurses' perceptions of patients' self-care deficits because subjects' accounts of the self-care deficits are elicited with this method.

Significance of the Study

The legitimacy of nursing as a profession is based on the premise that nursing responds to the health needs of society. Cancer and its treatment represent a significant societal health problem to which nursing must respond. Answers to the problem question will contribute to nursing knowledge in the areas of practice, education, and research. Self-care deficits perceived by patients and nurses to arise during a course of chemotherapy, and verbally expressed by both patients and nurses, will be categorized, analyzed, and compared.

In practice, nurses will be provided with information which will help them to assist patients who are undergoing cancer chemotherapy in a manner that is consistent with patients' realities. Categories of perceived self-care deficits will be useful as a body of knowledge for determining when patients need assistance and how to assist them. Results of the comparison of nurse and

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patient perceptions will be useful for either instituting measures to validate nurses' perceptions with those of patients, or for maintaining the existing method of assessment.

The study results will be useful to nurse educators who teach nursing students how to care for cancer patients undergoing chemotherapy. Categories of self-care deficits will serve as a body of knowledge about the needs of individuals who are receiving chemotherapy. Results of the comparison of nurse and patient perceptions may indicate a need to teach students how to assess their own as well as patients' perceptions before planning methods of assistance.

In theory, the experiencing of a self-care deficit signals the need for nursing care. Analysis of the categories of self-care deficits perceived by cancer patients and nurses in a chemotherapy clinic will provide information which will enhance understanding of conditions and situations where nursing is required in society. Analysis of patient and nurse responses will provide information about self-care agency and nursing agency which will enhance understanding of the constructs.

Assumptions

The study was based on the following assumptions:

1. Self-care is valued by society.
2. Self-care is a requirement of every person.
3. Patients undergoing cancer chemotherapy experience self-care deficits.
4. Patients and nurses are able to perceive and express self-care deficits associated with cancer chemotherapy.
5. Patients' and nurses' verbal expressions are a function of their perceptions at the moment of expression.

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Hypothesis

The research hypothesis for this study was: There is a statistically significant difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy.

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CHAPTER 2

REVIEW OF RESEARCH

The review of research consisted of published studies and selected unpublished master's theses and doctoral dissertations related to patient perceptions of cancer and illness, nurse perceptions of patients, and self-care. The studies are discussed in that respective order.

Patient Perceptions of Cancer and Illness

Studies concerning patients' perceptions of illness in general were found in the psychosocial literature. Research regarding patients' perceptions of cancer and the cancer experience was reported primarily in the nursing and medical literature.

Zola (1966) analyzed patients' presenting symptoms from a sociocultural perspective. The study sample consisted of 63 Italian and 81 Irish patients who were new admissions to three large outpatient clinics of two urban teaching hospitals. Both cultural groups contained an almost equal distribution of men and women, and all subjects were white and able to speak English.

Data were gathered from the patient, the medical record, and the physician. Subjective data regarding patient or family responses to the patient's presenting symptoms were elicited by means of a focused open-ended interview which included checklists, forced-choice comparisons, and scales. Demographic information was obtained from patients by questionnaire method. Ratings on the seriousness and urgency of the patient's presenting symptoms were obtained from the examining physician.

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Comparison of the responses of Italian and Irish subjects revealed that the two groups differed in their perceptions of their overall health and in the number and nature of their presenting symptoms. The Irish more than the Italians tended to perceive themselves as having poor health, although the Italians presented significantly more symptoms in more areas of the body. The Irish group more than the Italian group localized their symptoms within a specific body part. Italians tended to generalize in this respect. Also, the Irish denied the symptom of pain more than did the Italians. These findings were supported by further analysis which compared a subsample of pairs that were matched for ethnicity, sex, diagnosis, duration of illness, seriousness rating, age, marital status, and educational level.

The researcher further examined the quantifiable data by performing correlational analysis. Ethnicity of the individual was the variable that consistently correlated most highly with symptom presentation. The researcher suggested that valuable information may be lost to health care professionals who are unaware of the sociocultural orientation of the patient.

Additional support for the influence of ethnicity on patients' perceptions was provided in a descriptive study by Fitzgibbons and associates (1971). The purpose of the study was to determine self-perceived treatment needs of psychiatric patients and to assess the relationships between stated needs and patient age, gender, and ethnic background. The study sample consisted of 118 female and 114 male patients of Caucasian, Puerto Rican, and black ethnic backgrounds who were admitted as inpatients or seen as outpatients in a metropolitan hospital that primarily served medically indigent patients. Twenty subjects were initial visitors to the walk-in clinic and the remaining 212 were consecutive inpatient admissions.

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A 93-item needs scale was utilized to collect the data. Items were developed by the investigators on the basis of needs identified during interviews with 40 psychiatric inpatients. The investigators identified seven major need areas: anxiety-depression, superego, psychosis, physical symptoms, economic-vocational, inadequacy, and marriage problems. The reporting of economic-vocational needs correlated significantly with patient age, sex, and ethnicity. Needs in this area were associated with a younger age group, female gender, and Puerto Rican ethnic background. Needs related to superego complaints were associated with female sexual status and Puerto Rican ethnicity. Physical symptom needs were significantly related to ethnicity. Caucasians reported less need than Negro and Puerto Rican subjects for psychiatric help to relieve physical symptoms.

The researchers concluded that the variables age, gender, and ethnic background were unrelated to overt psychiatric symptoms. However, these patient variables were significantly related to patients' perceived psychosocial needs. A limitation of the study was that the effect of previous illness or hospitalization on the subjects' perceptions of their needs was not controlled.

An extensive descriptive study of patient responses to the cancer experience during the first 100 days after diagnosis was reported by Weisman and Worden (1976). The researchers assessed 120 newly diagnosed cancer (breast, colon, lung, Hodgkin's disease, malignant melanoma) patients within 10 days of hospital admission and at 4 to 6 week intervals for 100 days. Three data gathering methods were used: psychological testing, semistructured interview, and rating scales. The Profile of Mood States (POMS), Minnesota Multiphasic Personality Inventory (MMPI), and Thematic Apperception Test (TAT) were administered during the initial assessment. A researcher developed interview and four rating scales to elicit information about coping, resolution, predominant

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concerns, and vulnerability were used initially and during each follow-up assessment.

Findings revealed that 10% of the patients denied having knowledge of their diagnosis, despite having been told. In addition, this group perceived no need for more information. Correlations among scores on the scales and selected patient characteristics revealed that patients who scored high on vulnerability tended to be passive, withdrawn, submissive, and pessimistic. Patients who scored low on vulnerability were open, accepting, and optimistic. Pessimistic patients scored high on emotional distress whereas optimistic patients scored low in this area.

Age and diagnosis also influenced patient responses. Older patients tended to talk openly about death. Younger patients' concerns centered around interruptions in their lives. In regard to diagnosis, patients with advanced lung cancer were the most distressed group as evidenced by their high scores on predominant concerns and vulnerability. Patients with colon cancer and malignant melanoma consistently scored lower on psychosocial concerns than the other diagnostic groups.

The researchers concluded that all cancer patients experience concerns related to their existence during the first 100 days following diagnosis. The quantity and nature of these concerns can be used to predict future distress and to plan appropriate interventions.

Numerous nursing studies have been conducted in relation to individuals' perceptions of cancer and aspects of the cancer experience. The remainder of this section of the review of research focuses on nursing studies.

Stillman (1977), Trotta (1980), and Hallal (1982) investigated women's beliefs about breast cancer and the practice of breast self-examination (BSE). Convenience samples were used and sample sizes were 122, 446, and 207

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respectively. Questionnaires based on variables identified in the Health Belief Model (HBM) were used to gather data.

Stillman (1977) analyzed her data using descriptive statistics and found that one-third of the women scored high on beliefs as well as practice of BSE. One-fourth of the women had never practiced BSE despite their beliefs that they were susceptible to breast cancer and could benefit from practicing BSE. Hallal (1982) computed point biserial correlations and found that being a practicer of BSE correlated significantly with high belief scores. Trotta (1980) used multiple regression analysis to determine which variables most accurately predicted BSE practice. She reported that the number of perceived barriers had the most significant negative influence on the practice of BSE. Interestingly, perceived seriousness and perceived susceptibility did not correlate with BSE behavior.

Trotta's findings may be explained by the nature of her questionnaire. Stillman and Hallal did not attempt to measure perceived seriousness and perceived barriers. All three researchers concluded that variables other than health beliefs may affect behavior.

In addition to health beliefs, Hallal (1982) studied the relationship of health locus of control and self concept to the practice of BSE. The Tennessee Self Concept Scale (TSCS) and the Multidimensional Health Locus of Control (MHLC) Scales were administered along with the Health Beliefs Instrument to 207 women. High scores on all subscales of the TSCS correlated significantly with being a practicer of BSE, although the same did not hold true for high scores on the Internal subscale of the MHLC Scales. Overall self-esteem was the best single predictor of BSE practice.

Self-concept, as measured by the TSCS, was also studied in a group of cancer patients (Jenkins, 1980). The study sample consisted of 23 women between the ages of 40 and 60 years who had had unilateral mastectomies 3

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to 48 months previous to the study. Scores on total self-concept and body image were compared with the scores of 23 women of similar age and socioeconomic status who did not have malignant disease or apparent alterations in body configuration. No significant differences in self-concept or body image were found between the two groups. The researcher suggested that self-concept may be stabilized and not susceptible to change in the age group represented in the sample.

Wagner and Bye (1979) compared body image and social activity in two groups of cancer patients, one with and one without chemotherapy-induced alopecia. A total of 77 patients participated in the study, 43 of whom had alopecia. All patients completed a Body Cathexis Scale, a Social Activity Scale, and a questionnaire related to drug side effects. Three-way analysis of variance comparing groups by performance level by gender revealed that patients with a decreased performance level scored lower on the Body Image Scale than patients with normal activity. Body image and social activity scores did not differ significantly between the groups with and without alopecia. Repeat analysis of the data using only subjects who reported that hair was important to them revealed significantly different body image scores for the two groups. The authors concluded that alopecia may be perceived as a threat to body image by only individuals who value their hair. The influence of age on patients' perceptions of alopecia was not addressed in this study.

Fitzpatrick, Donovan, and Johnston (1980) investigated perception of time in non-hospitalized, terminally ill cancer patients. Four groups of patients representing four different intervals from time of diagnosis were compared with one another and with a control group of 22 individuals without a health crisis who were matched on age, gender, and socioeconomic status. The total number of

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cancer patients was 22. The number in each group was not specified nor were the criteria for terminal status.

Four time questionnaires were used to collect data: The Time Reference Inventory (TRI), The Time Opinion Survey (TOS), The Time Metaphor Test, and the Money Game. The instruments assess, in respective order, relative direction of time orientation, attitudes about the passage of time, descriptions of time, and willingness to fantasize about the past and future.

The researchers reported statistically significant differences between the responses of the cancer group and the control group. Compared to the control group, the cancer group exhibited a shorter projection into the future, assigned more positive than negative statements to the past, and reported more spare time, more free time, more time pressure, and more interest in the historic past and future. There were few reported differences among the four cancer groups based on length of time since diagnosis.

A limitation of this study was the nature and size of the sample. The small size prohibited the investigators from analyzing differences among pairs matched on age, gender, and socioeconomic status. These variables may have influenced perception of time more than did length of time since diagnosis. A study of cancer patients who are not considered terminal and a study comparing time perceptions of terminal and nonterminal cancer patients may provide valuable comparisons.

Several nurse investigators systematically assessed cancer patients' views and concerns for the purpose of developing assessment tools (Cain & Henke, 1978; McCorkle & Young, 1978). Cain and Henke interviewed 50 randomly selected patients in a hematology-oncology clinic to identify patients' nonmedical needs. The sample represented a variety of diagnoses and treatment modalities although 96% of the patients had had or were currently undergoing

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chemotherapy. Length of time of illness varied greatly, from 2 months to 17 years, as did age which varied from 15 to 83 years. Men and women were approximately equally represented in the sample.

Analysis of the data revealed that 36% of the patients were unable to function as they did previously and 40% were unable to work. Seventy-six percent worried to some degree about dependency, 66% worried about the future, 44% worried about dying. Interestingly, the 56% who did not worry about dying were all over 50 years of age. More younger than older patients reported this concern. Regarding religious beliefs, 80% of the respondents found their beliefs helpful all of the time. Comparing present to preillness quality of life, 22% of the respondents reported that life was better and 50% reported that life was worse. Those patients who reported an improved quality of life were in a lower income bracket and had less formal education. Based on their findings, Cain and Henke developed a psychosocial assessment form. The tool was not described in the research report.

McCorkle and Young (1978) developed a symptom distress scale based on the concerns expressed by 26 cancer patients during interview. Approximately one-half of the interviewees were receiving chemotherapy and one-half radiation therapy. More than 80% of the chemotherapy patients identified physical symptoms as their major concerns. Ten major symptom areas identified in this preliminary study were nausea, mood, appetite, insomnia, pain, mobility, fatigue, bowel pattern, concentration, and appearance.

The distress scale consisted of each symptom typed on a 5 x 7 card with a scale of 1 to 5, 5 indicating the greatest symptom-distress and 1 indicating normalcy. Reliability of the scale was established using reliability coefficient alpha and the standardized item alpha.

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The cards were given one at a time to a total of 60 volunteer patients from radiation oncology and medical clinics of a university hospital. Of the 45 cancer patients who completed the scale, 28 (62.2%) expressed a high level of distress for one or more items, 13 of these expressing high distress for three or more items. Symptoms in order of frequency of expression were: bowel pattern, appearance, appetite, insomnia, fatigue, mood, mobility, pain, concentration, and nausea.

Of the five family members who also rated the items as they perceived the patient, three perceived that the patients had greater distress than the patients had reported. The researchers suggested that further studies be done to compare patient-family and nurse-patient scores on the Symptom Distress Scale.

Googe and Varricchio (1981) conducted a descriptive study to determine the home care needs of cancer patients and their families. Fifteen patients and families who were receiving home health care participated in the study. Family members were identified as spouse, child, sibling, niece, or friend.

A two-part questionnaire with multiple choice, listing, checking, and open-ended items was utilized to collect the data. Patients completed the first section which was designed to elicit their needs in regard to physical care and comfort. Family members completed the second section related to finances and altered family routine.

Problem areas as perceived by the patients were: eating, bathing, ambulation, special skills, equipment, transportation, pain management, sleep, elimination, and information about home care. Nursing functions listed by patients as most helpful were providing physical care such as bathing and giving back rubs, monitoring, and advising.

Problem areas identified by family members were (a) needing household help, (b) needing help with shopping, (c) needing more information about home

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care, (d) interruption in the family eating schedule, (e) loss of sleep, (f) unsatisfactory health, and (g) additional expenses. In regard to helpful nursing functions, family members listed giving moral support and decreasing the number of visits to the physician in addition to listing physical care.

Problems identified by the patients in this investigation were similar to those that were identified by patients in the McCorkle and Young (1978) study. The researchers in the current investigation did not specify the treatment modalities that patients were receiving.

Todres and Wojtiuk (1979) focused their descriptive study on patients' perceptions of chemotherapy and its impact on their lifestyles. A total of 67 patients from the case loads of two chemotherapists in the Toronto area were interviewed using fixed alternative and open-ended questions. Of the 67 participants, 60 were women and 50 had breast cancer. Subjects ranged in age from 21 to 84 and had been receiving chemotherapy for an average of 12 months. A variety of chemotherapeutic agents were represented in the sample.

Patients expressed a number of lifestyle changes associated with chemotherapy. Although 19 continued working despite negative side effects, 16 had to quit their jobs. A decrease in strength was reported by 64% and 53% stated that their ability to do household work was greatly reduced. Regarding mood and interaction with others, 45% reported increased moodiness, 28% reported negative effects in their sex lives, and 23% reported negative effects on family relationships.

