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University of Washington

Abstract

THE NEEDS OF FAMILY MEMBERS
OF CANCER PATIENTS

by Jaime Sue Iversen

Chairperson of the
Supervisory Committee: Professor Maxine L. Patrick
Department of Physiological Nursing

This study was a replication of one conducted by Tringali in 1986. The purpose of this study was to identify the importance of cognitive, emotional, and physical needs to family members of cancer patients. The sample consisted of 28 family members, either spouse or adult children, who accompanied the cancer patient to a clinic in a military hospital in the Northwest. All the cancer patients were in the initial stage of treatment. The family members rated the importance of 53 need statements on a four point Likert-type rating scale. The need statements were divided into cognitive (23), emotional (21), and physical (9) categories.

The findings were similar in both studies. In this study, 27 of 53 need statements were rated as most important; in Tringali's study 20 need statements were rated in the same class. The majority of needs in both studies were cognitive followed by emotional needs. Only one physical need in this study was rated as a most important need. Nurses should plan interventions to meet cognitive needs so that family members can function effectively as a source of support for the cancer patient.

R/S

**THE NEEDS OF FAMILY MEMBERS
OF CANCER PATIENTS**

by

Jaime Sue Iversen

**A thesis submitted in partial fulfillment
of the requirements for the degree of**

Master of Nursing

University of Washington

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Master's Thesis

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CHAPTER I

Statement of Problem

A diagnosis of cancer affects the family as well as the patient. The patient with cancer does not exist in isolation but rather is part of a complex network of interpersonal relationships (Welch, 1981). The family, as part of this network, provides care, encouragement, and solace to each other and the patient. The functioning of the family is disrupted by the diagnosis of cancer. Cohen and Wellisch (1978) stated that "the word 'cancer' hurls a powerful blow in slow motion at the emotional solar plexus of everyone."

Reactions of anger, fear, grieving, and uncertainty (Tringali, 1986), along with disruptions in roles and relationships among family members are commonly seen after a family member is diagnosed with cancer. Yet, at this time of disruption and emotional upheaval, the support provided by the family is considered to be crucial in helping the patient adjust to the diagnosis of cancer and the ensuing treatment (Wright & Dyck, 1984).

There are numerous references in the nursing, sociological, and psychological literature concerning the critical role the family plays in furthering positive adjustment to the cancer diagnosis and treatment. Giaquinta (1977) stated that the family is viewed as the

first line of defense for a family member undergoing a crisis. Kaplan, Grobstein, and Fishman (1973) stated that adjusting to a serious illness, such as cancer, is not solely the patient's function. They believe the role that the family plays is important and can make the difference between effective or ineffective coping. So it follows that the needs of the family must be identified and assessed in order for interventions to be planned to meet these needs. Only then can the family function fully as a source of support for the family member with cancer. Yet, there is very little documentation of the needs of family members. The purpose of this study was to identify the cognitive, emotional, and physical needs of importance to family members of cancer patients.

CHAPTER II

Conceptual Framework

Cancer produces problems for patients and their families. Families are a source of support to patients during diagnosis and treatment. But though the needs of the patients are met, the needs of the families may not be met. Meeting these needs would allow the family to provide additional support to their family member with cancer.

This conceptual framework will provide a literature review and development of concepts in the following areas: the family, the family as a source of social support, the effects of serious illness on the family, the effects of cancer on the family, and research concerning the needs of family members of cancer patients.

The Family

One definition of the family is "a social system with elements of structure, boundaries, and function" (Taylor, 1979). Gillis (1983) conceptualizes the family as a complex unit that has attributes of its own in addition to the significance of the individual components. Smilkstein (1980) defines the family as "a basic societal unit in which members have a commitment to nurture each other emotionally and physically." Two types of families are mentioned in the literature: nuclear and extended. Duvall

(1977) stated the nuclear family consists of husband, wife, and children while the extended family is made up of the nuclear family and a network of relatives who interact with the nuclear family but usually do not live in the same household. The nuclear family is the type of family that will be studied in this study. The definition of nuclear family used for this study is a social system in which members have roles such as husband-father, wife-mother, son-brother, and daughter-sister with corresponding relationships and expectations of each other (Cassileth & Hamilton, 1979; MacVicar, 1980).

Families perform several functions in the performance of these roles, relationships, and expectations. The family is the mediator between the individual and society (Cassileth & Hamilton, 1979). This mediation is accomplished by teaching the child the beliefs, norms, and values of their culture. The internalization of the beliefs, norms, and values also enables the family to plan for the future of the unit itself and its members in the areas of education, vocational, financial, and social endeavors.

The nuclear family has connections with extended family members and social groups such as vocational and friendship circles. These connections serve as interpersonal contacts and as a framework against which the family's behavior can be measured. Cassileth and Hamilton

(1979) believe that the family may be perceived of as a system due to the systematic interacting of family members in performance of their roles and relationships.

It is helpful to understand general systems theory in order to understand how a family functions. Sills and Hall (1985) stated general systems theory defines a system as "a set of components or units interacting with each other within a boundary that filters both the kind and rate of flow of inputs and outputs to and from the system." This definition points out that systems have structural and functional aspects. The structural aspect is determined by the composition and arrangement of the units, and the functional aspects are seen in the interaction between the units (Auger, 1976).

General systems theory can be utilized with the family since the family has been defined as a system. Taylor (1979) stated the structural component is the nuclear family of father, mother, and child which can be considered as the units or elements. Structure can also be seen in the arrangement of the family and the pattern of relationships between the members. The functional component of a system is noted in the interdependent actions among the family members to meet economic, psychological, social, and biologic needs (Taylor, 1979).

Boundaries are also present in the family system. Taylor (1979) stated that boundaries in the family system

may be viewed as the rules that exist for interpersonal contacts and subsequent interaction. The family system receives input across its boundaries from the interaction of family members with each other and the outside environment (Bertrand, 1972; Miller, 1969). Miller (1969) stated that the family will receive feedback from the interaction which allows the family system to adapt further to the previous input and to new input. This process of feedback and adaption allows the family to maintain a stabilized mode of functioning.

The Family as a Source of Social Support

There are numerous references in the sociological, psychological, and nursing literature concerning the importance of the family as a source of social support to the patient. The early studies were greeted with great enthusiasm because researchers believed that social relationships could be more easily dealt with than coping styles, amount of exposure to stress, and personality traits. However, in spite of many articles on the subject, there is a lack of consensus regarding the precise nature and means of measuring the concept of social support. Currently, the concept of social support includes many different kinds of indicators and a broad range of related constructs. Little is known about the underlying processes and alternative explanations for the observed phenomena.