Despite the negative lifestyle changes reported by patients, one-half stated that their overall health had improved. Some of the findings of this study are consistent with those of Cain and Henke (1978), although the previous researchers reported a higher percentage of patients who were unable to work and a lower percentage who expressed overall improvement. Differences in the

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interview formats and in the sample compositions may have accounted for these findings.

Nurse Perceptions of Patients

Davitz and Pendleton (1969) reported four descriptive studies which investigated nurses' inferences about patients' suffering. Variables identified in the studies were cultural group of the nurse, clinical specialty of the nurse, patient diagnosis, and patient characteristics: age, gender, and socioeconomic status. Four different researcher developed questionnaires were used to collect the data. Reliability of the instruments was established using the Spearman Brown Prophecy formula.

The first study was conducted to determine if nurses from different cultures and subcultures view patients' suffering differently. A total of 130 professional nurses (32 Korean, 30 Thai, 23 Puerto Rican, 20 American Negro, and 25 American white) completed the questionnaire. Data analysis revealed significant differences among the groups, between American Negro nurses and the other groups, and between Puerto Rican and white American nurses. Puerto Rican nurses had the highest total suffering scores and American Negro nurses the lowest.

Clinical specialty of the nurse was the variable explored in the second study. A total of 116 professional nurses, approximately evenly distributed among the four major specialty areas, participated in the study. All nurses were within the age range 20 to 59 and worked in urban hospitals. Analysis of the data revealed no statistically significant differences among the specialty groups in regard to inferences about patients' suffering.

In the third study, nurses' inferences of suffering were explored in relation to four diagnoses: depression, leukemia, diabetes, and second and third degree burns. The sample consisted of 94 professional nurses who were employed in a

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variety of specialty areas in urban hospitals. Nurses ranged in age from 20 to 69 and in work experience from less than 1 to 20 years. Results of the study indicated that nurses inferred the greatest amount of suffering with the diagnosis of burns and the least amount with diabetes mellitus. Suffering was rated equally for depression and leukemia.

The fourth study examined the influence of patient age, gender, and socioeconomic status on nurses' perceptions of suffering. Sixty-seven profesional nurses between the ages of 20 and 59 participated in the study. Patient age and socioeconomic status were found to significantly influence inferences of suffering. Nurses perceived younger patients as suffering more than older patients and lower and middle class patients as suffering more than upper class patients.

Based on the findings of their studies, Davitz and Pendleton (1969) suggested that nurses' inferences of suffering are influenced by the culture of the nurse and the diagnosis, age, and socioeconomic status of the patient. The researchers identified nurse age, experience, and socioeconomic background as variables for further research.

The influence of patient socioeconomic status and diagnosis on nurses' perceptions of patients was also studied in a factorial experiment by Larson (1977). Diagnosis was studied in terms of two dimensions, seriousness and social acceptability. The study sample consisted of 78 professional nurses from three community hospitals.

A questionnaire developed by the researcher was utilized to collect the data. The questionnaire consisted of a case description followed by seven-point semantic-differential scales. Patient descriptions differed among questionnaires on the variables socioeconomic status, social acceptability of illness, and seriousness of illness. Questionnaires were arranged in random order in a stack

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so that subjects were randomly assigned to one of eight experimental conditions, depending upon the case description.

Results of the study indicated that nurses' perceptions of patient characteristics were influenced by the socioeconomic status of the patient, the seriousness of the illness, and the social acceptability of the illness. Lower-class patients were attributed more negative characteristics in comparison to middle-class patients. Patients with less socially acceptable diagnoses and those with more serious diagnoses were likewise viewed more negatively than their counterparts.

The researcher cited two limitations of the study. Some of the significant findings may have occurred by chance because a large number of tests for significance were computed. Also, the instrument may not be reliable as the scales were not correlated with one another. A third limitation may be the researcher's operational definition of a less socially acceptable illness. Despite the limitations of this study, the findings supported those of Davitz and Pendleton (1969), that nurse perceptions are influenced by patient diagnosis and socioeconomic status.

The remainder of this section of the review of research is focused on nurses' perceptions related to cancer and cancer patients. In three studies, the investigators compared perceptions of cancer patients and nurses.

Groszek (1981) hypothesized that nurses would be more likely to identify a cancer patient as terminally ill than a patient who was suffering from another chronic disease. In her descriptive study a sample of 32 nurses were randomly selected from the staffing lists of the medical-surgical units of a large teaching hospital. The nurses represented a variety of ages, educational backgrounds, and work experience.

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A researcher developed questionnaire was used to gather the data. Nurses were offered forced choice responses to four pairs of vignettes relating to terminally ill patients, one with cancer and one with another disease. Validity and reliability of the instrument were not established. Data supported the hypothesis. Eighteen of the 32 nurses selected the cancer patient as terminally ill. Further analysis of the data revealed no relationship between the nurse variables of age, years of experience, and educational background and the findings of the study.

Although the sample size in this study was relatively small, the findings were in concurrence with those of Davitz and Pendleton (1969) and Larson (1977). Nurses' perceptions of patients are influenced by diagnosis.

Craytor, Brown, and Morrow (1978) and Johnson, Mosier, and Johnson (1982) reported that nurses do not perceive cancer patients as being different from typical patients. In three studies nurses' perceptions were measured by the "Port-a-Punch" version of the Activity Vector Analysis (AVA), a checklist of 81 adjectives which are used to describe human behavior. Adjectives are scored on four major vectors: aggressiveness, sociability, emotional control, and social adaptability. Analysis of the adjectives checked in all areas produces a personality description.

Nurses in all studies completed five separate cards, selecting adjectives which described their perceptions of the typical patient, cancer nurse, ideal patient, real self, and cancer patient. Pearson product-moment correlation coefficients were calculated between pairs of personality profiles.

Craytor and associates utilized the AVA in two different studies. The first was a descriptive study to explore nurses' readiness to become involved in cancer nursing. A random sample of 100 nurses representing four clinical areas and a variety of ages, work experiences, and educational backgrounds participated in

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the study. Nurses in this sample stereotyped cancer patients and typical patients similarly. Both were perceived differently than the ideal patient. Nurses also perceived themselves as somewhat different from the cancer nurse.

In the second study a quasi-experimental design was used to determine the effects of a 13-week educational program on nurses' attitudes toward cancer patients and nurses. Twelve staff nurses on a gynecological unit completed the AVA before and immediately after the educational intervention. On the first measurement nurses stereotyped cancer patients and typical patients similarly. On the second measurement there was less stereotyping of cancer patients and a more positive correlation between nurses' perceptions of themselves and the cancer nurse.

Johnson and associates replicated this study with a sample of 36 registered nurses who participated in a three-day cancer nursing course. Results of the study supported the previous finding that nurses do not perceive cancer patients and typical patients differently. However, pre- and post-course scores indicated no changes in the nurses' perceptions. The researchers suggested that the duration and nature of the course may have accounted for this finding. A longer course specifically designed to change nurses' perceptions might have produced different results.

Felton, Reed, and Perla (1981) also attempted to measure the effects of an educational intervention on nurses' and nursing students' attitudes toward cancer, cancer patients, and cancer nursing. They used The Cancer Attitude Survey (CAS), a questionnaire that is based on medical student and physician attitudes toward cancer. The study sample consisted of 397 registered nurses, baccalaureate nursing students, and licensed practical nurses who were enrolled in three different educational programs that had similar content. Subjects were asked to complete the questionnaire at the beginning of the course and 6

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months after completing the course. Only 148 post-course questionnaires were returned. No significant differences were found between pre- and post-course responses.

Several nurse researchers have compared cancer patient and nurse perceptions (Bryant & Gorton, 1982; Jennings & Muhlenkamp, 1981; Lauer et al., 1982; Marecki, 1981). Jennings and Muhlenkamp conducted a descriptive study to determine if there was a difference between care-givers' and patients' perceptions of patients' levels of anxiety, hostility, and depression. Wright's requirement of mourning was the conceptual framework for the study. The sample consisted of 28 patients with incurable disease and the care-givers (R.N.'s, L.P.N.'s, M.D.'s, nurses' aides, nursing students) from an inpatient cancer unit in a teaching hospital.

The Multiple Adjective Affect Check List (MAACL) and the Digit Span Backwards Test (DSBT) from the Wechsler-Bellevue Intelligence Scale were utilized to collect the data. The DSBT was administered only to patients, to measure denial. Care-givers completed the MAACL in 5 minutes to 2 hours after patients completed the instrument.

Analysis of the scores on the three affective states revealed that care-givers perceived patients as feeling significantly more anxious, hostile, and depressed than patients perceived themselves as feeling. Further, patient responses could not be attributed to denial. Variables that influenced care-givers' perceptions were length of time having worked on the unit and patient age.

In another study, a comparison was made between physicians' and nurses' charting of side effects of chemotherapy and patients' reports of side effects (Bryant & Gorton, 1982). The study was conducted following an educational program to assist chemotherapy nurses to recognize and record side effects.

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Thirty patients from a community oncology practice were asked, in an 18-item questionnaire, to report the side effects they were experiencing. Results of the study were reported in a table of frequencies. Patients reported each side effect more frequently than did physicians and nurses. For both groups, the most frequently reported side effect was nausea.

The study had several limitations. Different methods were used for measuring perceptions of the comparison groups. In addition, the investigators did not report an assessment of validity and reliability of the tools.

In their studies of cancer patients' needs, Marecki (1981) and Lauer and associates (1982) also found differences in the perceptions of cancer patients and nurses. Marecki compared the need priorities of adrenalectomy patients as perceived by 20 patients, 5 registered nurses, and 5 physicians from an outpatient clinic. All subjects rated a total of 34 physical, psychological, and psychosocial needs of adrenalectomy patients on a 5-point Likert-type scale. Content validity of the needs list was established by a panel of experts.

Analysis of the data revealed that all three study groups assigned different priority to patients' needs. Patients' overall ratings in each need area were higher than nurses' ratings, and highest priority was assigned to physical needs. Nurses assigned highest priority to psychological needs and second highest priority to physical needs. The data were not analyzed to test whether differences in ratings were statistically significant. The researchers discussed the findings in relation to provision of patient care.

Lauer and associates (1982) compared nurse and patient perceptions of patients' learning needs. The study sample consisted of 33 registered nurses and 27 patients from three medical-surgical units of a large urban hospital. All patients had received or were currently receiving radiation and/or chemotherapy.

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A structured interview technique utilizing a 2-part researcher developed questionnaire was used to collect the data. The first part of the questionnaire consisted of 36 informational items with a 5-point Likert-type scale. Subjects rated each item according to its importance to the cancer patients. The second part of the questionnaire consisted of six areas which subjects ranked according to degree of problem they represented for patients, patients' present knowledge, and patients' desire for information. Content validity of the instrument was established by three nurse experts. Reliability of the instrument was not established.

Analysis of the data revealed that nurses rated almost all informational items as significantly more important for the patients to know than did the patients. Regarding chemotherapy, nurses placed greater priority on learning the side effects of drugs than on learning the purpose of the treatment. Chemotherapy patients ranked these needs in the opposite order. Nurses identified dealing with feelings as the most important problem whereas patients identified reducing the side effects of treatment as the most important problem.

Selected patient and nurse variables were correlated with responses. Black patients assigned significantly less importance to informational items than did white patients. No significant differences were found on the basis of patient gender, nurse age, and nurse educational background. The researchers recognized that the study sample may have been too small and homogeneous to demonstrate the influence of these variables.

Self-care

Backscheider (1974) reported a systematic attempt to assess self-care agency, therapeutic self-care demand, and self-care deficits of outpatients with a diagnosis of diabetes mellitus. Therapeutic self-care demand was operationalized as the specific action responsibilities that were assigned to

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patients by virtue of their diabetic conditions and the concomitant therapeutic regimen. Assessment of therapeutic self-care demand was made using a list of physical, mental, motivational and emotional, and orientational capabilities that were essential for diabetic patients to engage in self-care. Although Backscheider's work was not reported as a formal controlled study, it represents an early attempt to objectively identify the self-care demand imposed on a group of individuals by virtue of their illness experience.

Two other attempts to measure objectively a self-care construct were reported by Kearney and Fleischer (1979) and Denyes (1980). Kearney and Fleischer viewed the construct "exercise of self-care agency" as a measurable dispositional trait of the person. Indicants of the construct were identified as "(a) an attitude of responsibility for self, (b) motivation to care for self, (c) the application of knowledge to self-care, (d) the valuing of health priorities, and (e) high self-esteem" (Kearney & Fleischer, 1979, p. 27). From these indicants, a 43-item 5-point Likert scale was developed. Content validity was established by a panel of experts. Construct validity was assessed by comparing responses on the instrument with scores obtained on Rotter's Internal-External Locus of Control Scale and Gough and Heilbrun's Adjective Check List. Test-retest and split-half procedures were used to assess reliability. The instrument was tested on a group of volunteers that consisted of 160 nursing students and 153 students enrolled in two university psychology courses. A positive correlation was found between exercise of self-care agency and (a) self-confidence, (b) achievement, (c) intraception, and (d) internal control. A negative correlation was found between exercise of self-care agency and abasement.

Denyes (1980) developed a 35-item 7-point Likert scale to measure self-care agency in adolescents. The instrument was administered in two different forms to 161 adolescents from grades 10, 11, and 12 of the public

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school system. Procedures for evaluating internal consistency and stability yielded data that established the reliability of the instrument. Results of factor analysis and correlation of instrument scores with measures of self-care practice and health status indicated that the instrument had construct validity. Components of self-care agency that were identified by factor analysis were "(a) ego strength and health decision-making capability, (b) relative valuing of health, (c) health knowledge and decision-making experience, (d) physical energy levels, (e) feelings, and (f) attention to health" (Denyes, 1980, p. 58).

Denyes suggested that her instrument could be useful in designing health care strategies for adolescents. The instrument was not designed to predict self-care behavior.

Horn and Swain (1977) developed an instrument to measure health status of patients as an indicator of quality of nursing care. Domains of health status were identified as physical and emotional status, knowledge, ability to perform self-care, and motivation. A total of 539 items were constructed utilizing the universal self-care and health deviation self-care categories developed by Orem (1971).

Content validity of the instrument was assessed by two panels of experts. All items were found to be valid and appropriate. Inter-observer reliability was at least .80 and was statistically significant at the .05 level for 280 items. Twenty-six items were not tested due to an insufficiency of patients for whom the measures were applicable. The criteria for reliability were not met for the remaining 108 items. The researchers suggested that the instrument could be used for research on alternative approaches to the delivery of nursing care and in quality assurance programs.

Unpublished accounts of studies to identify patients' self-care needs from the patients' perspective are found in several master's theses from the University

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of Southern Mississippi (Davis, 1980; Johnson, 1978; Kubricht, 1980; Rachel, 1978). In all four studies self-care needs were classified into the universal self-care categories identified by Orem (1971).

Johnson (1978) constructed a questionnaire to ascertain the perceived self-care needs of 30 hospitalized psychiatric patients who were ready for discharge. Validity and reliability of the instrument were not reported. Patients reported the greatest number of needs in the categories "being normal," "hazards to life and well-being," and "solitude and social interaction."

Rachel (1978) compared residents' and care-givers' perceptions of residents' therapeutic self-care demands. The sample consisted of 25 mildly and moderately retarded individuals and 17 care-givers in an institutional setting. An interview guide with 10 agree-disagree statements and one open-ended question was used to collect the data. Validity and reliability of the instrument were not established. Although there were some differences in the responses of residents and care-givers, analysis of the responses using the chi-square test revealed no significant difference between the groups.

Kubricht (1980) and Davis (1980) both used an open-ended interview technique to elicit the self-care needs of 30 cancer patients who were undergoing treatment. Kubricht's subjects had received at least one-half of a course of external radiation therapy. The patients expressed a total of 553 therapeutic self-care demands which they associated with radiation therapy. The greatest number of demands related to the universal self-care category of protection from hazards. All subjects expressed demands related to the categories of food and water, excrements, activity and rest, hazards, and normalcy.

Subjects in Davis's study were receiving chemotherapy on an outpatient basis and had been receiving treatment for at least 3 months. A total of 399

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health deviation requisites associated with chemotherapy were reported by patients. The greatest number of reported requisites related to activity and rest. All subjects expressed changes in this category. Additional requisites were reported, in descending order of frequency, in the categories of hazards, normalcy, food, solitude and social interaction, excrements, air, and water.

Results of the studies to identify patients' self-care needs support the premise that patients experience and are able to express demands that arise as a result of a health condition and the concomitant treatment regimen. A major limitation of the studies was the failure of the researchers to establish validity and reliability of the tools.

Dodd (1982b) reported a study to assess patients' self-care activities in relation to side effects of cancer chemotherapy. Assessment was made by administering a questionnaire to 48 outpatients who had been receiving chemotherapy for at least 2 weeks. Patients were asked to indicate, on a list of 44, the side effects they were experiencing and, on a 5-point scale, the severity of the side effects. In addition, patients were asked to report the actions they had taken to relieve the side effects, the effectiveness of each action, and the source of information for each action. Items in the questionnaire were assessed by two groups of experts and were found to be valid.

Results of the study indicated that patients identified an average of 3.13 side effects which were attributed to chemotherapy. The side effects most frequently identified were nausea and vomiting, hair loss, taste and smell change, and decreased appetite. An average of .81 self-care actions were taken and actions were most frequently taken for nausea and vomiting, constipation, and hair loss. Sources of information about self-care were cited, in order of frequency, as self, physician, family, and nurse.

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Summary

The review of research focused on patient perceptions of illness and cancer, nurse attitudes and perceptions, and self-care. Studies on patient perceptions revealed that patients may perceive a number of changes resulting from the cancer experience. Perceptions and expressions of these changes are influenced by multiple variables. Zola (1966) and Fitzgibbons and associates (1971) reported evidence that cultural background may influence an individual's perception of illness, pain and psychosocial needs. Weisman and Worden (1976) found that age, personal characteristics, and organ site influenced individuals' responses to cancer during the first 100 days after diagnosis.

Hallal (1982) suggested that self-esteem may influence a woman's practice of BSE, a cancer self-detection procedure. Jenkins (1980) found no difference in self-concept or body image in a group of women who had undergone a mastectomy as compared to women without a mastectomy. Wagner and Bye (1979) provided evidence that an individual's values influence perceptions of body changes associated with cancer therapy. Studies by Cain and Henke (1978), McCorkle and Young (1978), and Todres and Wojtiuk (1979) reported that patients undergoing cancer chemotherapy perceive physical, psychological, and psychosocial changes that influence their lives and daily activities.

The review of research on nurse perceptions revealed that nurses' perceptions of patients are influenced by the cultural background of the nurse, and the age, diagnosis, and socioeconomic status of the patient (Davitz & Pendleton, 1969; Groszek, 1981; Larson, 1977). Evidence that nurses do not perceive cancer patients and typical patients differently was provided by the studies of Craytor and associates (1978) and Johnson and associates (1982).

Studies comparing nurse and patient perceptions revealed that nurses and patients perceived the patients' situation differently (Bryant & Gorton, 1982;

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Jennings & Muhlenkamp, 1981; Lauer et al., 1982; Marecki, 1981). Differences in perception were found in relation to patients' side effects from chemotherapy, patients' affective states, and priorities of patients' physical, psychological, psychosocial, and educational needs.

Published studies in the area of self-care focused on researchers' efforts to objectively identify and measure self-care constructs (Backscheider, 1974; Denyes, 1980; Dodd, 1982b; Horn & Swain, 1977; Kearney & Fleischer, 1979). The unpublished theses of Davis (1980), Johnson (1978), Kubricht (1980), and Rachel (1978) were concerned with patients' subjective identification of their own self-care needs. The studies of Kubricht and Davis support the findings of previous studies that cancer patients perceive changes as a result of the treatment regimen.

In the review of research, several comparative studies pertained to nurse and patient perceptions of patients' needs. No comparative studies were found that pertained to nurse and patient perceptions of patients' self-care deficits associated with cancer chemotherapy.

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CHAPTER 3

METHODOLOGY

Purpose and Problems

A comparative descriptive survey research design was used to ascertain if there is a difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy. Sub-problems in relation to patient demographic, medical, and procedural variables were formulated in the null hypotheses statements.

Hypotheses

The overall research hypothesis for the study was that there is a difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy. To test the hypothesis statistically, the null form was used: There is no statistically significant difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy. Each category of self-care deficits was tested as contributing to the null hypothesis. Additional null hypotheses which were tested were:

1. For female patients there is no statistically significant difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy.
2. For male patients there is no statistically significant difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy.

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3. For black patients there is no statistically significant difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy.
4. For white patients there is no statistically significant difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy.
5. For patients whose ages are between 25 and 36 there is no statistically significant difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy.
6. For patients whose ages are between 43 and 54 there is no statistically significant difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy.
7. For patients whose ages are between 56 and 63 there is no statistically significant difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy.
8. For patients whose ages are between 67 and 79 there is no statistically significant difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy.
9. For patients with breast cancer there is no statistically significant difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy.
10. For patients with lung cancer there is no statistically significant difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy.
11. For patients with Hodgkin's disease, lymphoma, or leukemia there is no statistically significant difference between patient and nurse

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perceptions of patients' self-care deficits associated with cancer chemotherapy.

12. For patients who receive two chemotherapeutic agents there is no statistically significant difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy.
13. For patients who receive three or four chemotherapeutic agents there is no statistically significant difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy.
14. For patients who receive the third or fourth chemotherapy treatment of the regimen there is no statistically significant difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy.
15. For patients who receive the fifth or sixth chemotherapy treatment of the regimen there is no statistically significant difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy.
16. For patients who receive the seventh or more chemotherapy treatment of the regimen there is no statistically significant difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy.
17. For interviews conducted during the first week of the study there is no statistically significant difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy.

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18. For interviews conducted during the second week of the study there is no statistically significant difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy.
19. For interviews conducted during the third week of the study there is no statistically significant difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy.
20. For nurse interviews conducted within 1 hour after the patient-nurse contact there is no statistically significant difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy.
21. For nurse interviews conducted between 1 and 2 hours after the patient-nurse contact there is no statistically significant difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy.
22. For nurse interviews conducted between 2 and 4 hours after the patient-nurse contact there is no statistically significant difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy.
23. For nurse interviews conducted more than 4 hours after the patient-nurse contact there is no statistically significant difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy.

Scope and Limitations

The focus of this study was on patients who were receiving cancer chemotherapy and nurses who cared for them. The sample consisted of adult

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outpatients who were receiving cancer chemotherapy and nurses who provided care for them in a hematology-oncology clinic. Thirty patients were interviewed immediately before receiving at least the third chemotherapy treatment. This minimum treatment number was specified to allow time for the cumulative effects of the chemotherapy to develop. Each patient's assigned nurse was interviewed as soon as possible after the chemotherapy administration. Nurses were instructed to respond on the basis of patients' conditions at the time the patients received chemotherapy. These procedures were specified to control threats to internal validity related to contemporary history and maturation. To reduce the effect of the interaction of maturation and instrumentation on the internal validity of the study, nurses were also asked to avoid altering their usual routines and to refrain from discussing the study with others.

Limitations for the study were:

1. The study sample was a sample of convenience selected from a population of patients undergoing cancer chemotherapy at one particular clinic. To the extent that the sample was not representative of all cancer patients undergoing cancer chemotherapy, the study findings are not generalizable to the target population.
2. Data collection consisted of self-reports of perceptions. Therefore, study findings depended upon subjects' willingness to give valid and accurate responses to interview questions.
3. Nurses were interviewed more than one time, depending upon the number of patient subjects to whom they were assigned. Sensitization to the interview questions may have altered the nature and quantity of nurses' responses over time.
4. Unfamiliarity of the investigator to the patients may have influenced patients' responses to the interview question.

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Setting

The hematology-oncology clinic is part of a comprehensive cancer center that is affiliated with a large, urban university medical center. The clinic serves approximately 50 patients per day. The majority of patients are receiving or have completed a course of chemotherapy. A variety of cancer sites are represented by the patient population. In descending order of frequency, the most common sites are non-Hodgkin's lymphoma, breast, Hodgkin's disease, leukemia, lung, myeloma, and testicular.

The physical facilities of the clinic include a receptionist's area, a waiting area with 36 seats and a television, 6 examination rooms, a nurses' station, a treatment area, and a laboratory. The staff is composed of a receptionist, a licensed practical nurse, a registered dietitian, a pharmacist who prepares and dispenses all medications, registered nurses, physicians, and rehabilitation counselors. Each physician has an ongoing caseload and works in the clinic on the same day each week. On a given day one or two physicians and two or occasionally three registered nurses are working in the clinic at the same time.

Patients in the clinic are given scheduled appointment times. The usual procedure for patients undergoing chemotherapy includes, in the following order, (a) signing in with the receptionist, (b) going to the lab for blood tests, (c) having vital signs taken by a licensed practical nurse, (d) waiting to be called to an examination room, (e) waiting approximately one-half hour in the examination room, (f) being examined by a physician, (g) returning to the waiting area until called to the treatment area, and (h) receiving chemotherapy administered by a registered nurse. Patients may have several contacts with registered nurses during the clinic visit. The longest interval of contact between patients and nurses occurs in the treatment area, immediately before and during chemotherapy administration. For patients who receive two or more drugs

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intravenously, the length of the contact varies from 20 minutes to more than 1 hour. In addition, patients may be seen by a rehabilitation counselor or a registered dietitian during the waiting period. The total length of time of the clinic visit varies from 2 to 3 hours.

Subjects

Thirty selected patients and their assigned registered nurses participated in the study. The names of patients were selected, in the order in which they appeared, from the daily clinic list of patients who were scheduled to receive chemotherapy. Selected patients had to meet the following criteria to participate in the study: (a) be at least 18 years of age, (b) be receiving more than one chemotherapeutic agent, (c) be receiving at least the third chemotherapy treatment of the prescribed regimen, (d) have ability to understand questions and respond verbally, and (e) agree to participate in the study. The selection process continued until 30 patients were accrued into the study.

The names of the registered nurses who worked in the clinic were obtained from the head nurse. All registered nurses who would be administering chemotherapy to patient participants in the clinic during the period of data collection were asked to participate in the study. Each registered nurse participant had to be assigned to the care of the patient participant on the day of the interview and had to consent to participate in the study by completing a data form.

Method and Materials

Two open-ended, semi-structured interview schedules, constructed by the investigator, were used to obtain the data. Both interview schedules, one for nurses and one for patients, consisted of an introductory statement, an open-ended question, and neutral probes to clarify responses and to elicit further

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information. The introductory statement and open-ended question were derived from Orem's (1980) self-care model of nursing and were designed to elicit respondents' perceptions of patients' self-care deficits associated with cancer chemotherapy. Wording of the two interview schedules was identical with the exception that nurses were instructed to respond in relation to the patient's needs at the time of chemotherapy administration. Samples of the interview guides are included with the data collection tools in Appendix A.

An Interview Recording Sheet constructed by the investigator was used to record subjects' responses verbatim. Respondents were identified as patient or nurse by circling a 1 or 2, respectively, in the upper right-hand corner of the sheet. The sheet also included space for recording case number, subject code, paired respondent code, date of interview, time interview started and ended, total length of interview, time of contact with paired respondent, date interview transcribed, and comments or problems. A sample of the Interview Recording Sheet is included with the data collection tools (see Appendix A). Interviews were also tape recorded.

Content validity of the interview questions was assessed by submitting the interview schedules to four experts on Orem's model of nursing. The experts were asked to evaluate the wording and appropriateness of the questions for eliciting perceptions of self-care deficits in relation to the event of undergoing cancer chemotherapy. All four experts agreed that the introduction and open-ended questions were congruent with Orem's model. Suggested changes for simplifying the wording of the introduction to the questions and for altering the sequence of the questions were incorporated into the interview guides. A sample of the content validity procedure is presented in Appendix B.

The content experts had extensive experience with Orem's nursing model. All four experts were prepared at the master's level in nursing and two had

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doctoral degrees. The first expert was a member of Orem's original Nursing Development Conference Group and co-author of two editions of a book on the group's work in developing and refining the self-care model. The second expert developed, in consultation with Orem, an integrated nursing curriculum based on the model. In addition, she had worked with the model for 13 years, was teaching a course on nursing theories to graduate students in nursing, and was writing a dissertation research proposal using Orem's model as the theoretical framework for the study. The third expert was a clinical specialist in mental health nursing who had used the self-care model as the theoretical framework for her master's thesis. Additionally, she had had five years of experience in presenting classes and workshops on the model and was implementing the model as the basis for nursing practice in a rehabilitation hospital. The fourth expert had designed and was implementing a study based on Orem's model.

Stability in using the interview schedule was assessed throughout the study. A peer of the investigator randomly selected one out of every six interviews, listened to the tape, and checked the corresponding recording sheet to ascertain if questions were asked in the same manner, neutral probes were used in the same way, and responses were recorded verbatim. Use of the interview schedule was found to be stable, and recording of verbatim responses was accurate.

Interrater reliability in classifying responses was assessed by submitting responses to three experts on Orem's self-care model. Responses from each subject were transcribed from the Interview Recording Sheet onto a Content Analysis Sheet. This form also provided space for recording case number and subject code, for checking categories of universal self-care requisites, and for writing comments. A sample of the Content Analysis Sheet is included with the data collection tools (see Appendix A). Three content experts and the investigator independently classified each response by placing a check mark in

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one of the seven columns of universal self-care requisites or in the column labeled other. The criterion for inclusion of the response in one of the categories was that three of the four raters had to agree on the classification of the response.

Descriptions of the categories of universal self-care requisites were derived from the self-care model and were identified in the conceptual framework of this study. Copies of the descriptions were submitted for evaluation to each content expert before the study. All experts agreed that the categories were congruent with Orem's model. A sample of the descriptions is included with the content validity procedure (see Appendix B).

Two additional tools developed by the investigator were used to gather data on each subject. For each nurse participant, a Nurse Data Sheet was used to record code number, gender, race, nursing educational experience, years of nursing experience, years of cancer nursing experience, and length of work experience in the hematology-oncology clinic. A sample of the Nurse Data Sheet is included with the data collection tools (see Appendix A). For each patient participant, a Patient Data Sheet was used to record case number, subject code, gender, race, age, cancer diagnosis, chemotherapy regimen, and number of chemotherapy treatments received in the current regimen. A sample of the Patient Data Sheet is included with the data collection tools (see Appendix A).

Pilot Study

On July 1, 1983, a pilot study was conducted in the hematology-oncology clinic. Three paired patients and nurses were interviewed to evaluate the procedures and data collection tools and to assess interrater reliability in categorizing responses. Minor procedural problems were encountered in selecting subjects. Few patients whose names appeared on the daily schedule met the criteria for participation in the study. Several patients who were

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scheduled to receive chemotherapy were not treated because of fever or low blood counts. Therefore, names were selected in the order in which they appeared on the schedule rather than at random. No patients refused to participate in the study.