Even though there is still considerable confusion regarding the definition and measurement of social support, it is believed by many to buffer stressful life events and to effect a wide variety of outcomes in the social function, physical, and mental health areas.

Caplan (1974) believed social support referred to lasting interpersonal relationships that could be counted on to provide emotional support, help, and reassurance when needed. These interpersonal relationships would also provide feedback and shared needs and values. Dean and Lin (1977) defined social support by describing its functions. The functions that social support provides are:

- 1) an accent on shared responsibility, concern, and caring;
- 2) strong shared identification;
- 3) importance placed upon a person as a unique individual and not on their performance;
- 4) provision of face to face interaction and commitment;
- 5) intimacy;
- 6) close bonds and associations;
- 7) provision of sustenance, affection, shelter, and response.

The definition of social support used for this study is the widely quoted definition by Cobb (1976). He believed social support was a function of one or more of the following classes of information:

Information leading the subject to believe that he is cared for and loved; information leading the subject to believe that he is esteemed and valued; and information leading the subject to believe that he belongs to a network of communication and mutual obligation. (p. 300)

Wortman (1984) reviewed the many indicators of social support she found in the literature and identified six common types of social support:

- 1) exhibition of positive affect or information that one is cared for, loved, and esteemed;
- 2) display of agreement with or appropriateness of another's beliefs, feelings, or interpretations of events;
- 3) inviting open expression of beliefs and feelings;
- 4) proffering of information and advice;
- 5) material aid provision;
- 6) producing information that the individual is included in a support system of reciprocal help.

After looking at the different types of social support, Wortman (1984) stated it was important to assess each of the types of social support separately because each type might not be equal in their effectiveness in relieving stress.

In addition to the different types of support, House (1981) identified different providers of social support. These different providers were: spouse or partner; other relatives; friends; neighbors; one's work supervisor; coworkers; care or service givers such as domestics; self-help or peer support groups; and health professionals.

Lindsey, Norbeck, Carrieri, and Perry (1981) stated that it is not feasible to assess social support from numerous sources in an investigation. Additionally, Wortman (1984) felt it was important to ask about different providers of social support and not to lump them all together. She believed that lumping the different types of social support together would not provide a true representation of the level of support. This need to assess providers of support separately is due to the fact that what is considered supportive from one provider may not be considered so when offered by another provider.

During the last decade, researchers have started to investigate social support and the cancer patient. Maxwell (1982) stated that social support has been revealed to be an important variable in ascertaining how well a cancer patient will cope with their illness. As to which group of providers was most desirable for assessing the social support provided to cancer patients, Lindsey, et al. (1981) believed that the spouse and immediate family were the group to be assessed. Their review of the literature indicated the reaction of families to the cancer patient was a crucial factor in the patient's adjustment to the disease and treatment. Marrow, Hoaglund, and Morse (1982) interviewed 107 parents of children with different types of cancer. The majority of the parents were white, married mothers with a mean age of 37 years. The parents felt they

received the most support from their family rather than health professionals, churches, and other professionals. Bullough (1982) reported similar results with a group of breast cancer patients. She interviewed 139 white middle class women who had a mastectomy and noted that the women rated family or friends as their most significant source of support. Besides the above studies, there are also studies showing that social support is beneficial to the cancer patient.

In 1981, Northouse studied post mastectomy patients and their fear of recurrence. The study consisted of 30 women between the ages of 37-74 who had a mastectomy within four years of the start of the study. The results revealed these women feared recurrence of the cancer less when they had a high number of significant others they could turn to than the women without this support group. Weisman and Worden (1971) studied the coping behaviors of 120 adult patients with various cancers the first 100 days after diagnosis. They found a relationship between expectation of little interpersonal support and the occurrence of emotional distress and marital problems. They concluded that the presence of strong interpersonal support was an asset that contributed to successful coping. Additionally, Woods and Earp (1978) discovered that social support mediated the effects from surgical complications seen in 49 post mastectomy patients ranging in age from 25-71. The

women in their study had less depressive symptoms if they received social support, but this effect was negligible if the woman had a high number of complications. This suggests that the effectiveness of social support may have its limits.

Previously mentioned theory and research both point to the fact that the family is a potent source of social support for the cancer patient. So it follows that a major task of the family is to provide social support when one of its members is ill.

The Effects of Serious Illness on the Family

The nurse needs to recognize that illness is a stress or crisis to the family as well as the patient. Since the family is an interdependent system, the one member becoming ill will affect the others. Mallick (1979) stated that it is not tolerable to treat a person's illness without consideration of both the person and those in the person's social surroundings. In Hill's (1949) classic research on family stress, a crisis is defined as any eventful change in the family social system for which the usual patterns of coping are inadequate. These eventful changes influence aspects of the family social system such as boundaries, structure, goals, processes, roles, or values. Hill (1949) asserted that several other factors interact with each other and the crisis or stress event. These other factors

are the resources of the family to meet the crisis and the definition that the family makes of the event. These factors along with the stress event determine whether a family feels it has been threatened by a crisis.

Burr (1973) took this crisis theory and reworked it to include the amount of change that the stress event causes. Burr believed that the larger the amount of change in the family social system, the more the family would feel they had been threatened by a crisis. He felt that the amount of change was an important addition to the factors that determine whether a family perceives it has experienced a crisis.

Current definitions of crisis are similar to the ones proposed by Hill (1949) and Burr (1973). Janosik (1984) defined a crisis as a precipitating event which causes tension that is not relieved by the person's usual coping mechanisms. She stated the tension level will continue to rise until the person is overpowered by the event. In 1986, Aguilera defined crisis as a turning point in a person's life when they are confronted by a problem which cannot be readily solved by the usually employed coping mechanisms. Thus, serious illness can be considered a crisis for the family because it often produces changes in the family for which the usual patterns of coping are inadequate.

Illness in the family can cause changes in assignment of tasks, responsibilities, roles, and relationships. When a family member cannot fulfill his roles, tasks, responsibilities, or relationships, extra stress is placed on the functioning of the family system (Craven & Sharp, 1972; Leavitt, 1982; Stuifbergen, 1987). Mallick (1979) stated that there are several tasks that the family faces after a family member has been diagnosed with a serious illness. The first of these tasks is dealing with feelings. The family must manage feelings resulting from enduring the patient's suffering in addition to feelings of powerlessness, guilt, anger, ambivalence, and fear for the patient and themselves. Another task for the family is learning how to respond and interact with health personnel involved in their family member's care in order to take an active part in the plans that are made. The family also needs to discover a method for balancing the demands made upon them to rearrange their lives so that the patient will get the care that he/she needs but still allow for family members' needs for growth and differentiation. A further task for the family is the management of role changes because this requires performing the former functions of the ill family member while not excluding him or her from everyday family life. Lastly, the family needs to learn to communicate their feelings and needs so that they can continue to function effectively.