The data collection tools were found to be appropriate for eliciting responses and recording data. To increase the sensitivity of the open-ended interview question, the clarifying sentence, "By activities, I mean mental and emotional as well as physical activities," was added after the initial question (see Appendix A).

In relation to interrater reliability in classifying responses, 42.3% of responses from the pilot study were classified similarly by three of the four raters. Based upon this finding and upon recommendations from the raters, rules were formulated for classifying responses, case numbers and subject codes were omitted from the raters' data sheets, and copies of the interview question were included with the data sheets. Instructions and enclosures for the raters are presented in Appendix C.

Procedure for Data Collection

An Institutional Review Board application was completed and submitted for approval to the chairman of the Institutional Review Board of the University of Alabama in Birmingham. Subjects were deemed to be not at risk, and approval was granted to conduct the study. A letter of request for approval to implement the study was sent to the Director of the Comprehensive Cancer Center where the study was conducted, and an appointment was made to meet with the director to discuss the purpose and procedures of the study. The director granted approval to implement the study.

After the meeting with the director, an appointment was made to meet with the nursing personnel in the clinic to discuss the purpose and procedures of

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the study and to solicit their support and cooperation. All registered nurses who would be administering chemotherapy to patients in the clinic during the period of data collection, in July 1983, were asked to participate in the study. Nurses were informed that their participation would involve responding to an open-ended interview question about the needs of selected patients in the clinic who were undergoing chemotherapy and who were assigned to their care. In addition, nurses were told that they would be interviewed as soon as possible after they had contact with the patient, that each interview would last about 10 minutes, and that they would be interviewed a number of different times throughout the 3-week data collection period, depending upon the number of their assigned patients who were selected to participate in the study. Prospective nurse participants were informed that no discomforts or risks would be associated with the interview, that they would be able to withdraw from the interview at any time, that employment in the clinic would in no way depend upon participation in the study, that privacy and confidentiality would be maintained, and that no individual would be identified in any report about the study. Nurses were also informed that a tape recorder would be used, with their approval, that tapes would be identified by number, and that tapes would be erased at the end of the study. A Nurse Data Sheet (see Appendix A) was completed by each nurse who was eligible to participate in the study. Two other nurses who were not present at the meeting were approached individually afterward. Both nurses agreed to participate in the study.

Daily clinic lists were obtained from the bulletin board in the nurses' station. Each day, during the period of data collection, the names of all patients who were scheduled to receive chemotherapy were selected from the list of approximately 50 names appearing on the morning and afternoon schedules. Patient records were used to determine if selected patients met the specified

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criteria for participation in the study. If a selected patient did not meet the criteria, the next name was selected from the list. The selection process continued until 30 patients were accrued into the study. Patients were contacted in person in the clinic during a scheduled visit. The study was explained to them and they were asked to participate. A sample of the instructions is included with the data collection tools (see Appendix A). Prospective participants were informed that no discomforts or risks were associated with the interview, that they were free to withdraw from the interview at any time, that treatment in the clinic in no way depended upon participation in the study, that information obtained from the study would be kept in strict confidence, and that no individual would be identified in any report about the research. Potential participants were also informed that a tape recorder would be used, with their approval; that tapes would be identified by numbers; and that tapes would be erased at the end of the study.

Interviews were conducted separately in a private examination room in the clinic. Patients were interviewed after they were examined by the physician, before they received chemotherapy. The Open-Ended Patient Interview Guide (see Appendix A) was used for all interviews. Patient interviews lasted from 5 to 16 minutes. Nurses were interviewed as soon as possible after they had administered chemotherapy to the patients. Nurse interviews lasted from 2 to 6 minutes. Written notes were made on the Interview Recording Sheet (see Appendix A) during the interviews. Additional tape recorded data were transcribed from the tapes onto the Interview Recording Sheets as soon as possible after the interviews. Subjects' responses were recorded verbatim. At the completion of each interview, the participant was thanked for his or her cooperation. Medical and demographic data were obtained from the patient

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record and recorded on the Patient Data Sheet (see Appendix A) after the interview. Data collection and transcription was completed in three weeks.

Procedure for Data Analysis

The data received from each subject were transcribed from the Interview Recording Sheet onto the Content Analysis Sheet (see Appendix A). Four copies of each content analysis sheet, without the case number and subject code, were made for the raters. One copy was completed by the investigator and the other three were completed independently by three experts on Orem's self-care model. Each participant response on the Content Analysis Sheet was categorized by placing a check mark in one of the seven columns of universal self-care requisites or in the column labeled other. Data were given to the experts weekly for 3 weeks.

After the three content experts returned the completed forms, all classifications of responses were compiled on one set of forms. Only responses which were classified similarly by at least three of the four raters were included in the data analysis. The data were analyzed according to frequency and percentage of responses for nurses and for patients. The null hypothesis that there is no statistically significant difference between patient and nurse perceptions of patients' self-care deficits was tested through use of the chi-square goodness-of-fit test to test whether a significant difference existed between observed and expected numbers of patient and nurse responses in each category and in total number of responses. The level of significance was set at .05. Additional sub-hypotheses in relation to patient demographic, medical, and procedural variables were tested similarly. Calculations were done by computer using the Statistical Package for the Social Sciences (SPSS), a system of computer programs developed for analysis of social science data (Hull & Nie, 1981; Nie, Hull, Jenkins, Steinbrenner, & Bent, 1975).

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CHAPTER 4

PRESENTATION AND ANALYSIS OF DATA

Purpose

The purpose of this study was to ascertain if there is a difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy. Paired open-ended interviews were conducted to obtain the data.

Description of the Subjects

Five registered nurses and 30 patients in a hematology-oncology clinic participated in the study. All nurses were white females who had 3 to 13 years of nursing practice experience, 1 to 13 years of cancer nursing experience, and 2 months to 2 years of work experience in the clinic. One nurse worked in the clinic full time, two worked part time, and two were employed full-time in the Division of Hematology-Oncology but were assigned to the clinic part-time on a temporary or periodic basis. Four of the nurses had baccalaureate degrees in nursing and one had an associate degree in nursing. One nurse was interviewed nine times, one was interviewed eight times, two were interviewed six times, and one was interviewed one time.

The majority (60%) of patients in the study were white, female, and over 55 years of age. A classification of subjects by gender, race, and age category is presented in Table 1. The mean age was 57.36 years. There were no black male subjects in the study. White male patients represented 26.7% of the sample and black female patients represented 13.3% of the sample.

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Table 1

Classification of Subjects by Gender, Race, and Age Category

Gender and Race	Age Category 25-36	 43-54	 56-63	 67-79	Total
Female					
Black	2	1	0	1	4
White	1	1	9	7	18
Male					
Black	0	0	0	0	0
White	1	3	2	2	8
Total	4	5	11	10	30

All patients in the study had cancer and were being treated with chemotherapy. A classification of subjects by cancer site and number of chemotherapy treatments received in the current regimen is presented in Table 2. The majority (16) of patients had breast cancer. More than one half (19) of the patients had received between two and five treatments. Eight patients were receiving 2 chemotherapy drugs, 21 were receiving 3, and 1 was receiving 4 drugs. A list of the chemotherapeutic agents is included in Appendix D.

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Table 2

Classification of Subjects by Cancer Site and Number of Chemotherapy Treatments

	No. of Chemotherapy Treatments					
Cancer Site	3-4	5-6	7-8	9-10	11-12	Total
Breast	3	6	6	0	1	16
Lung	4	0	1	0	0	5
Lymphoma	3	1	0	0	0	4
Hodgkin's	0	1	0	1	0	2
Leukemia	1	0	0	0	1	2
Pancreas	0	0	0	1	0	1
Total	11	8	7	2	2	30

Four patients declined an invitation to participate in the study. Of these four, three patients initially agreed to participate but later changed their minds. The reasons given for declining were pain, fatigue, and concern about a grandchild in the waiting area.

Self-care Deficits Expressed by the Subjects

Self-care deficits were derived from patients' and nurses' verbal responses to an open-ended interview question. Responses were classified independently by the investigator and three experts on Orem's (1980) model of nursing. The universal self-care requisites were used as the classification scheme.

The number of responses for each interview ranged from zero to eight for patients and zero to five for nurses. The respective means were 2.97 and 1.90. One patient and three nurses reported no self-care deficits.

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A total of 146 responses was reviewed by the investigator and the three experts. Of the 146 responses, 122 (83.6%) were classified similarly by at least three of the four raters. The remaining 24 (16.4%) responses did not have sufficient interrater agreement on classification and were not included in further data analysis. These 14 patient and 10 nurse responses are presented in Appendix E.

The number and percentage of patient and nurse responses classified in each category is illustrated in Table 3. No responses were classified in the categories of air and excrements. The greatest number of responses (36) were classified in the category of activity and rest. There were more patient than nurse responses in three of the categories and more overall patient responses. The verbatim patient and nurse responses are presented in Appendix F.

Table 3

Number and Percentage of Patient and Nurse Responses by Category

Category of Universal Self-Care Requisite	Responses					
	Patient		Nurse		Total	
	No.	%	No.	%	No.	%
Activity and Rest	27	36.0	9	19.1	36	29.5
Food and Water	20	26.7	10	21.3	30	24.6
Normalcy	13	17.3	16	34.1	29	23.8
Hazards	9	12.0	5	10.6	14	11.5
Solitude and Social Interaction	6	8.0	7	14.9	13	10.6
Air	0	0	0	0	0	0
Excrements	0	0	0	0	0	0
Total	75	100.0	47	100.0	122	100.0

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Hypotheses Tests

The overall null hypothesis for the study was that there is no statistically significant difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy. Sub-hypotheses pertained to patient demographic, medical, and procedural variables. All hypotheses were tested using the chi-square goodness-of-fit test to ascertain whether statistically significant differences existed between the observed and expected numbers of responses for patients and nurses. The expected numbers were based on the null hypothesis that nurses and patients would have an equal proportion of responses. For each hypothesis the decision rule, reject Ho if chi-square ≥ 3.84, was based upon the chi-square distribution with one degree of freedom and a significance level of .05.

The numbers of patient and nurse responses, chi-square values, and levels of significance for each category are presented in Table 4. For responses in the category of activity and rest and for total number of responses, the chi-square values exceeded 3.84 and the levels of significance were less than .05. Therefore, the null hypothesis that there is no statistically significant difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy was rejected for responses in the category of activity and rest and for overall number of responses. In the remaining categories of food and water, normalcy, hazards, and solitude and social interaction, the chi-square values were less than 3.84. Therefore, the null hypotheses pertaining to these categories were retained.

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Table 4

Number of Patient and Nurse Responses,
Chi-square, and Level of Significance
by Category

Category of Universal Self-Care Requisite[a]	No. of Responses		Chi-square (df = 1)	Level of Significance
	Patient	Nurse		
Activity and Rest (17)	27	9	9.000	0.003
Food and Water (14)	20	10	3.333	0.068
Normalcy (11)	13	16	0.310	0.577
Hazards (8)	9	5	1.143	0.285
Solitude and Social Interaction (6)	6	7	0.077	0.782
Total	75	47	6.426	0.011

[a] Numbers in parentheses indicate the number of patient subjects whose responses were classified in the category.

Patient Demographic Variables

Sub-hypotheses were tested in the null form for sub-categories of patients based on the variables of gender, race, and age. The numbers of patient and nurse responses, chi-square values, and levels of significance for each demographic variable are presented in Table 5. For female patients and for white patients, the chi-square values exceeded 3.84 and the levels of significance were less than .05. Therefore, the null hypothesis that there is no statistically significant difference between patient and nurse perceptions associated with cancer chemotherapy was rejected for (a) female patients and (b) white patients. Chi-square values were less than 3.84 for male patients, for black patients, and for patients in each of the four age categories. Therefore, the null hypotheses pertaining to these variables were retained.

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Table 5

Number of Patient and Nurse Responses,
Chi-square, and Level of Significance
by Patient Demographic Variable

Patient Demographic Variable[a]	No. of Responses		Chi-square (*df* = 1)	Level of Significance
	Patient	Nurse		
Gender				
Female (22)	54	33	5.069	0.024
Male (8)	21	14	1.400	0.237
Race				
Black (4)	13	8	1.190	0.275
White (26)	62	39	5.238	0.022
Age Category				
25-36 (4)	14	7	2.333	0.127
43-54 (7)	17	8	3.240	0.072
56-63 (9)	19	13	1.125	0.289
67-79 (10)	25	19	0.818	0.366

[a] Numbers in parentheses indicate the number of patient subjects.

Medical Variables

Sub-hypotheses were tested in the null form for sub-categories of patients based on the medical variables of cancer site, number of chemotherapy drugs, and number of chemotherapy treatments. The numbers of patient and nurse responses, chi-square values, and levels of significance for each medical variable are presented in Table 6. For patients who received two chemotherapy drugs, the chi-square value exceeded 3.84 and the level of significance was less than .05. Therefore, the null hypothesis that for patients who received two chemotherapy drugs there is no statistically significant difference between patient and nurse perceptions associated with cancer chemotherapy was rejected. Chi-square values for the remaining medical variables were less than

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3.84. Therefore, the null hypotheses pertaining to three or four drugs, cancer site, and number of treatments were retained.

Table 6

Number of Patient and Nurse Responses,
Chi-square, and Level of Significance
by Medical Variable

Medical Variable[a]	No. of Responses Patient	No. of Responses Nurse	Chi-square (df = 1)	Level of Significance
Cancer Site				
Breast (16)	36	22	3.379	0.066
Lung (5)	16	10	1.385	0.239
Lymphoma, Leukemia, Hodgkin's (8)	20	14	1.059	0.303
Number of Drugs				
2 (8)	22	7	7.759	0.005
3-4 (22)	53	40	1.817	0.178
Number of Treatments				
3-4 (11)	25	18	1.140	0.286
5-6 (8)	21	13	1.882	0.170
7-12 (11)	29	16	3.756	0.053

[a] Numbers in parentheses indicate the number of patient subjects.

Procedural Variables

Sub-hypotheses related to week of interview and interval between patient-nurse contact and nurse interview were tested in the null form. The numbers of patient and nurse responses, chi-square values, and levels of significance for each procedural variable are presented in Table 7. For interviews conducted during the first week of the study and for the interval of 1 hour or less between patient-nurse contact and nurse interview, the chi-square values exceeded 3.84 and the levels of significance were less than .05. Therefore, the null hypothesis

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that there is no statistically significant difference between patient and nurse perceptions associated with cancer chemotherapy was rejected for (a) interviews conducted during the first week of the study and (b) nurse interviews conducted within 1 hour after the patient-nurse contact. Chi-square values for the remaining procedural variables were less than 3.84. Therefore, the null hypotheses pertaining to these variables were retained.

Table 7

Number of Patient and Nurse Responses,
Chi-square, and Level of Significance
by Procedural Variable

Procedural Variable[a]	No. of Responses		Chi-square ($\underline{df} = 1$)	Level of Significance
	Patient	Nurse		
Week of Interview				
First (11)	36	20	4.571	0.033
Second (10)	24	17	1.195	0.274
Third (9)	15	10	1.000	0.317
Interval Between Patient-Nurse Contact and Nurse Interview				
$\leq$ 1 hour (7)	22	9	5.452	0.020
$\bar{1}$-2 hours (9)	22	13	2.314	0.128
2-4 hours (10)	21	19	0.100	0.752
> 4 hours (4)	10	6	1.000	0.317

[a]Numbers in parentheses indicate the number of patient subjects.

Summary

Thirty paired open-ended interviews were conducted to elicit patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy. A total of 146 responses were reviewed, by the investigator and three experts, for classification in the categories of universal self-care requisites (Orem, 1980). Of the 146 responses, 122 (83.6%) were classified in the

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categories of activity and rest, food and water, normalcy, hazards, and solitude and social interaction. The remaining 24 (16.4%) responses did not have sufficient interrater agreement on classification.

The null hypothesis that there is no statistically significant difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy was rejected for the category of activity and rest, chi-square (1, n = 36) = 9.00, p = .003, and for total number of responses, chi-square (1, N = 122) = 6.426, p = .011. In relation to demographic variables, the null hypothesis was rejected for female patients, chi-square (1, n = 87) = 5.069, p = .024, and for white patients, chi-square (1, n = 101) = 5.238, p = .022. For medical variables, the null hypothesis pertaining to patients who received two chemotherapy drugs was rejected, chi-square (1, n = 29) = 7.759, p = .005. The null hypothesis was also rejected for the procedural variables (a) interviews conducted during the first week of the study, chi-square (1, n = 56) = 4.571, p = .033, and (b) nurse interviews conducted within 1 hour after the patient-nurse contact, chi-square (1, n = 31) = 5.452, p = .020.

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CHAPTER 5

SUMMARY, FINDINGS, DISCUSSION, CONCLUSIONS, AND RECOMMENDATIONS

Summary of the Study

The purpose of this study was to ascertain if there is a difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy. The conceptual framework for the study was derived from Orem's (1980) model of nursing, perceptual theory of behavior (Allport, 1955; Combs & Snygg, 1959), and constructivist methodology (Magoon, 1977). A comparative descriptive survey research design was used to address the problem: Is there a difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy? Additional sub-problems were related to patient variables of gender, race, and age category; medical variables of cancer site, number of chemotherapeutic agents, and number of chemotherapy treatments; and procedural variables of week of interview and interval between patient-nurse contact and nurse interview. The overall research hypothesis was that there is a difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy. Similar research sub-hypotheses were formulated for each patient, medical, and procedural variable.

Using a convenience sample of patients and nurses in a hematology-oncology clinic, 30 paired open-ended interviews were conducted to elicit patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy. Interviews were tape recorded and later transcribed. Subjects' verbatim reports of self-care deficits were independently classified, by the investigator and three experts, using the categories of universal self-care

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requisites described by Orem (1971; 1980). Frequency and percentage of patient and nurse responses were calculated for each category. The null hypotheses were through use of the chi-square goodness-of-fit test.

Findings

The findings of the study are listed in relation to the research problems. Findings were as follows:

1. The number and percentage of classified patient and nurse responses were: (a) there were 122 self-care deficits classified, 75 (61.5%) were reported by patients and 47 (38.5%) were reported by nurses; (b) the greatest number of self-care deficits, 36 of the 122 (29.5%), were classified in the category of activity and rest and of the 36 deficits, 27 (75%) were reported by patients and 9 (25%) were reported by nurses; (c) there were 30 (24.6%) self-care deficits classified in the category of food and water and of the 30 deficits, 20 (66.7%) were reported by patients and 10 (33.3%) were reported by nurses; (d) there were 29 (23.8%) self-care deficits classified in the category of normalcy and of the 29 deficits, 13 (44.8%) were reported by patients and 16 (55.2%) were reported by nurses; (e) there were 14 (11.5%) self-care deficits classified in the category of hazards and of the 14 deficits, 9 (64.3%) were reported by patients and 5 (35.7%) were reported by nurses; (f) there were 13 (10.6%) self-care deficits classified in the category of solitude and social interaction and of the 13, 6 (46.2%) were reported by patients and 7 (53.8%) were reported by nurses; (g) there were no self-care deficits classified in the categories of air and excrements.
2. The null hypothesis that there is no statistically significant difference between patient and nurse perceptions of patients' self-

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care deficits associated with cancer chemotherapy was (a) rejected for the category of activity and rest and for total number of responses; (b) retained for the categories of food and water, normalcy, hazards, and solitude and social interaction.

3. In relation to patient demographic variables, the null hypothesis was (a) rejected for female patients and for white patients; (b) retained for male patients, for black patients, and for patients in each of the four age categories.
4. For medical variables, the null hypothesis was (a) rejected for patients who received two chemotherapy drugs; (b) retained for patients who received three to four chemotherapy drugs, for patients with breast cancer, for patients with lung cancer, for patients with lymphoma, leukemia, or Hodgkin's disease, for patients who received 3 or 4 treatments, for patients who received 5 or 6 treatments and for patients who received 7 to 12 treatments.
5. The null hypothesis pertaining to procedural variables was (a) rejected for interviews conducted during the first week of the study and for nurse interviews conducted within 1 hour after the patient-nurse contact; (b) retained for interviews conducted during the second week, for interviews conducted during the third week, for nurse interviews conducted between 1 and 2 hours, between 2 and 4 hours, and more than 4 hours after the patient-nurse contact.
6. An additional finding was that there was not sufficient interrater agreement on classification of 24 (16.4%) of the 146 reported self-care deficits. Of these 24 deficits, 14 were reported by patients and 10 were reported by nurses.

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Discussion

Findings Related to the Review of Research

None of the studies cited in the review of research were concerned specifically with the self-care deficits of patients undergoing cancer chemotherapy. Nevertheless, similarities and differences can be seen between the findings of the present study and the findings of previous research. Kubricht (1980) and Davis (1980) respectively reported far greater numbers of therapeutic self-care demands and health deviation requisites than the number of self-care deficits found in the present study. Because different concepts were measured, these differences in findings were not surprising. Also, neither Kubricht nor Davis reported difficulty in attaining interrater agreement on the classification of subjects' responses. They did not fully describe their criteria and procedures for establishing interrater reliability. In the present study, 24 (16.4%) of subjects' responses did not have sufficient interrater agreement on classification and were not included in data analysis. This specification resulted in a decrease in the number of reported self-care deficits. Differences in criteria and procedures for assessing interrater reliability may have accounted for the dissimilarity between the results of the former studies and those of the present study.

In both the present study and in the Davis (1980) study, the greatest number of responses were related to the category of activity and rest. It is logical that the greatest number of deficits were found in the area where the requirements for self-care action were greatest. These findings are also congruent with the findings of Cain and Henke (1978) and Todres and Wojtiuk (1979) that a large percentage of patients undergoing cancer chemotherapy reported a decrease in strength, inability to function as previously, and inability to work.

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Kubricht (1980) reported the greatest number of therapeutic self-care demands in the category of protection from hazards. The incongruency between this finding and the finding of the present study may be explained by the fact that Kubricht's sample consisted of patients who were receiving radiation therapy for cancer.

For the remaining categories of universal self-care requisites, the order of frequency of responses differed between the present study and the Davis study. Also, Davis reported health deviation requisites for each category. In the present study there were no self-care deficits related to the categories of air and excrements. This finding may indicate that patients in the present study were able to meet adequately the requirements for self-care actions related to these areas. Davis separated the categories of food and water, whereas in the present study the categories were combined. This difference in the classification scheme may have accounted for differences in the ordering of the categories.

McCorkle and Young (1978), Googe and Varricchio (1981), and Dodd (1982b) respectively reported patients' symptoms, needs, and side effects of chemotherapy that parallel the self-care deficits reported by subjects in the present study. The finding that one-fourth of the self-care deficits were associated with food and water supports previous findings that many patients undergoing cancer chemotherapy experience problems with appetite and nausea and vomiting.

Dodd (1982b) found that patients receiving chemotherapy most frequently took self-care action in relation to the problems of nausea and vomiting, constipation, and hair loss. The findings of the present study that many deficits were found in the category of food and water and none were found in the category of excrements may be indicative of the effectiveness of self-care

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actions taken by patients. The findings may also reflect the relative severity of patient problems in these areas.

In the present study, a statistically significant difference was found between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy. Patients reported more self-care deficits than did nurses. This finding supports the finding of Bryant and Gorton (1982) that patients perceived more side effects of chemotherapy than did doctors and nurses. In that study, patients reported each side effect more frequently than did the caregivers, whereas in the present study patients reported more self-care deficits than nurses did for three of the five categories. However, Bryant and Gorton (1982) used two different methods for measuring perceptions of the comparison groups and did not test for statistical significance of the findings.

Jennings and Muhlenkamp (1981), Lauer and associates (1982), and Marecki (1981) presented evidence that there was a disparity between nurses' and cancer patients' perceptions of the patients' situations. The findings of this study are further evidence of the disparity between patients' and nurses' perceptions. Jennings and Muhlenkamp (1981) reported that care-givers perceived patients as feeling more anxious, hostile, and depressed than patients perceived themselves. In the present study, the two categories for which nurses reported more self-care deficits than did patients were categories that encompassed problems with affective states and social interaction. However, the differences between the numbers of patient and nurse responses in these categories were very small and were not statistically significant. Also, because the two studies were different in terms of sample, setting, and methodology, the findings must be compared with caution. In the Jennings and Muhlenkamp study, the sample consisted of hospitalized cancer patients who had incurable disease. The caregivers included physicians, L.P.N.'s, nursing students, and aides, in addition to R.N.'s. In

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the present study, curability of the disease was not a criterion for patient selection and the caregivers were exclusively R.N.'s.

Lauer and associates (1982) found that nurses identified dealing with feelings as the most important problem whereas patients assigned highest priority to reducing the side effects of chemotherapy. In the present study there were more patient than nurse responses in the categories which included problems with common physical side effects of chemotherapy and more nurse than patient responses in the categories which encompassed problems with feeling states. However, the difference between patient and nurse responses was statistically significant for only the category of activity and rest. In the present study, subjects were not asked to assign priority to self-care deficits. Also, the two studies differed in sample and methodology. In the previous study, a questionnaire was used to gather data from hospitalized patients.

The findings of the present study also appear to support Marecki's (1981) finding that patients assigned highest priority to physical needs and nurses assigned highest priority to psychosocial needs. Again, because the two studies were different in terms of sample and methodology, the comparison of findings must be viewed with caution.

In the review of research there was evidence that patients' perceptions of illness and nurses' perceptions of patients were influenced by certain patient variables. Patients' perceptions of illness were influenced by gender (Fitzgibbons et al., 1971), ethnic background (Fitzgibbons et al., 1971; Zola, 1966), and age (Fitzgibbons et al., 1971; Weisman & Worden, 1976). Nurses' perceptions of patients were influenced by patients' ages (Davitz & Pendleton, 1969). Therefore, in the present study it was hypothesized that patient and nurse perceptions of patients' self-care deficits would be different for sub-groups of patients based on these variables. Statistically significant differences were

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found for female patients and for white patients but not for male patients, black patients, and patients in each age category. These findings may be explained by the fact that the majority of subjects were white, female patients. Therefore, there were more self-care deficits for these sub-groups than for the other sub-groups. Because all nurses in the study were white and of the same gender, the difference in patients' and nurses' perceptions is not explained by racial and gender differences between patients and nurses.

In the present study, comparisons were limited to nurse and patient perceptions of self-care deficits. No comparisons were made between sub-groups of patients. Previous studies were concerned primarily with comparisons among patients. Therefore the findings of this study are not comparable to those of Davitz and Pendleton (1969), Fitzgibbons and associates (1971), Weisman & Worden (1976), and Zola (1966).

Davitz and Pendleton (1969), Groszek (1981), and Larson (1977), reported that nurses' perceptions of patients were influenced by patients' diagnoses. Weisman and Worden (1976) found that patients' responses to cancer were influenced by the location of the cancer. No studies were found in which comparisons between nurse and patient perceptions were made for sub-groups of patients based on medical variables. In the present study, hypotheses were tested for sub-groups of patients based on the variables of cancer site, number of chemotherapy drugs, and number of chemotherapy treatments. A statistically significant difference between patient and nurse perceptions was found for patients who received two chemotherapy drugs. Differences between nurse and patients' perceptions of self-care deficits were not statistically significant for patients who received three to four drugs or for any of the sub-groups of patients based on cancer site or number of treatments. Most of the patients who

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received two drugs were on a regimen of methotrexate and 5-fluorouracil. These drugs are less toxic than are a number of the other drugs. Therefore, the type of drugs in the regimen might have contributed to the disparity between patients' and nurses' perceptions. Nurses reported fewer self-care deficits than did patients, which suggests that, with a regimen of fewer, less toxic drugs, nurses did not perceive the extent to which patients required assistance with self-care.

Findings Related to Methodology and Procedure

A limitation of this study was that nurses were interviewed more than one time. Sensitization to the interview questions may have influenced the nature and quantity of nurses' responses over time. The finding that nurse and patient perceptions were significantly different for interviews conducted during the first but not the second or third weeks of the study suggests that nurses might have become sensitized to the research methodology.

To reduce the effects of history and maturation on subjects' responses, patients were interviewed immediately before receiving chemotherapy and nurses were interviewed as soon as possible after administering the chemotherapy. All except 2 of the 30 patients received chemotherapy within 1 hour after they were interviewed. The time interval between the patient-nurse contact and the nurse interview varied from less than 1 to more than 4 hours. Because it was logical that the length of this interval could influence nurses' recall and reporting of patients' self-care deficits, a null hypothesis was tested for each of four different intervals. The results indicated that the longer intervals did not negatively influence nurses' responses. There was a statistically significant difference between patient and nurse perceptions of patients' self-care deficits for nurse interviews conducted within 1 hour after the patient-nurse contact. However, there were not statistically significant differences for nurse interviews conducted at intervals greater than 1 hour.

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Several additional factors should be considered in the interpretation of the results of the hypotheses tests relating to patient, medical, and procedural variables. The interaction of two or more variables may have accounted for some of the findings. It was not possible to test statistically for interactions of variables because the data were nominal. Also, nurse variables may have accounted for some of the findings. Because the sample of nurses was small and homogeneous, there were no hypotheses developed for nurse variables.

Findings Related to the Conceptual Framework

According to Orem's (1980) model of nursing, a self-care deficit exists when an individual's self-care agency is inadequate to meet the therapeutic self-care demand. This condition signals the need for nursing service. In the present study, patients who were undergoing cancer chemotherapy and their nurses reported a variety of patient self-care deficits which they associated with the event of undergoing chemotherapy. The number and percentage of self-care deficits in each category suggest the areas where nursing service was required. The finding that nearly 30% of the deficits were related to the category of activity and rest suggests that a comparable amount of nursing care should be directed toward assisting patients to restore a balance between activity and rest. That no self-care deficits were reported in relation to the categories of air and excrements suggests that both nurses and patients perceived that patients were able to meet adequately the demands for self-care in these areas.

The finding that there was a statistically significant difference between patient and nurse perceptions of patients' self-care deficits in the category of activity and rest indicates that patients and nurses in this study did not similarly perceive patients' needs for assistance in this area. Patients reported more self-care deficits than did nurses, which suggests that nurses might not have been aware of the extent to which services were required by patients.

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Orem (1980) stated that the universal self-care requisites are interrelated. The finding that 16.4% of subjects' responses were not classified similarly by three of the four raters indicates that the categories of universal self-care requisites may not be mutually exclusive. Many of the responses that were not classified illustrate the nature of the interrelatedness of the categories. For example, nausea and vomiting were commonly reported by both patients and nurses. These problems clearly related to the category of food and water but the assistance required to alleviate the problems could have related to one of several categories depending upon the nature of the deficit.

In support of the assumptions of constructivist methodology, subjects in this study were able to construct their own responses. The verbatim reports of self-care deficits represented the perspectives of patients and nurses in relation to cancer chemotherapy. In relation to perceptual theory of behavior, the finding that there was a significant difference between patient and nurse perceptions of self-care deficits suggests that there was a lack of commonality between patients' and nurses' perceptual fields.