In addition, Craven and Sharp (1972) point out that illness is just one of the stressors impacting a family at a given point in time. They believe these other stresses need to be considered because they influence family functioning and can also be affected by the illness event. These additional stressors include: interpersonal problems between family members; job changes, unemployment, and financial debt; recent change of address; illness of another family member; and problems associated with child care and discipline.

Klein, Dean, and Bogdonoff (1967) conducted a study on the effects of chronic illness upon the patient's spouse. Seventy-three spouses were interviewed ranging in age from 20 to 55 years. Forty-six of the spouses were men and 27 were women. Sixty-seven percent of the spouses reported an increase in symptom levels after their mate became ill with the two most common symptoms being nervousness and feelings of fatigue. Fifty-six percent of the spouses also indicated an increase in role tension indicated by increased ease in becoming angry and depressed, and in feeling more jittery.

A study which looked at the impact of a husband's chronic illness was directed by Sexton and Munro (1985). The sample consisted of 76 women, 46 of which had husbands with chronic obstructive pulmonary disease (C.O.P.D.) and 30 whose husbands did not have a chronic illness. When the

C.O.P.D. wives were asked how much their husband's illness had affected their lives, 4.3% rated the impact as excessive, 21.7% rated the impact as a great deal, 32.6% rated it as moderate, 21.7% as slight, and 15.2% felt there was no impact on their lives. C.O.P.D. wives also reported that they had to take on additional roles such as caretaker, decision maker, errand doer, and finance manager. Concerning marital relations, 48% of the C.O.P.D. wives stated that they had no desire for sexual relations as compared to only 15% of the wives whose husbands were not ill. The C.O.P.D. wives reported experiencing poor sleep with 22 stating they woke up several times at night and 12 more reporting overall poor sleep as compared to only two wives of the comparison group. Lastly, 30.4% of the C.O.P.D. wives stated that they had to give up social activities since their husband became ill while only 13.3% of the comparison wives reported a decrease in social activities. The preceding discussion demonstrates the far-reaching effects that an illness has on a family. Cancer is an example of a serious illness that causes stress in the family system.

The Effects of Cancer on the Family

Cancer strikes at any age. Seventy-four million Americans now living will eventually have cancer. In 1987, 965,000 people were diagnosed with cancer affecting

approximately three out of every four families (American Cancer Society, 1987). A diagnosis of cancer creates fear for all involved. Due to the meaning of cancer-related stress to the family system the family should not be viewed as the main refuge for the sick, but as part of the unit facing the crisis and thus the target of nursing care.

Lewis (1986) conducted an analysis of thirty studies concerning the impact of cancer on the family. She identified eleven separate issues: emotional strain; physical demands of care; uncertainty about the patient's health status; fear of the patient dying; altered household roles and lifestyles; finances; concern over ways to comfort the patient; perceived inadequacy of services; existential concerns; sexuality; and nonconvergent needs among household members.

The first issue identified was emotional strain which is seen in all phases of the illness, from diagnosis of cancer to the terminal stage (Lewis, 1986). Germino (1984) conducted a descriptive study of patients with recently diagnosed cancer and their families. Ninety families were interviewed consisting of 75 spouses and 67 adult children. She reported that the most frequently mentioned concern for both spouses and children was their own levels of restlessness and anxiety. Krant and Johnston (1978) studied family members' perceptions of communications in late stage cancer. The sample consisted of 108 family

members, 42 of which were spouses, 56 were adult children, and ten children between the ages of 14-18. They discovered that almost two-thirds of the complaints mentioned by the families could be categorized as feelings of helplessness and fears. In a study by Wellisch, Jamison, and Pasnau (1978), the psychosocial aspects of mastectomy from a man's perspective was investigated. The sample consisted of 31 men ranging in age from 34-74 years old. Forty percent of the men reported sleep disorders and nightmares, 30% reported eating disorders, and over 50% felt their ability to work was negatively affected by the patient's illness and surgery.

The second issue to impact the family concerns the physical demands of care (Lewis, 1986). Googe and Varriccho (1981) conducted a pilot study of the home health care needs of cancer patients and their families. The sample size contained 15 families of patients ranging from newly diagnosed to having cancer for over three years. The family members interviewed consisted of spouses, adult children, other relatives, and friends. Fifty-three percent of the family members noted that they had lost sleep or had suffered unsatisfactory health due to the patient care demands. In 1983, Holing studied the primary caregiver's perceptions of the dying trajectory. She interviewed 14 spouses, 12 of which were female and two male. She discovered that 43% of the spouses had

experienced physical hardships in providing physical care for the mates with cancer.

The third issue Lewis (1986) noted as impacting families pertains to the uncertainty surrounding the patient's health. The uncertainty concerning the patient's health is seen throughout the illness trajectory and is related to the uncertainty about the patient's prognosis, the outcome of recurrence and treatment, and the patient's further vulnerability to the disease. Gotay (1984) conducted a descriptive study of how female patients and their spouses viewed their experiences during early and advanced stage cancer. Thirty-nine spouses and 73 patients were interviewed. The most commonly reported problem of both the patients and spouses was fear of the cancer diagnosis itself and the disease progression or recurrence. In a study by Chekryn (1984), women with recurrent disease and their mates were interviewed to determine what recurrence meant to them and the impact on their communication and marital adjustment. Twelve patients and 10 spouses participated with both patients and their mates reporting feelings of uncertainty. Many stated the uncertainty was constant, and was related to the future, the patient's treatment outcomes, and survival.

The fourth issue touching the families of cancer patients is the possibility that the patients might die (Lewis, 1986). This concern is noted in all stages of the

disease. In Gotay's (1984) study, spouses expressed concern over the possible death of the patient. Thirty-nine spouses were interviewed with 20% of the 19 spouses of patients with early stage cancer and 35% of the 20 spouses of patients with late stage cancer fearing the death of their mate. Krant and Johnston (1978) interviewed 108 family members of cancer patients with advanced disease. The sample consisted of 42 spouses, 66 adult children, and ten children between the ages of 14-18. They found that 38% of the family members mentioned major concerns about the patient dying.

The fifth issue that Lewis (1986) felt families of cancer patients have to deal with is the alteration of roles and lifestyles caused by the disease. Roles may be surrendered, inadequately performed, or only partially filled which can, in turn, affect the overall functioning of the family. Welch (1981) interviewed 41 families of patients with cancer to determine their needs and plan interventions. Family members in this study consisted of spouses, adult children, siblings, and other relatives with a mean age of 44. During the interview, 20% of the family members stated they had experienced changes in their household roles in the areas of parenting and homemaking. Gotay's (1984) study revealed that 20% of the 39 partners of cancer patients believed their household roles and

lifestyles were altered due to restrictions in their activities resulting from the patient's disease experience.

Even though it would appear that the sixth issue dealing with financial concerns would be of primary importance to families, very few families have felt it was important in the studies reviewed (Lewis, 1986). Germino's (1984) study of 90 families who had a member with early stage cancer documented that patients ranked their concern about work and finances as important while spouses and children did not. Gotay's (1984) study revealed similar results. Twenty-nine percent of 73 patients were worried about the effect of the illness upon their job, while only 5.2% of the 39 spouses were likewise concerned about the patients' jobs.

The seventh area of concern identified by Lewis (1986) impacting the family pertains to the most effective ways to care for their family member with cancer. In 1982, Skorupka and Bohnet studied caregivers' perceptions of nursing behaviors that best met their needs in a home care hospice setting. The sample consisted of 20 primary caregivers, five male and 12 female, ranging in age from 25 to 85 years old. The results pointed out that families believed it was important for the nurse to show them how to care for the family member with cancer. Grobe, Ahmann, and Ilstrup (1982) conducted a needs assessment of cancer patients and their families who were involved in a hospice

program. In this study people considered to be family members were spouses, adult children, other relatives, and friends. Fifty percent of the 22 family members of patients with advanced cancer and the 29 family members of deceased patients expressed a need for help in the care of, monitoring of, transporting of, and equipment provision for their family member with cancer.

The eighth issue impacting the family of the cancer patient is the perceived inadequacy of services (Lewis, 1986). Studies show that families feel supportive services are inadequate or do not exist. Twenty percent of the 41 family members Welch (1981) interviewed in her needs assessment of family members of cancer patients did not believe there were services available to enable them to cope with the patient's emotional concerns. In Grobe, Ahmann, and Ilstrup's (1984) study, over 50% of the 41 family members interviewed could not identify services of emotional support, counseling, respite care, or provision of home care equipment. Similar results were noted in Hinds' (1985) study of family members caring for cancer patients at home. The sample consisted of 83 family members, 43 male and 40 female, with an average age of 52. Only 23% of the family members knew of existing community services and even less, 8%, had availed themselves of these services.

Lewis (1986) noted that the ninth area of concern for the family is related to existential concerns. Existential concerns deal with the purpose and meaning of life and with death and dying. Germino (1984) conducted a study which examined the concerns of family members of newly diagnosed cancer patients. The 90 families, which consisted of 75 spouses and 67 adult children, placed life and death concerns near the top of the list of identified concerns.

In addition, the tenth issue of sexuality affects the family from the early to the late stages of disease (Lewis, 1986). In 1978, Wellisch, et al., studies the psychosocial aspects of mastectomy from a man's perspective. When the 31 spouses were asked how the mastectomy had affected their sexual relationship, 14.3% rated the impact as "bad," 21.4% rated it as "somewhat bad," 57.1% as "no influence at all," and 7.1% rated the impact as "somewhat for the good." Hinds' (1985) study of 83 family members caring for cancer patients at home revealed that 38% of them reported problems in the area of sexuality. Chekryn (1984) interviewed 12 women with cancer recurrence and 10 spouses to determine what the recurrence meant to them and its impact on their communication and marriage. In contrast to the previous study, 20% of the spouses and 50% of the patients felt that recurrence of the disease had fostered marital closeness.

The last issue of concern to the family is the non-convergence of needs experienced by the patient and family members (Lewis, 1986). In Germino's (1984) study, both spouses and adult children were worried about their own restlessness and anxiety while the patients were concerned about their fatigue levels. Gotay's (1984) study revealed that the 73 patients mentioned more problems than did the 39 spouses and that there was little similarity between the two lists of problems. Both patients and partners feared cancer and worried about the patient's emotional state in the early stage of disease. But it was also noted in this stage that the female patients were concerned about their jobs and future ability to bear children while their spouses expressed little worry concerning these areas. The same phenomena were also noted in women with late stage disease. These patients were worried about restriction of activities, treatment side effects, and the future of their families while their mates voiced much lower levels of concern on the same subjects. This review points out that the family as well as the patient is impacted by the demands of cancer and its treatment. Yet, health professionals frequently expect the family to function as a primary source of support for the patient.

Research Concerning Needs of Family
Members of Cancer Patients

Since the family is affected by a diagnosis of cancer as well as the patient and a major task of the family is to support the cancer patient, it follows that family needs should be assessed and met in order to insure that the family is providing effective social support. Numerous studies have been conducted to assess the impact of cancer on the family but little research was found that would assist in determining the needs of family members of cancer patients. Studies which examine the needs of family members of cancer patients have been completed by Hampe (1975), Molter (1979), Welch (1981), O'Brien (1983), Wright and Dyck (1984), and Tringali (1986).

Hampe (1975) conducted a study of grieving spouses of terminally ill patients to determine whether they could recognize their own needs and whether these needs were being met. A semi-structured interview with open-ended questions was used with 27 spouses, 16 male and 11 female, ranging in age from 20 to 71. Hampe identified eight needs from a review of death, grief, and bereavement literature. These needs were: the need to be with the dying person; the need to be helpful to the dying person; the need for assurance of the comfort of the dying person; the need to be informed of their mates' condition; the need to ventilate emotions; the need for comfort and support from

family members; and the need for support, acceptance, and comfort from health professionals. Twenty-five spouses identified all eight need statements as needs that they had and the other two spouses identified five and seven needs, respectively. The majority of the spouses felt the identified needs were being met except the needs for assurance of the comfort of the dying person and to be informed of their mates' condition. The spouses also believed that the nurses' main responsibility was to the patient and not to them.

In 1979, Molter did a descriptive study which examined the needs of relatives of critically ill hospitalized patients. The sample consisted of 40 relatives; 10 women and 30 men ranging in age from 18 to over 60 years of age. Family members in this study were considered to be spouses, adult children, siblings, and other relatives. A structured interview format was used in which family members rated 45 need statements on a Likert-type scale as to whether it was a need for them, the importance of the identified need, and was the need being met and by whom. The statements were developed from a literature review of cognitive, emotional, and physical areas and a survey of 23 graduate students of nursing. The most highly ranked needs were: for honesty, to feel there is hope, for the staff to have a caring attitude towards the patient, to have explanations given in understandable terms, and provision

of information concerning prognosis and the patient's condition. Most needs, including the most highly ranked ones, were met more than 50% of the time. The families felt the nurses met their needs the majority of the time but as in Hampe's (1975) study, they felt the nurse's focus should be on the patient's care and not theirs'.