Implications

Because of the limited generalizability of the findings of this study, only tentative implications are presented. Nurses are responsible for assisting patients to cope with the side effects of chemotherapy and for helping patients to adjust their lifestyles as necessary during the treatment period. To provide appropriate assistance, nurses need to assess patients' perceptions of their self-care abilities in relation to the self-care demand associated with chemotherapy. If there is a disparity between patients' and nurses' perceptions, then nursing measures to assist patients may be inappropriate.

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Nurses may not be aware of the areas in which patients require assistance or the extent to which assistance is required. For example, in this study, nurses were not aware of the extent to which patients who received fewer, less toxic drugs required assistance or the extent to which patients in general required assistance to maintain a balance between activity and rest. Also, patients were generally more concerned than nurses about the physical side effects of their treatment, and nurses were more concerned than patients about patients' psychosocial problems. The potential incongruity between patients' and nurses' goals and actions is evident.

Clearly, measures for validating nurses' perceptions with those of patients are needed to reduce the disparity between patients' and nurses' perceptions. The categories of universal self-care requisites could be used as a nursing assessment guide for determining the areas in which patients require assistance and for planning the type of assistance. Analysis of the self-care deficits reported by patients in this study, particularly by the patients who received relatively less toxic drug regimens and by patients who experienced problems with activity and rest, could serve as a body of knowledge from which to design specific nursing technologies to assist patients with their self-care.

The finding in this study that nurses' and patients' perceptions became similar over time, suggests that the nurses changed their assessment practices when an element of accountability for assessment was temporarily introduced into the nursing system. To maintain the similarity between patients' and nurses' perceptions, a comparable, ongoing measure of accountability could be implemented in the clinical practice setting. Perhaps the solution to the problem of disparate perceptions between patients and nurses is less complex than the potential problems associated with ignoring the disparity.

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Conclusions

Conclusions of the study were derived from the findings. The conclusions were as follows:

1. Patients and nurses perceived multiple patient self-care deficits which they associated with cancer chemotherapy. Although significant differences were found for only overall number of responses and for the category of activity and rest, patients generally perceived more self-care deficits than did nurses in the categories that included problems with physical side effects of therapy, which included not only activity and rest but also food and water and protection from hazards. Nurses perceived slightly more patient self-care deficits than did patients in relation to the categories of normalcy and solitude and social interaction, which included psychosocial problems. Neither nurses nor patients perceived self-care deficits in relation to the categories of air and excrements.
2. In descending order of overall numbers of self-care deficits, the categories were (a) activity and rest, (b) food and water, (c) normalcy, (d) hazards, and (e) solitude and social interaction. These categories represented broad areas in which patients required assistance with self-care.
3. There was a significant difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy. Significant differences were found in the category of activity and rest and in overall number of responses. Differences in the remaining categories were not statistically significant. It was concluded that nurses did not perceive the extent to which patients required assistance to maintain a balance between activity and rest.

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4. For female patients and for white patients there were significant differences between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy. No significant differences were found for male patients, for black patients, and for patients in each of the four age categories. It was concluded that nurses perceived fewer self-care deficits than did white patients and female patients but had perceptions similar to black patients, male patients, and patients in each category. Because the study sample was small and homogeneous, these conclusions must be viewed with caution.

5. For patients who received two chemotherapy drugs there was a significant difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy. No significant differences were found for patients who received three or four chemotherapy drugs, for patients in any of the diagnostic categories, and for patients in any of the categories related to number of treatments. Because the majority of patients who received two drugs also received a relatively less toxic regimen than did patients who received three or four drugs, the finding was inconclusive. It is possible that the type of drugs in the regimen contributed to the disparity between patients' and nurses' perceptions. For patients who received two relatively less toxic drugs, nurses perceived fewer self-care deficits than did patients. There was no disparity between patients' and nurses' perceptions for patients who received three or four drugs, for patients in any of the diagnostic categories, and for patients in any of the number of treatment categories.

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6. For interviews conducted during the first week of the study and for nurse interviews conducted within 1 hour after the patient-nurse contact there was a significant difference between patients' and nurses' perceptions of patients' self-care deficits. There were no significant differences for interviews conducted during each of the other 2 weeks of the study and for nurse interviews conducted within each of the three intervals that were greater than 1 hour. It was concluded that nurses might have become sensitized to the research methodoiogy and that intervals of more than 1 hour did not negatively influence nurses' perceptions of patients' self-care deficits associated with cancer chemotherapy.
7. A number of reported self-care deficits were related to more than one category of universal self-care requisites, which suggests that the categories are not mutually exclusive.

Recommendations

Recommendations derived from the findings, discussion, and conclusions of this study are as follows:

1. This study should be replicated in several different geographical locations to test the validity of the findings.
2. A study should be conducted to ascertain the effectiveness of nursing technologies and patient self-care actions in meeting the therapeutic self-care demands related to cancer chemotherapy.
3. Studies should be conducted to ascertain the influence of basic conditioning factors on patients' and nurses' perceptions of patients' self-care deficits associated with cancer chemotherapy.

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4. A study should be conducted to ascertain if there is a difference between patients' and nurses' perceptions of priorities of patients' self-care deficits associated with cancer chemotherapy.
5. There should be further exploration of the components of self-care deficits associated with cancer chemotherapy.

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APPENDICES

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Appendix A

Data Collection Tools

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Open-Ended Patient Interview Guide

"Everyone needs to do things every day in order to live and to be as healthy as possible. People also need to do certain things to control the effect of illness on their lives. Medical treatment for an illness can affect your ability to do the things you normally do to take care of yourself."

"You have been receiving chemotherapy. What activities do you need help with to take care of yourself now that you are getting chemotherapy treatments? By activities I mean mental and emotional as well as physical."

If clarification is requested by respondent, repeat the question. If further clarification is requested, follow with: "Now that you are getting chemotherapy treatments, what activities do you need to do to take care of yourself, that you are not able to do by yourself?"

If a more detailed response is required, follow with:

"Could you please explain further?"

If clarification of an earlier response is needed, follow with:

"You mentioned__________________(use respondent's exact words).

"Could you explain that further?"

If interviewee responds and then pauses, wait several seconds and then follow with:

"Can you think of anything else?"

Conclude the interview with:

"Thank you very much for your time and consideration. I sincerely appreciate your participating in the study."

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Open-Ended Nurse Interview Guide

"Everyone needs to do things every day in order to live and to be as healthy as possible. People also need to do certain things to control the effect of illness on their lives. Medical treatment for an illness can affect one's ability to do the things one normally does to take care of oneself."

"________________ has been receiving chemotherapy. What activities does this patient need help with to take care of himself/herself now that he/she is getting chemotherapy treatments? By activities I mean mental and emotional as well as physical."

"Please respond in relation to the patient's needs at the time of chemotherapy administration."

If clarification is requested by respondent, repeat the question. If further clarification is requested, follow with: "Now that the patient is getting chemotherapy treatments, what activities does he/she need to do to take care of himself/herself, that he/she is not able to do by himself/herself?"

If a more detailed response is required, follow with:

"Could you please explain further?"

If clarification of an earlier response is needed, follow with:

"You mentioned__________________(use respondent's exact words).

"Could you explain that further?"

If interviewee responds and then pauses, wait several seconds and then follow with:

"Can you think of anything else?"

Conclude the interview with:

"Thank you very much for your time and consideration. I sincerely appreciate your participating in the study."

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Interview Recording Sheet

Respondent:

1 = patient

2 = nurse

Case Number___________________

(assign exact value in order of paired interview)

Subject Code___________________ Paired Respondent Code________

(Patient = chart number; nurse = assigned code number)

Date of Interview___________________

Time Interview Started___________________ A.M. P.M.

Time Interview Ended___________________ A.M. P.M.

Time of Contact with Paired Respondent___________________ A.M. P.M.

Date Interview Transcribed___________________

Total Length of Interview______________minutes.

Comments or Problems:____

____

____

____

Responses to Open-Ended Interview Question:

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Content Analysis Sheet

Case #____________________

Subject Code____________________

	Categories of Universal Self-Care Requisites								
Participant Responses	Air	Food & Water	Excrements	Activity/Rest	Solitude/Social	Hazards	Normalcy	Other	Comments/Problems

Nurse Data Sheet

1. Assigned Code Number________________.
2. Sex:

   1 = Female

   2 = Male
3. Race:

   1 = Black

   2 = White

   3 = Oriental

   4 = Hispanic

   5 = Other____________________.
4. Nursing Educational Preparation:

   (Circle all that apply)

   1 = A.D.N.

   2 = Diploma

   3 = B.S.N.

   4 = M.S.N.
5. Years of Nursing Practice Experience Since Graduation_______.
6. Years of Cancer Nursing Experience________.
7. Length of Time Worked in Hematology-Oncology Clinic_________.

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Patient Data Sheet

1. Case Number_________.

   (assign exact value in order of paired interview)

2. Subject Code_________.

   (chart number)

3. Sex:

   1 = Female

   2 = Male

4. Race:

   1 = Black

   2 = White

   3 = Oriental

   4 = Hispanic

   5 = Other___________.

5. Age_________.

6. Cancer Diagnosis_______________________________________.

7. Chemotherapy Regimen___________________________________

   ____.

8. Number of chemotherapy treatments received in current regimen

   _________.

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Instructions

Hello, I am Jayne Fernsler. I am a registered nurse and a doctoral student at the University of Alabama in Birmingham working on a doctoral degree in nursing.

I am conducting a study of nurses and patients in the hematology-oncology clinic to find out the things which persons who are receiving chemotherapy need help doing. Basically, I want to know what you need to do to take care of yourself, in relation to chemotherapy, that you are unable to do for yourself or need help doing now.

To obtain this information I would like to talk with you today. We will talk in a private room for about 15 minutes. With your approval I will use a tape recorder so that I will not miss anything you say. The tapes will be erased at the completion of the study. Your privacy will be maintained and all information you relate will be kept in strict confidence. If you agree to participate you will be identified by number rather than by name. No individual will be identified in any report about the research.

There are no risks involved with this interview. Your participation is voluntary and you are free to decline to participate at any time. Your refusal will in no way affect your treatment at the clinic. The information obtained from the interviews can be used to help nurses to understand what it is like to be a patient undergoing chemotherapy and to improve the quality of nursing care that is provided to patients.

Would you be interested in participating in the study? If so, may I have your consent to tape the interview?

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Appendix B

Content Validity Procedure

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656 Idlewild Circle
Birmingham, AL 35205
May 16, 1983

Dear________:

Thank you for agreeing to serve as a content expert for assessing the validity and appropriateness of tools which will be used in my dissertation research. The content validity procedure involves your checking yes or no responses to questions related to two open-ended interview guides and to descriptions of categories that will provide the classification scheme for content analysis. In addition, you will be asked to write any additional evaluative comments or suggestions you may have.

For your information, a brief overview of the study is presented. The purpose of the study is to ascertain if there is a difference between patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy. Thirty adult outpatients, who are receiving chemotherapy in a hematology-oncology clinic, and their assigned registered nurses will be interviewed separately. Open-ended interview questions will be used to elicit nurses' and patients' perceptions of self-care deficits, which are operationally defined as verbal expressions of what patients and nurses view as the requirements for self-care actions, arising from the event of undergoing cancer chemotherapy, which patients are unable to adequately meet.

Responses from each subject will be content analyzed and categorized according to Orem's universal self-care requisites. Experts will be asked to validate the categorization of responses, using the attached form. Frequencies and percentages of responses for patients and nurses in each category and in total number of responses will be calculated. The chi-square two-way test for association will be used to test for significant differences between frequencies of patient and nurse responses.

The content validity procedure is divided into three sections. The first section relates to the patient interview guide, the second section relates to the nurse interview guide, and the third section concerns descriptions of the universal self-care requisites. A copy of each tool is attached to the corresponding section of the content validity procedure.

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I am asking that you complete the procedure and return it to me in the enclosed envelope by May 30. Please feel free to call me collect at (205) 251-6430 if you have questions about the content validity procedure.

Thank you for assisting me in completing my dissertation research.

Sincerely,

Jayne Fernsler, R.N., M.S.

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Content Analysis Sheet

Case #__________________

Subject Code______________

	Categories of Universal Self-Care Requisites								
Participant Responses	Air	Food & Water	Excrements	Activity/Rest	Solitude/Social	Hazards	Normalcy	Other	Comments/Problems

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Content Validity Procedure

Section 1

Patient Open-Ended Interview Guide

1. Is the introduction to the open-ended question congruent with Orem's model?

   _____Yes _____No

2. Is the introduction appropriate for patients in a hematology-oncology clinic?

   _____Yes _____No

3. What further comments or suggestions do you have regarding the wording of the introduction?

   ____

   ____

   ____

   ____

4. Is the open-ended question congruent with Orem's model?

   _____Yes _____No

5. Is the open-ended question appropriate for eliciting patients' perceptions of self-care deficits associated with cancer chemotherapy?

   _____Yes _____No

6. What further comments or suggestions do you have regarding the wording of the open-ended question?

   ____

   ____

   ____

   ____

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Open-Ended Patient Interview Guide

"All persons need to do things every day, either to themselves or to control conditions in their surroundings, to maintain life and health, to grow and develop, and to have a sense of well-being. People may also need to do certain things to control or manage an illness and its effect on their lives. Peoples' health states affect their abilities to do these things. Medical treatment for an illness can also affect a person's ability to do the things one normally does."

"You have been receiving chemotherapy. What activities do you need to do to take care of yourself, that you are not able to do by yourself, now that you are getting chemotherapy treatments?"

If clarification is requested by respondent, repeat the question. If further clarification is requested, follow with:

"What activities do you need help with to take care of yourself now that you are getting chemotherapy treatments?"

If a more detailed response is required, follow with:

"Could you please explain further?"

If clarification of an earlier response is needed, follow with:

"You mentioned__________________(use respondent's exact words).

"Could you explain that further?"

If interviewee responds and then pauses, wait several seconds and then follow with:

"Can you think of anything else?"

Conclude the interview with:

"Thank you very much for your time and consideration. I sincerely appreciate your participating in the study."

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Content Validity Procedure

Section 2

Nurse Open-Ended Interview Guide

1. Is the introduction to the open-ended question congruent with Orem's model?

    _____Yes _____No

2. Is the introduction appropriate for nurses in a hematology-oncology clinic?

    _____Yes _____No

3. What further comments or suggestions do you have regarding the wording of the introduction?

    ____

    ____

    ____

    ____

4. Is the open-ended question congruent with Orem's model?

    _____Yes _____No

5. Is the open-ended question appropriate for eliciting nurses' perceptions of self-care deficits associated with cancer chemotherapy?

    _____Yes _____No

6. What further comments or suggestions do you have regarding the wording of the open-ended question?

    ____

    ____

    ____

    ____

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Open-Ended Nurse Interview Guide

"All persons need to do things every day, either to themselves or to control conditions in their surroundings, to maintain life and health, to grow and develop, and to have a sense of well-being. People may also need to do certain things to control or manage an illness and its effect on their lives. Peoples' health states affect their abilities to do these things. Medical treatment for an illness can also affect a person's ability to do the things one normally does."

"________________ has been receiving chemotherapy. What activities does this patient need to do to take care of herself/himself, that she/he is not able to do by herself/himself, now that she/he is getting chemotherapy treatments?"

"Please respond in relation to the patient's needs at the time of chemotherapy administration."

If clarification is requested by respondent, repeat the question. If further clarification is requested, follow with:

"What activities does the patient need help with to take care of himself/herself now that he/she is getting chemotherapy treatments?"

If a more detailed response is required, follow with:

"Could you please explain further?"

If clarification of an earlier response is needed, follow with:

"You mentioned__________________(use respondent's exact words).

"Could you explain that further?"

If interviewee responds and then pauses, wait several seconds and then follow with:

"Can you think of anything else?"