Welch directed a study in which the needs of family members of hospitalized cancer patients in all phases of the illness trajectory were assessed and suggestions for nursing interventions made. Forty-one family members participated in the study with a mean age of 44. Family members consisted of spouses, adult children, and other relatives. A questionnaire with a Likert-type rating scale was used in the assessment. The needs identified as most important by the families were: assurance the patient was receiving excellent personalized care; the receiving of adequate and understandable information about the patient's disease, treatment, and condition; and provision of emotional support for the family. Again, as in the previous studies reviewed, family members felt the nurse should center her care on the patient and not themselves.

O'Brien's (1983) study of 20 relatives of hospitalized terminally ill patients looked at the importance of needs to the family and whether these needs were being met and by whom. The 20 relatives, spouses and adult children, consisted of 16 women and 4 men ranging in age from 23 to

80. Structured interviews were conducted using Molter's (1979) need statements which had been adapted to the hospital setting. There were no new needs identified. The most important needs were for: honesty; provision of the best care for the patient; patient comfort; caring attitude of the staff; provision of information about the patient's condition, treatment, and prognosis; use of understandable terms; and to feel there is hope. Sixty-six percent of the relatives felt their needs were being met at least half of the time by a combined effort of both doctors and nurses.

In 1984, Wright and Dyck conducted a descriptive study of the needs of 45 family members of hospitalized cancer patients. Family members of patients who were newly diagnosed, had recurrent disease, or were terminally ill were studied. There were equal groups for each stage. A semi-structured interview was utilized along with a 12 item needs scale. The needs most often identified were: to be kept informed of the patient's condition; to be assured that the patient was comfortable; and to know what to expect in the future. These results are similar to the ones obtained in the studies previously reviewed in this section.

A descriptive study by Tringali (1986) assessed the needs of 25 family members who had relatives undergoing initial treatment of cancer, follow up treatment, or treatment for recurrent disease in an outpatient setting.

The age range was 22 to 71 years old; 16 of the participants were female and nine were male. In the study, family members were considered to be spouses, adult children, relatives, and friends. She took the need statements developed by Molter (1979) and others, adapted them for the outpatient setting, and grouped them into categories of cognitive, emotional, and physical needs. Family members rated the importance of these 53 need statement using a Likert-type scale. Cognitive needs were rated the highest followed by emotional and then physical needs. This ranking held up in all phases of illness. Family members felt the most important cognitive needs were the use of understandable terms and honest answers concerning the patient's disease, treatment, and prognosis. The most important cognitive need in all phases of illness was to have questions answered honestly. The most highly ranked emotional needs were for hope, to feel the clinic personnel care about the patient and were providing the best care possible. None of the physical needs were ranked as most important by the family members.

Statement of Purpose

The study was a replication of the one conducted by Tringali (1986). The study was again conducted in an outpatient setting but the study site and sample were changed. The change in sample was done to see if the

results obtained in Tringali's study were found in other populations of families with cancer patients.

The purpose of this study was: (1) identify the cognitive, emotional, and physical needs of nuclear family members of adult cancer patients in a clinic; and (2) to compare the results of this study with the needs of relatives of cancer patients in a study conducted by Tringali (1986).

CHAPTER III

Methodology

Research Design

The research design selected for this study was descriptive. As stated in the problem statement and conceptual framework, there are few studies in the literature that have identified the needs of family members of cancer patients. More descriptive research is needed before the area can be subjected to a more rigorous research design.

Setting and Sample

The study was conducted in a military medical center located in the northwestern United States. The sample was drawn from patients and their families who attended the oncology clinic. The patients and family members consisted of either active duty military members, dependents of active duty members, or civilians. The radiation and surgery clinics were not used. The cancer patient had to be at least 21 years of age and had to have been diagnosed as having cancer of any body system or organ. The cancer patients in the study were undergoing treatment at all stages of the disease from time of diagnosis to remission. The family member was either the patient's spouse or adult child. The family member had to be 21 years of age or

older, able to read and write English, and willing to participate. The family members who met these criteria and accompanied the cancer patient to the clinic were given the tool to complete. If more than one family member accompanied the patient to the oncology clinic, the family members decided who should complete the tool.

Data Producing Instrument

This study was a replication of one on the needs of family members of cancer patients conducted by Tringali in 1986. The tool contained a list of 53 need statements. The need statements were divided into cognitive (23), emotional (21), and physical (9) categories. As can be seen, the tool contained different numbers of need statements in each category, especially the physical category. There was space at the end of the tool where the respondent could write in needs they had which were not already identified. Content validity of the need statements was established by Tringali. The need statements were developed from a review of the literature and work done by Molter (1979). Tringali deleted some need statements and added others in order to make the questionnaire suitable for an outpatient population. The need statements were reviewed by nurse experts. Reliability of the tool has not been established.

Subjects were asked to respond to each item on a four point Likert-type rating scale. Columns were labeled "not important," "slightly important," "fairly important," and "very important" with the numbers 1, 2, 3, 4, assigned to the columns respectively. These numbers were printed in columns following each need statement and subjects were asked to circle the number which best represented the importance the need statement had for them (Appendix B).

The responses to the need statements were analyzed according to Tringali's (1986) study. The mean score for each need statement was determined. The need statements receiving a mean score of 3.50 to 4.00 were considered to be the "most important" needs. Need Statements which received a mean score of 1.51 to 3.49 were "important," and those with mean scores between 1.00 and 1.50 were regarded as "not important" needs. Data from this study were compared to the results found by Tringali. Demographic information was obtained from each family member; age, sex, relationship to the patient, education level, and occupation. Information on the patient's age, sex, diagnosis, disease site, date of diagnosis, and treatment modalities undergone by the patient was also collected from the family member.

Protection of Human Subjects

Before data collection started, approval for this study was obtained from the University of Washington Human Subjects Review Committee and the Clinical Investigations Committee at the military hospital. Subjects gave permission to be included in the study by agreeing to complete the tool. There was no benefit to the subjects. The potential risk to the subjects was that information gathered could have been an invasion of their privacy. The subjects may have been afraid that their names and information would be given to the health care professionals in the clinic and that this might compromise the patient's care. This was prevented by the assignment of numbers to each of the subjects and always referring to their information by their numbers. The consent was verbal and there was no way to trace responses to respondents. The only persons with access to the raw data was the researcher and her advisor.

Methods of Procedure

Approval to conduct the study was obtained from the Chief Nurse, the Director of Clinical Nursing, the Clinical Investigations Committee, and the Chief of the Oncology Service. The study was explained to each of these professionals in individual meetings and in that order.

Permission was obtained from all three to conduct the study. Then a copy of the proposal was sent to the Clinical Investigations Committee of the hospital for their review and approval.

The researcher then explained the study to the oncology clinical nurse specialist (ONS) and the clinic nurse. The CNS's role was concerned with education of the staff, patients, and family about cancer, its treatment, and associated problems such as nutrition, pain, and nausea. The clinic nurse was mainly involved with the administration of cancer chemotherapy agents to patients. They agreed to ask patients if the researcher could approach their family member. This was done to prevent coercion of the subjects. Both nurses had inpatient as well as outpatient duties which took them away from the clinic. By enlisting the aid of both, it was hoped to have one of them in the clinic at all times to screen potential subjects. When a patient arrived in the clinic, they were approached by the clinic nurse or the clinical nurse specialist. They explained that the researcher was conducting a study on family needs and asked if the researcher could approach their family member about participating in the study. If the patient agreed, the family member was approached by the researcher. The researcher then read a prepared statement which explained the purpose of the study and what the family member was

expected to do (Appendix A). If they agreed to participate in the study, the subject was taken to a quiet place in the clinic area and given the tool. The researcher then left the family member alone to complete the tool in order to insure privacy for the respondent. The subject was given as much time as needed to complete the tool. When the tool was completed, the family member returned it to the researcher. Completion of the tool took approximately 20 minutes.

CHAPTER IV

Findings

This chapter presents the results of the study. This includes: characteristics of the subjects, characteristics of the patients, the importance of the needs, and the comparison of importance of the needs with Tringali's (1986) results.

Characteristics of the Subjects

The sample consisted of twenty-eight family members of patients with cancer attending an oncology clinic in a military hospital. Almost all family members approached agreed to participate in the study; several did decline. Nine (32%) of the participants were male and 19 (68%) were female. The family members ranged in age from 26 years to 72 years, with a mean age of 51.3 years. Twenty-three (82%) of the family members were spouses of the patients and five (18%) were adult children.

Nine of the family members were employed, nine were homemakers, six were retired, one was a volunteer worker, and the rest (n=3) were not working due to illness or unemployment. The occupations of the subjects were: service provider (n=8), homemaker (n=7), manager (n=4), sales (n=4), professional (n=3), and clerical help (n=1). One subject did not respond to the question.

The majority of the subjects (n=9), had completed some course work passed high school. One subject had only completed grade school, another had some high school, six had finished high school, one college, and one had completed graduate school. The education level of the sample was comparable to level seen in the general population.

Characteristics of the Patients

Of the twenty-eight cancer patients, 17 (61%) were males and 11 (39%) were females. The patients ranged in age from 22 years to 73 years, with a mean age of 56.5 years. Almost all of the patients had been diagnosed as having cancer in the last two years. Seven (26%) of the patients were diagnosed with cancer in 1988, 12 (44%) were diagnosed in 1987, six (22%) in 1986, one patient in 1985, and one in 1984. One subject did not respond when asked the date of his family member's diagnosis. The patients had several different types of cancer. Seven patients had breast cancer, five patients had lung cancer, five more had cancer of the gastrointestinal tract, three had cancer of the liver or pancreas, three other patients had lymphoma, two had genital cancer, two had cancer of the bone, and one patient had rhabdomyosarcoma. Two of the subjects did not state the site of their family member's cancer and two subjects gave two answers to the question. The double

answers were: lung/bone cancer and colon/liver cancer. The patients had undergone multiple therapies with 22 (47%) having received chemotherapy, 13 (28%) had surgery, 11 (23%) had undergone radiation treatment, and one patient underwent immunotherapy.

Needs of the Families

Data were analyzed according to Tringali's (1986) methods for comparability of findings. A mean score was determined for each item from the 28 responses. The items that received a mean score of 3.50 to 4.00 were regarded as "most important," those needs receiving a mean score of 1.51 to 3.49 were considered to be "important," and those items with mean scores of 1.00 to 1.50 were regarded as "not important." Appendix C contains a listing of the need statements with their mean scores. Overall, 27 out of 53 need statements were rated as "most important" by family members. Twenty-five of the need statements were rated as "important," and one need was placed in the "not important" category.

Twenty-seven (51%) of the 53 need statements had a mean score of 3.50 to 4.00, the "most important" category. Three of these items received a mean score of 4.00. These three needs were: to know specific facts concerning the patient's progress; to be informed of changes in the patient's condition; and to be assured the patient was

receiving the best possible care. Nineteen (70%) of the items were needs from the cognitive category, seven (26%) of the items were from the emotional category, and one need was in the physical category. The cognitive needs that family members felt were important were concerned with the use of understandable, honest answers to questions about the treatments, changes in condition, prognosis of the patient, symptoms caused by the disease and/or treatments, who was caring for the patients, and how to care for the patient at home. The emotional needs that concerned family members were to feel that clinic personnel care about the patient and the family, gave the best care, and would keep the family informed of changes in the patient's condition. The physical need dealt with the location of the bathroom to the waiting room. Table 1 lists the "most important" need statements.

Twenty-five (47%) of the 53 need statements were classified as "important" needs. The mean scores given by the family members were from 1.67 to 3.46. Fourteen (56%) of the needs were from the emotional category, seven (28%) were from the physical category, and four (16%) were needs from the cognitive category. In the cognitive category, family members felt it was important to: know who can help with family and financial problems, and to have explanations about the environment before arriving. Their concerns in the emotional area were the needs to: see the

TABLE 1

**Family Members' Most Important Needs*
by Need, Mean, and Category**

<u>Item</u>	<u>Mean</u>	<u>S.D.</u>	<u>Category**</u>
1. To know specific facts concerning the patient's progress	4.00	0.00	C
2. To be informed of changes in the patient's condition	4.00	0.00	E
3. To be assured that the best possible care is being given to the patient	4.00	0.00	E
4. To have questions answered honestly	3.96	0.18	C
5. To know exactly what is being done for the patient	3.96	0.18	C
6. To have explanations given in terms that are understandable	3.96	0.18	C
7. To feel there is hope	3.96	0.18	E
8. To know what symptoms the treatment of disease can cause	3.96	0.18	C
9. To know when to expect symptoms to occur	3.96	0.18	C
10. To feel that clinic personnel care about the patient	3.92	0.26	E
11. To know the name of your doctor in the clinic	3.92	0.26	C
12. To know what treatment the patient is receiving	3.89	0.31	C
13. To be told about changes in treatment plans while they are being made	3.89	0.31	C
14. To know why things are done for the patient	3.85	0.44	C