Conclude the interview with:

"Thank you very much for your time and consideration. I sincerely appreciate your participating in the study."

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Content Validity Procedure

Section 3

Descriptions of the Universal Self-Care Requisites

Are the descriptions of the categories congruent with Orem's model?

1. Air Yes____ No____

Comments/suggestions:____

____

2. Water Yes____ No____

Comments/suggestions:____

____

3. Food Yes____ No____

Comments/suggestions:____

____

4. Elimination Yes____ No____

Comments/suggestions:____

____

5. Activity and Rest Yes____ No____

Comments/suggestions:____

____

6. Solitude and social interaction Yes____ No____

Comments/suggestions:____

____

7. Hazards Yes____ No____

Comments/suggestions:____

____

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8. Normalcy Yes_____ No_____

Comments/suggestions:____

____

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Descriptions of the Universal Self-Care Requisites

From: Nursing: Concepts of Practice by D. Orem. Copyright 1971, 1980

by McGraw-Hill, Inc.

1. Maintenance of sufficient intake of air - provides individuals with material required for metabolism and energy production. Dyspnea, hypoxia, shortness of breath, and alterations in the structure and function of the respiratory system signal the need to attend to the intake of air. Actions for meeting the requirement for air include taking in a sufficient amount for normal functioning, adjusting air intake when internal and external factors affect the requirement, preserving the anatomy and physiology of the respiratory system, and enjoying the experience of breathing.

2. Maintenance of sufficient intake of water - provides individuals with material required for metabolism and energy production. Thirst, sweating, deprivation of water, and alterations in fluid and electrolyte balance signal the need to attend to water intake. Actions for meeting the requirement for water include taking in a sufficient amount for normal functioning, adjusting fluid intake when internal and external factors affect the requirement, preserving the anatomy and physiology of associated body parts, and enjoying the experience of drinking.

3. Maintenance of sufficient intake of food - provides individuals with material required for metabolism and energy production. Hunger, changes in appetite, changes in weight, and alterations in the structure and functioning of the gastrointestinal tract signal the need to attend to food intake. Actions for meeting the requirement for food include taking in a sufficient amount for normal functioning, adjusting food intake when internal and external factors affect the requirement, preserving the anatomy and physiology of the gastrointestinal tract, and enjoying the experience of eating.

4. Provision of care related to elimination and excrements - ensures the integrity of excretory processes and effective control of materials eliminated. Alterations in structure and function of the excretory organs, urges to eliminate, and the substances eliminated signal the need to attend to elimination. Urine, sweat, respiratory tract excretions, feces, menstrual flow, and seminal fluid are normal excrements. Actions for meeting the requirement for elimination include regulating internal and external conditions that influence elimination, disposing of excrements, protecting the structure and function of excretory organs, providing hygienic care to the body, and maintaining sanitary conditions in the environment.

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5. Maintenance of balance between activity and rest - controls voluntary energy expenditure, regulates environmental stimuli, and provides variety, outlets for interests and talents, and the sense of well-being that comes from both. Intense prolonged emotional states, fatigue, weakness, and insomnia signal the need for action to restore a balance between activity and rest. Actions for meeting the requirement for rest and activity include selecting activities that maintain physical movement, affective responses, intellectual effort, and social interaction; recognizing and acting on needs for activity and rest; and developing a pattern of rest and activity that is personally and culturally appropriate.

6. Maintenance of balance between solitude and social interaction - provides conditions essential for developmental processes in which knowledge is acquired, values and expectations are formed, and a measure of security and fulfillment is achieved. Solitude reduces the number of social stimuli and demands for social interaction and provides conditions conducive to reflection; social contacts provide opportunities for the interchange of ideas, acculturation, and socialization, and the achievement of the human potential. Social interaction is also essential for obtaining the material resources essential to life, growth, and development. Loneliness, excessive social stimuli, noisy and crowded environments, and problems in forming and maintaining interpersonal relationships signal the need for action to meet the requirement for solitude and social interaction. Actions for meeting the requirement include developing and maintaining autonomy and social relationships; fostering love, affection, and friendship while respecting the rights of others; and providing for social warmth and closeness.

7. Prevention of hazards to human life, functioning, and well-being - contributes to the maintenance of human integrity and to the effective promotion of human functioning and development. Hazards to life and well-being include accidents, natural disasters, extremes in climate, substance abuse, slum conditions, scarce resources, and problems arising from faulty interpersonal relations. Actions to prevent hazards include being aware of what constitutes a threat to life and well-being and taking specific action to prevent and control hazardous situations.

8. Promotion of human normalcy - promotes conditions that lead individuals to feeling and knowing their individuality and wholeness, to cognitional objectivity, and to freedom and responsibility as human beings. Changes in usual height, weight, physical ability, mental ability, emotional state, and general pattern of structure and functioning signal the need to attend to the requirement for normalcy. Actions which meet this requirement include developing and maintaining a realistic self-concept, maintaining and promoting human structure and functioning, fostering human developments, and recognizing and attending to deviations from one's normal structure and function.

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Appendix C

Instructions for the Raters

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656 Idlewild Circle
Apt. 10
Birmingham, AL 35205
July 30, 1983

Dear________:

Enclosed are the responses which were obtained during the second week of interviews. You should have 16 content analysis sheets along with a copy of the interview guide, descriptions of the universal self-care requisites, and rules for classifying responses. The rules were developed from the comments and suggestions of the validators in relation to data obtained from the pilot study.

When you have completed the classification process please mail the content analysis sheets to me in the enclosed envelope. Please do not hesitate to call me collect at (205) 251-6430 should you have any questions. Thank you again for helping me to complete my dissertation research.

Sincerely,

Jayne Fernsler, R.N., M.S.

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Open-Ended Patient Interview Guide

"Everyone needs to do things every day in order to live and to be as healthy as possible. People also need to do certain things to control the effect of illness on their lives. Medical treatment for an illness can affect your ability to do the things you normally do to take care of yourself."

"You have been receiving chemotherapy. What activities do you need help with to take care of yourself now that you are getting chemotherapy treatments? By activities I mean mental and emotional as well as physical."

If clarification is requested by respondent, repeat the question. If further clarification is requested, follow with: "Now that you are getting chemotherapy treatments, what activities do you need to do to take care of yourself, that you are not able to do by yourself?"

If a more detailed response is required, follow with:

"Could you please explain further?"

If clarification of an earlier response is needed, follow with:

"You mentioned________________(use respondent's exact words).

"Could you explain that further?"

If interviewee responds and then pauses, wait several seconds and then follow with:

"Can you think of anything else?"

Conclude the interview with:

"Thank you very much for your time and consideration. I sincerely appreciate your participating in the study."

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Descriptions of the Universal Self-Care Requisites

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1. Maintenance of sufficient intake of air - provides individuals with material required for metabolism and energy production. Dyspnea, hypoxia, shortness of breath, and alterations in the structure and function of the respiratory system signal the need to attend to the intake of air. Actions for meeting the requirement for air include taking in a sufficient amount for normal functioning, adjusting air intake when internal and external factors affect the requirement, preserving the anatomy and physiology of the respiratory system, and enjoying the experience of breathing.

2. Maintenance of sufficient intake of water - provides individuals with material required for metabolism and energy production. Thirst, sweating, deprivation of water, and alterations in fluid and electrolyte balance signal the need to attend to water intake. Actions for meeting the requirement for water include taking in a sufficient amount for normal functioning, adjusting fluid intake when internal and external factors affect the requirement, preserving the anatomy and physiology of associated body parts, and enjoying the experience of drinking.

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4. Provision of care related to elimination and excrements - ensures the integrity of excretory processes and effective control of materials eliminated. Alterations in structure and function of the excretory organs, urges to eliminate, and the substances eliminated signal the need to attend to elimination. Urine, sweat, respiratory tract excretions, feces, menstrual flow, and seminal fluid are normal excrements. Actions for meeting the requirement for elimination include regulating internal and external conditions that influence elimination, disposing of excrements, protecting the structure and function of excretory organs, providing hygienic care to the body, and maintaining sanitary conditions in the environment.

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5. Maintenance of balance between activity and rest - controls voluntary energy expenditure, regulates environmental stimuli, and provides variety, outlets for interests and talents, and the sense of well-being that comes from both. Intense prolonged emotional states, fatigue, weakness, and insomnia signal the need for action to restore a balance between activity and rest. Actions for meeting the requirement for rest and activity include selecting activities that maintain physical movement, affective responses, intellectual effort, and social interaction; recognizing and acting on needs for activity and rest; and developing a pattern of rest and activity that is personally and culturally appropriate.

6. Maintenance of balance between solitude and social interaction - provides conditions essential for developmental processes in which knowledge is acquired, values and expectations are formed, and a measure of security and fulfillment is achieved. Solitude reduces the number of social stimuli and demands for social interaction and provides conditions conducive to reflection; social contacts provide opportunities for the interchange of ideas, acculturation, and socialization, and the achievement of the human potential. Social interaction is also essential for obtaining the material resources essential to life, growth, and development. Loneliness, excessive social stimuli, noisy and crowded environments, and problems in forming and maintaining interpersonal relationships signal the need for action to meet the requirement for solitude and social interaction. Actions for meeting the requirement include developing and maintaining autonomy and social relationships; fostering love, affection, and friendship while respecting the rights of others; and providing for social warmth and closeness.

7. Prevention of hazards to human life, functioning, and well-being - contributes to the maintenance of human integrity and to the effective promotion of human functioning and development. Hazards to life and well-being include accidents, natural disasters, extremes in climate, substance abuse, slum conditions, scarce resources, and problems arising from faulty interpersonal relations. Actions to prevent hazards include being aware of what constitutes a threat to life and well-being and taking specific action to prevent and control hazardous situations.

8. Promotion of human normalcy - promotes conditions that lead individuals to feeling and knowing their individuality and wholeness, to cognitional objectivity, and to freedom and responsibility as human beings. Changes in usual height, weight, physical ability, mental ability, emotional state, and general pattern of structure and functioning signal the need to attend to the requirement for normalcy. Actions which meet this requirement include developing and maintaining a realistic self-concept, maintaining and promoting human structure and functioning, fostering human developments, and recognizing and attending to deviations from one's normal structure and function.

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Rules for Classifying Responses

1. In this study subjects are responding to an open-ended question in their own words. Responses are individuals' expressions of their perceptions of self-care deficits. Therefore self-care deficits may be expressed in a variety of ways. Deficits may be implied or explicit in the responses.

2. All patients in the study are receiving chemotherapy for a health deviation. Therefore, some of the actions or activities may be stated in terms of health deviation self-care. In this study we are looking at the inability or difficulty in meeting the universal self-care requisites as adjusted to the treatment for a health deviation. Therefore we will try to classify each response into the best fitting universal self-care category. Please feel free to comment about your selection of a category.

3. Assume that activities done by someone else are done for the subject. The activity done by another may not be health related self-care but may be related to the subject's need to meet a universal self-care requisite. Classify the response according to that requisite.

4. General actions taken in relation to scarce resources are listed in the category of prevention of hazards. Classify them as such unless the action is specifically related to meeting another universal self-care requisite such as food.

5. Please check only one column for each response and feel free to comment regarding any difficulty in making the decision. Your comments are very helpful.

6. If a response does not fit any of the seven categories, check the column labeled other and write a comment.

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Appendix D

Chemotherapeutic Agents

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Chemotherapeutic Agents Received by Patients

Chemotherapy Regimen	Number of Patients
Cyclophosphamide, Doxorubicin hydrochloride, 5-Fluorouracil	8
Cyclophosphamide, Doxorubicin hydrochloride, Vincristine sulfate	7
Methotrexate, 5-Fluorouracil	5
Carmustine, Cyclophosphamide, Vincristine sulfate	2
Cyclophosphamide, Methotrexate, 5-Fluorouracil	2
Carmustine, Cyclophosphamide, Vinblastine sulfate	1
Cyclophosphamide, Doxorubicin hydrochloride, Vincristine sulfate, Bleomycin sulfate	1
Doxorubicin hydrochloride, Mitomycin -C, 5-Fluorouracil	1
Cyclophosphamide, Doxorubicin hydrochloride	1
Cyclophosphamide, Vincristine sulfate	1
Vincristine sulfate, Methotrexate	1

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Appendix E

Responses with Insufficient Interrater Agreement

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Patient Responses for Which Interrater Agreement Not Reached

Down to 2 days and that's a big jump and a move in my life right there because I'm used to working every day and I can't do that now.

I try to do things but then I get sick and hot—sort of nauseated—you just feel faint.

I don't like it—the side effects are bad, just a weakness, loss of appetite which I say I enjoy cooking and I like to eat but I know it's necessary.

We stayed with some people and I felt sick about it but I just couldn't eat—I know them people thought I was probably picky and stuff.

I don't go out and do things as much as I used to—just don't have the interest.

I don't like taking the leucovorin—it does taste bad—that to me is the worst part of the chemotherapy—I hate it—I beg my husband please don't make me take it but he makes me anyway and I don't mean that—I don't mean for him not [to] but I do fuss a lot.

I don't want to put my teeth in there as long as it hurts—they've been out a week—my talking, I feel funny mashing my chin together and I don't like that but that's not the big problem cause I know that's going to heal.

After you take chemotherapy there was about 5 days that I would be well, drugged so to speak, because I have to take the drugs to keep me from being nauseated and physically I could not operate.

My daughter won't let me go home because she sleeps with me now so's if I get sick during the night she'll know it—that's the reason she don't want me to go home.

The lady that comes in [housekeeper] she's a good driver so she comes along in case I don't feel like driving for myself—she takes over.

I vomit for about a couple of days at least overnight and into the next day and that pretty well saps me you know—I just have to go to bed I can't stay up.

It [chemotherapy] has affected my eyes to where the glare is so terrible I can't drive—have to have somebody go with me.

She [daughter] keeps me from cooking—I don't have to do my cooking.

I felt nauseous—I just lay down on the floor and try to relax myself and think about other things—sometimes its worse than others—last time I didn't take my nauseous pills in time and it was very bad—that's for about 24 hours at the most.

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Nurse Responses for Which Interrater Agreement not Reached

It's the anticipatory nausea that seems to be her biggest problem--she's gonna need some emotional support to overcome that.

He was forced to stop work because of the nature of the treatments so I see him now needing something to fill his life where that very important work used to be.

Coming here every 2 weeks--that's become real worrisome to her because she's tired of it.

Chemotherapy makes her sick for about a week and she does not like to be on the nausea medication because it makes her very drowsy and sometimes she doesn't take it.

She's a real quiet person--the chemotherapy disturbs her a lot--she's very, very frightened and has some real bad feelings about the chemotherapy and all she's been through--quietly supporting her and encouraging her to talk when she wants to but not probing is the best thing.

She has an aversion to taking the leucovorin--she just detests the leucovorin--we talked about this and she said I know it's all in my head--I said I think the leucovorin represents your whole thing of chemotherapy and she said I think you're right.

The only thing she voiced to me today was wanting to go home so I'm sure this does interfere with her homelife in that she has to come up here.

She said if I could just lay down I'd get rid of the heebiejeebies so that's why I laid her down--the thought of getting the chemo and the sickness after it kind of hits her before--she said sitting up just makes it worse for her.

She gives up easy at times when we can't stick her a couple of times she just wants to well that's just the way I am--I guess she just needs to have some positive support to where she can feel better about everything that's going on.

He got sick--didn't take the Compazine--woke up in the middle of the night and couldn't stop it--was glad it was Friday because he would not have been able to go to work--we told him to take the Compazine starting in 2 hours and do it every 4 hours and he agreed to that.

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Appendix F

Verbatim Patient and Nurse Responses

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Patient Responses Classified in the Category Activity and Rest

I'm weaker--I spend a lot of time now laying on the couch or the bed because I just don't feel good all over.

I don't do a lot of physical cause I'm too weak--my husband vacuums the house and things like that--occasionally my sister helps me.

I'm just too weak to go out--don't go shopping don't go out to affairs, cookouts and things cause I don't have the energy--if I need anything my daughter gets it.

Yesterday she [sister] was off [work] and she fixed me a real good dinner--I ate a little bit more than I usually do.

I do sleep a lot since I've been taking chemotherapy--the more I sleep the more I need to sleep.

The last 2 days I work I might have to ask someone to assist me in doing something I used to could do myself.

I haven't been exercising because I just didn't have the energy.

The main thing is weakness--my husband has to take over a lot of the household chores.

I'm still working 3 days a week--they cut me back--wanted me to have an easier shift, weekends and less work to do.

I feel kind of drug out several days after chemotherapy--just feel like sittin and doing nothing but as far as taking care of my personal needs and stuff I can still do all of those.

I can't hold out to do a full day's work--don't have as much strength.

It [chemotherapy] puts me to sleep--have to have somebody drive me home cause I just can't hardly hold my head up.

You have to give up really a lot just cause I don't have energy to do it--I used to be real active.

It's hard to get going--get up and get started.

I don't have strength really to do anything--not exercise or anything like that--some days I'm so weak I can hardly walk from one end of the house to the other--then I have to hold something.

Of course I'm not able to do anything I'm so sick--for at least 2 days my husband does everything that I need to have done.

I'm tired and I ache all over--I put off doing things that I should do--that's my main thing--I don't do anything I don't have to like that.

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I've had Charlie Horses in my legs when I first get up in the morning and stretch and one morning I had them in both legs simultaneously--and you think that didn't hurt it did--at night my calves draw a lot.

I've had a lot of phlebitis and had a couple of those in my leg and of course I have to sit then with my foot up and I can't do physical--I was walking an hour a day up until 5 or 6 weeks ago when this hit me in the leg.

Generally I sleep a while and wake up and can't go back to sleep for an hour or two--the last week I developed hiccups and that's something you can't sleep with.

I just don't have the energy to do the things that I used to do--don't feel like doing anything--when I sit down I hate to get up--I lay down I hate to get up--when you get in a condition like that seem like you're backing up instead of doing better.

From the standpoint of physical help, the heavier treatment that I get once every 3 weeks really is difficult to cope with--the first afternoon I've had a very hard chill that lasts up to an hour and then a fever for about 12 hours--the next day is similar to recovery from the flu--you feel very weak, very tired.

I have difficulty in the mornings--I have weak spells--can't endure anything--I just sit down because it's like I was going to faint. I have to have plenty of rest.

Have to stay in bed [first 1 or 2 days] I sleep a lot--just in bed and can't do anything.

Used to I was very independent and I'd get in the car and go where I pleased anytime I wanted to but I can't do that anymore--Lots of times I'd love to get in there and go shopping or something like that but it just can't be right now.

Certain days I don't have much strength--didn't feel like doing anything much--I just don't do anything, either lay down or sit down.

Having to take the medicine [anti-nausea], one is 3 hours apart and one is 4 hours apart--I set the alarm to be sure I take it on time and there's no way I can sleep, get back to sleep or go to sleep--so its Saturday night before I am getting sleep.

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Patient Responses Classified in the Category Food and Water

I didn't want to eat my own cooking cause my hands looked so bad.

My appetite is not any good--have to force myself to eat--but I do eat--there's days I can't think of anything I want.

For the first 1½ weeks [after chemotherapy] I have a lot of trouble with nausea--I'm allergic to many things I take for nausea so I just lay down.

Really I don't have an appetite to eat--I force myself to eat and then I get nauseated.

We eat out a lot--I get real tired of it but I don't feel like fixing the food I would eat.

My husband says that I would eat better if I wouldn't drink so much carbonated water drinks.

I have a bad defect of eating--been eating too much since I've been on chemotherapy and that's not good.

Feel like I can taste that medicine or something all throughout that month but I haven't found anything to do for it.

Three weeks out of this month's been real bad for me just tryin to eat--no appetite--sometimes everything tastes the same.

When I take all the doses, all three shots, I do need help with my meals then--wife or daughter has to be kind of on call to help me.

What do I need? Well about the only thing is something to give me an appetite--no appetite at all--I try to find something I can halfway swallow and eat as much of it as I can--if I could just eat I believe I'd feel better and have a better outlook on life.

She [housekeeper] fixes whatever she thinks I will eat or can eat and I think I disappoint her when I'm not able to eat it.

For several days I don't feel like eating very much--just drink liquids--have to stay away from food cause it makes me sick to smell it cooking--I try to eat after the second day.

My gums started getting sore about a week ago--felt like somebody had rubbed sandpaper over them and then they split wide open in a couple of places--Such a big piece of flesh came out and left a little hole in both places--it's just taking a long time to heal.

I haven't had an appetite but I make myself eat--sometimes it takes half an hour to eat a bowl of oatmeal but I keep on till I get it down--I just don't want food.

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I stay nauseated all the time—if I eat especially if I eat sweets that will make me nauseated and the last 2 or 3 days meat seems to bother me—I just don't eat those things.

I don't have a real good appetite—my son doesn't think I eat enough—lost 3 pounds since I was here before—this time I haven't eaten as much—so many things I did love I just can't stand.

I get sick along about sometime during the night—it's just awful to go through with—so bitter and bad—sometimes I don't have time for anything—I just have to another time and another time and after that I can't quit—just keep heaving, heaving.

My first 1 or 2 days I have to have somebody to help me to cook because I'm sick—nauseated, very nauseated for about 2 days.

My taste changes after I have the treatment—sweet things just taste sweeter and I don't eat as much—it lasts at least a week and then I want something all the time.

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Patient Responses Classified in the Category Normalcy

It turn my fingernails black and I got these spots on me--hands got black--have my feet dun covered up cause I don't want nobody to see them. This therapy made me a peculiar looking black.

My personality sort of changes--any little thing maybe might kind of tee me off a little bit--it gets me upset.

A day or two before I come down it kind of works on my mind about coming down for chemotherapy--you get a little bit apprehensive about it.

I'm just not the same--I'm 25 and I feel like I'm 50 or something.

I always dread it [chemotherapy] because I know it's going to make me so sick--wring my hands and shake--this morning immediately I got up and threw up--I think a lot of it's up here because I did the same thing the last time--started throwing up in anticipation of it.

Once in a while I get a little depressed and I just can't help that--losing your hair and things like that and then your wig--your whole body changes, emotions change, you change all over, everything changes--it doesn't seem real.

I have a good bit of depression--he [doctor] said that was to be expected--I just work at it--prayer is my biggest help--try to find something to do and to be with somebody.

It's not worth the effort to have to fool with the old wig and all that mess--I hate it--I hate the looks, I hate the feeling, I hate the thoughts.

I've got the worst depression this time than I've had the whole time--try to handle it myself--try to keep busy and try not to think about it.

I've always been afraid when I come down here--just something you fear--just the thoughts--you just don't get used to it--I don't--I haven't.

Probably the mental concentration is more difficult for a few days because you came back to it [business duties] and you still are not as sharp mentally there for a few days--you just have to almost overcompensate mentally and push yourself just a little harder to concentrate and be a little more deliberate.

I start getting a psychological effect by the time I get ready to come back knowing I'll be sick my first 1 or 2 days--seems like I can taste that medicine in my mouth--just laugh about it and go on--think its psychological.

I've felt a little depressed in the last month or 2 with this feeling I thought if I feel like this the rest of my life I wouldn't care about living a long time--I never had that feeling before--it's unusual for me--I just try to make the best of any situation.

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Patient Responses Classified in the Category Hazards

I was working full-time before and now I'm working 2 days out of a week—it is a big problem because of the financial situation.

Usually I'm off a week after I take chemotherapy cause I'm weak - don't have any sick leave or annual leave so I'm off without pay so that's the problem there.

I haven't been able to work here the last 6 months—I do have bills too.

What I have trouble with is trying to get insurance—I try every place I go—that's like a block wall right there.

Because of the particular drugs that they give me and living about 40 miles away, I need her [wife] to drive me back and forth on that particular day—one of the drugs in particular is an anti-nausea drug which tends to make you lightheaded and a little sleepy—so just as a precaution she drives me on that day.

I have a problem keeping my balance—I start to sit down in a chair and if my husband hadn't been there I'd have sat on the floor, I'd have missed it completely.

My daughter brings me over here—she drives back—I could drive but I get sick.

The day of the therapy I need help getting here and getting home mainly because of the influence of the anti-nausea medication—those Thursdays I'm totally dependent on somebody else for transportation.

It bothers me having to wear long sleeve shirts--it's just warm--been told the chemotherapy makes me more susceptible to the sun's rays.

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Patient Responses Classified in the Category Solitude and Social Interaction

I don't bother nobody for nothing—I only got one daughter and she got her family so I know I got to deal with my condition.

He [husband] bugged me so much about it [eating] for awhile till I got where I wouldn't eat in front of him—and then he didn't know whether I had or not.

I need help trying to communicate with the children better cause sometimes I find myself getting a little rough—sometimes I holler at them which I've never been accustomed to doing.

I'm a very outgoing person and I can't here—tell them things—it's just been unpleasant for me and it isn't the people, they've been really nice to me it's just me but I don't know what it is—just like you drew a curtain down over me or something.

I need more companionship—I don't go to church during that time which I need to do—I don't go out because it [chemotherapy] makes me susceptible to diseases.

The doctor told me to avoid large crowds—I didn't even go to my brother's funeral on account of that—I don't even go to church.

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Nurse Responses Classified in the Category Activity and Rest .

He has a lot of energy and he doesn't have the outlet for it right now that he used to have before.

His activity level's changed in that he has no energy—just doesn't do much so he's having to get used to that.

[She] has a real low level of energy right now and she's having a lot of difficulty with that.

She was sick for 3 or 4 days during the time to where she didn't feel like maybe up to a week where she didn't feel good—I think she was not working during that time.

[She] has had some physical limitations in that she's had some swelling in her legs and feet and that's kept her off her feet some which she's not used to.

I see his main need that he needs to continue his activity in his community, his church, and his family—its been an effort it would be easier for him to lay down and not do anything.

Just as most patients her physical status is not as good for about a week after her treatment—during that time she doesn't get much of her home work done.

Physically I think she is sick for a couple of days and I think she needs some help—don't know if she [daughter] stays with her or anything like that.

I assume that during the week she has chemotherapy she's not able to do a lot of things around the house like she used to—probably has to have either outside help or family help that she normally wasn't having.

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Nurse Responses Classified in the Category Food and Water

Is she eating right—who's helping her to the store to buy food?

He has trouble with nausea—we talked about that and came up with some ways for him to help control that.

He needed to drink his fluids for Cytoxan to make sure he didn't have bladder complications.

She's still losing weight—don't know if that's directly related to the chemotherapy or the disease—probably we won't know until she gets off chemotherapy.

I know that she is sick—throwing up and feeling bad for about 24 hours after her treatment—she pretty much stays in bed during that time.

She is gaining weight—eating a lot of ice cream—I mentioned that Fudgesicle now has this bar that's just 70 calories—don't know if she'll continue to gain weight which is gonna make her feel kind of lousy.

Her outstanding problem is her sore mouth—said she's been using our mouth rinse—I made sure she's added peroxide to it and told her to continue to do that—not to try to wear her dentures.

Loss of appetite—I said how about ice cream and milkshakes—she said I don't like sweet stuff that much—I called her [dietitian] in there for a consult.

It seemed like nutrition was the main thing—he's losing weight—he looks pretty thin—I gave him two different flavors of pudding and a couple of cans of Ensure Plus and told him to tell me how he liked it when he came back.

He said I just haven't got any appetite—I'm not eating—don't like cold foods—talked to her dietitian already—don't remember [what she said]—she told me a whole bunch of stuff I don't know.

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Nurse Responses Classified in the Category Normalcy

She's failed the first line of treatment--she is now having to resort to the second--she needs encouragement [from us] to face what she now has to do--she needs to keep that spirit of hope.

She gets sick as soon as she comes here--she's already sick before she gets her medicine--nearly always that's an emotional problem, a psychological problem.

She needs to know what's going on with her disease--she may not be accepting what's going on.

He still needs to do the things that are important for him to meet the developmental needs of his age.

He seemed a little flat to me--this is the first day I've seen him--he may be a little bit depressed.

She doesn't feel good period and she seems kind of depressed--her daughter seems to be helping her with an optimistic outlook--she seems to respond pretty well but still doesn't foresee anything in the future where she feels well enough to do all that she'd like to do for herself.

She needs to know enough about what's going on to realize that there is hope although there isn't a whole lot really right now.

One of her main problems has been between the fourth and fifth treatment she got real depressed--kind of has a flat affect.

I think she could do well with the TOUCH group or seeing someone that has been through the experience before just to help her see the reality of it because it seems like she does not accept for herself.

I don't know whether she really had a lot of hope or not--but she didn't seem to have--she seemed to be kind of accepting what was going on like this was just all you could do--she just didn't seem to have a lot of hope.

She's assumed the role of a sick person for eight treatments of Cytoxan, Adriamycin, 5FU--now she needs to reestablish her role as a well person again.

I wish I had longer [with him]--maybe he's depressed--maybe he just needs to talk with somebody--maybe he'd be good for the TOUCH group or something--he was kind of reticent.

What bothered her most was her hair coming out--the hair was the hardest thing because she said that was her only beauty asset--it was a thing of body image that that was her only beauty asset and going down the tubes.

The problem of emotionally trying to cope with getting the treatments--she really just dreaded coming in--each one gets more difficult and is harder for her to handle.

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She's having to or has chosen to change her lifestyle which is unfortunate for her because she's at retirement age--maybe she could have kept her place on the lake if she had waited until she was through with treatments and see how she was going to do.

Right before we start chemotherapy she becomes very, very agitated--she visibly starts shaking--what I'd like for her to do is start with some relaxation exercises so we can prevent the nervous reaction that she has as she's getting the treatment.

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Nurse Responses Classified in the Category Hazards

She has a hard time financially— [chemotherapy] contributes to it—even if you have good insurance it's still a financial burden.

I'm sure there's some financial problems—aggravated by the chemotherapy cause she's been at this a long time.

This [chemotherapy] does interfere with her work—she has to take off a week and she's the only breadwinner.

He needs to watch out for infection too cause it seems to me that both of those are myelosuppressive drugs.

He couldn't get out in the sun because of the 5FU and he loves the outdoors—I told him to put like a sunscreen on.

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Nurse Responses Classified in the Category Solitude and Social Interaction

She doesn't have a good support system as far as someone to help her with activities she can't do.

He does have a great need for socialization--it's been interrupted by his disease and it's treatment.

She doesn't have a lot of emotional support and maybe if anything that would be what she would need.

Somebody to talk to's a big thing--cause there's no one that's her age in the same place that I know of that's real close to her--maybe even a TOUCH group would be effective.

He and his wife might really benefit from the TOUCH group--should ask him if he'd enjoy talking with counselors and other cancer patients.

I just don't know whether she has anybody to talk with her about these things or that can help her to deal with them.

The thing that would keep her from doing the best she could do is her lack of a support system--she doesn't have a family member that lives with her or that she can call on when she's sick.

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GRADUATE SCHOOL
UNIVERSITY OF ALABAMA IN BIRMINGHAM
DISSERTATION APPROVAL FORM

Name of Candidate Jayne Irene Fernsler

Major Subject Adult Health Nursing

Title of Dissertation A Comparison of Patient and Nurse Perceptions of Patients' Self-Care Deficits Associated with Cancer Chemotherapy

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