TABLE 1 (continued)

Item	Mean	S.D.	Category**
15. To have a specific person to call at the clinic if problems arise at home	3.85	0.35	C
16. To have booklets that explain my family member's disease and treatment	3.85	0.35	C
17. To know the probable outcome of the patient's illness	3.84	0.61	C
18. To feel accepted by clinic staff	3.82	0.39	E
19. To have directions about what to do for the patient at home	3.82	0.61	C
20. To know what types of staff members are taking care of the the patient	3.75	0.44	C
21. To know at the time you leave the clinic when you are to return	3.75	0.51	C
22. To talk about the possibility of the patient's death	3.67	0.72	E
23. To receive information about the patient at each visit	3.67	0.66	C
24. To talk with the doctor at each visit	3.61	0.63	E
25. To know which staff members could give what type of information	3.60	0.56	C
26. To be told about other people who could help with problems	3.57	0.57	C
27. To have a bathroom near the waiting room	3.57	0.87	P

*Items Receiving a Mean Score of 3.50 to 4.00

**C = Cognitive, E = Emotional

same nurse and call her at any time; to be allowed to express feelings and receive emotional support; and to be alone and with the patient as needed. The physical needs were concerned with being able to visit the clinic at any time, to have nourishment available, and with the physical layout of the clinic. See Table 2 for a listing of need statements in the "important" category.

Only one need was rated as "not important." In this classification the mean scores ranged from 1.00 to 1.99. The item was a physical need having to do with being allowed to smoke in the waiting room of the clinic. The mean score the item received was 1.14 with an S.D. of 0.52. An analysis of the relationships between the demographic information on the sex and education level of the subjects and the cancer site and therapies of the patients and the importance of needs was looked at. Due to the similarity between demographic parameters and responses to the tool, no relationships were found.

Within the different categories of needs, which were the highest and lowest ranked needs? In order to determine this, the need statements were looked at by their respective categories and the mean scores the statements received were compared.

In the cognitive category, nineteen (83%) of the 23 need statements were ranked as "most important" with mean scores ranging from 3.50 to 4.00 by family members. Only

TABLE 2

**Family Members' Important Needs*
by Need, Mean, and Category**

Item	Mean	S.D.	Category**
1. To know the name of your nurse in the clinic	3.46	0.57	C
2. To have someone concerned with my health	3.42	0.63	E
3. To be able to call the nurse at any time	3.39	0.78	E
4. To have friends nearby for support	3.32	0.94	E
5. To visit the clinic at any time	3.32	0.72	P
6. To be allowed to cry	3.28	0.97	E
7. To be told about someone to help with family problems	3.25	0.79	C
8. To be assured that it is all right to leave the house for a while	3.25	0.98	E
9. To have explanations about the environment before going into the clinic for the first time	3.21	0.87	C
10. To have appointment times changed for special conditions	3.18	1.07	E
11. To have the waiting room near the patient examination room	3.14	0.65	P
12. To talk to the same nurse every visit	3.11	0.75	E
13. To be in the examining room with the patient	3.03	1.07	E
14. To talk about feelings such as anger or guilt	3.03	1.07	E
15. To have comfortable furniture in the waiting room	2.82	0.90	P

TABLE 2 (continued)

Item	Mean	S.D.	Category**
16. To be able to be alone at any time	2.67	1.18	E
17. To have someone to help with financial problems	2.57	1.16	C
18. To have a telephone near the waiting room	2.53	0.92	P
19. To have a short waiting period before being seen	2.52	1.13	E
20. To have someone with me when visiting the clinic	2.50	1.03	E
21. To have interesting magazines available at the clinic to read while waiting	2.28	1.01	E
22. To have my pastor or rabbi visit at home	2.25	1.10	E
23. To have a place to be alone while waiting at the clinic	1.92	0.97	P
24. To have beverages, such as coffee, available at the clinic	1.75	0.92	P
25. To have food available in the clinic	1.67	0.86	P

*Items Receiving a Mean Score of 1.51 to 3.49

**C = Cognitive, E = Emotional

one item, having to do with knowing specific facts about the patient's progress, received a score of 4.00. The dispersion of scores in this "most important" category was narrow, S.D. range = 0.00 to 0.71, which demonstrated agreement among the family members who completed the questionnaire. Four (17%) of the cognitive received mean scores between 1.51 to 3.49, placing them in the "important" category. The lowest ranked cognitive need, to have someone to help with financial problems, received a mean score of 2.57. The S.D. range for these need statements was from 0.57 to 1.16, indicating agreement among the family members who were ranking these items. Table 3 contains a ranking of the mean score of the cognitive need statements.

Seven (33%) of the 21 need statements in the emotional category were in the "most important" category by virtue of having mean scores of 3.50 to 4.00. Two of the need statements received scores of 4.00. These needs were to be informed of changes in the patient's condition and to be assured that the patient was getting the best possible care. The S.D. range for these items was 0.00 to 0.72 which indicates agreement among the family members in their ranking of the importance of these items. Fourteen (66%) of the emotional need statements were classified in the "important" category, mean scores of 1.51 to 3.49. The S.D. range for this classification was 0.63 to 1.16. The

TABLE 3
Items in the Cognitive Category by
Importance to Family Members

Item	Mean	S.D.
1. To know specific facts concerning the patient's progress	4.00	0.00
2. To have questions answered honestly	3.96	0.18
3. To know exactly what is being done for the patient	3.96	0.18
4. To have explanations given in terms that are understandable	3.96	0.18
5. To know what symptoms the treatment or disease can cause	3.96	0.18
6. To know when to expect the symptoms to occur	3.96	0.18
7. To know the name of your doctor in the clinic	3.92	0.26
8. To know what treatment the patient is receiving	3.89	0.31
9. To be told about changes in treatment plans while they are being made	3.89	0.31
10. To know why things are done to the patient	3.85	0.44
11. To have a specific person to cal' at the clinic if problems arise at home	3.85	0.35
12. To have booklets that explain my family member's disease and treatment	3.85	0.35
13. To know the probable outcome of the patient's illness	3.84	0.61
14. To have directions about what to do for the patient at home	3.82	0.61
15. To know what types of staff members are taking care of the patient	3.75	0.44
16. To know at the time you leave the clinic when you are to return	3.75	0.51

TABLE 3 (continued)

Item	Mean	S.D.
17. To receive information about the patient at each visit	3.67	0.66
18. To know which staff members could give which type of information	3.60	0.56
19. To be told about other people who could help with problems	3.57	0.57
20. To know the name of your nurse in the clinic	3.46	0.57
21. To be told about someone to help with family problems	3.25	0.79
22. To have explanations about the environment before going into the clinic for the first time	3.21	0.87
23. To have someone to help with financial problems	2.57	1.16

lowest ranked emotional need, to have a pastor or rabbi visit at home, received a mean score of 2.25. Table 4 contains a ranking of the emotional need statements.

Only one of the need statements in the physical category was ranked in the "most important" category. The item, to have a bathroom near the waiting room, received a mean score of 3.57. Seven out of the nine physical need statements were ranked in the "important" category, with mean score between 1.51 to 3.49. The S.D. range for these items were 0.65 to 0.97. The lowest score, 1.14, was for the need to be allowed to smoke in the waiting room which placed it in the "not important" classification. Table 5 contains the ranking of the needs in the physical category by mean scores.

A summary of the importance of each category of need statements to family members of cancer patients is presented in Table 6.

Each questionnaire provided space for comments or other needs that were not covered by the questionnaire. The family member's responses were coded into cognitive, emotional, and physical needs. There were ten responses: six were emotional needs, two were cognitive needs, and two were physical needs. The cognitive responses dealt with receiving information about the disease from the doctor and others, and having someone willing to discuss the information with the family member. The emotional

TABLE 4
Items in the Emotional Category by
Importance to Family Members

Item	Mean	S.D.
1. To be informed of changes in the patient's condition	4.00	0.00
2. To be assured that the best possible care is being given to the patient	4.00	0.00
3. To feel there is hope	3.96	0.18
4. To feel that the clinic personnel care about the patient	3.92	0.26
5. To feel accepted by clinic staff	3.82	0.39
6. To talk about the possibility of the patient's death	3.67	0.72
7. To talk with the doctor at each visit	3.61	0.63
8. To have someone concerned with my health	3.42	0.63
9. To be able to call the nurse at any time	3.39	0.78
10. To have friends nearby for support	3.32	0.94
11. To be allowed to cry	3.28	0.97
12. To be assured that it is all right to leave the house for a while	3.25	0.98
13. To have appointment times changed for special conditions	3.18	1.07
14. To talk to the same nurse every visit	3.11	0.75
15. To be in the examining room with the patient	3.03	1.07
16. To talk about feeling such as anger or guilt	3.03	1.07
17. To be able to be alone at any time	2.67	1.18
18. To have a short waiting period before being seen	2.52	1.13
19. To have someone with me when visiting the clinic	2.50	1.03
20. To have interesting magazines available at the clinic to read while waiting	2.28	1.01
21. To have my pastor or rabbi visit at home	2.25	1.10

TABLE 5
Items in the Physical Category by
Importance to Family Members

Item	Mean	S.D.
1. To have a bathroom near the waiting room	3.57	0.87
2. To visit the clinic at any time	3.32	0.72
3. To have the waiting room near the patient examination room	3.14	0.65
4. To have comfortable furniture in the waiting room	2.82	0.90
5. To have a telephone near the waiting room	2.53	0.92
6. To have a place to be alone while waiting at the clinic	1.92	0.97
7. To have beverages, such as coffee, available at the clinic	1.75	0.92
8. To have food available in the clinic	1.67	0.86
9. To be allowed to smoke in the waiting room	1.14	0.52

TABLE 6
Importance of Categories of Need to Family Members

	Most Important *	Important **	Not Important ***	Total Number of Items in Each Need Category
Cognitive	19	4	0	23
Emotional	7	14	0	21
Physical	1	7	1	9
Total # of Items in Each Ranking Category	27	25	1	53

*Items Receiving a Mean Score of 3.50 to 4.00

**Items Receiving a Mean Score of 1.51 to 3.49

***Items Receiving a Mean Score of 1.00 to 1.50

responses were concerned with the functioning of relationships, to have hope, to interact and receive hope from others, and to be able to spend time alone. The physical responses dealt with the physical status of the patient and the layout of the clinic and hospital.

Comparison of Study Results With Those Obtained by Tringali

The ranking of the need statements by the subjects in this study were compared with those of Tringali (1986). In her study, Tringali assessed family members who had cancer patients in initial, recurrent, or follow-up treatment. Since this study was concerned with family members of cancer patients receiving initial treatment, only those subject's responses of Tringali's that were also in the initial stage (n=10) were compared.

In this study, 27 (54%) of the 53 need statements were ranked as "most important." Three of the items received a mean score of 4.00. These needs were to know specific facts about the patient's progress, to be informed of changes in the patient's condition, and to be assured that the patient was receiving the best possible care. In Tringali's (1986) study, 20 (38%) of the need statements fell into this category. Six of the items received a mean score of 4.00. These needs were to have questions answered honestly, to be informed of changes in the patient's

condition, to know what treatment the patient is receiving, to have understandable explanations, to know symptoms the disease or treatment can cause, and when the symptoms can occur. All but one of the same needs were ranked as "most important" in the two studies. In this study, seven needs were ranked in the "most important" category that were in the "important" category in Tringali's study. These needs were: to know at the time you leave the clinic when to return; to talk about the patient's possible death; to receive information about the patient at each visit; to talk with the doctor at each visit; to know which staff members give what type of information; to be told about others who can help with problems; and to have a bathroom near the waiting room. Tringali's study had one need ranked in the "most important" category which this study did not. This item had to do with receiving directions about how to care for the patient at home. The categories of needs were the same between the two studies. Nineteen (70%) of the need statements in this study in the "most important" category were in the cognitive category, seven (26%) were in the emotional category, and one in the physical category. In Tringali's study, 15 (75%) were cognitive needs, five (25%) were emotional needs, and none were physical needs. See Table 7.

In this study, twenty-five (47%) of the 53 need statements were ranked as "important" by family members

TABLE 7

**Mean Ranking of Family Members' Most Important
Needs in Iversen's and Tringali's Studies***

Need	Iversen's Mean	Tringali's Mean	Category**
1. To know specific facts concerning the patient's progress	4.00	3.90	C
2. To be informed of changes in the patient's condition	4.00	4.00	E
3. To be assured that the best possible care is being given to the patient	4.00	3.90	E
4. To have questions answered honestly	3.96	4.00	C
5. To know exactly what is being done for the patient	3.96	3.90	C
6. To have explanations given in terms that are understandable	3.96	4.00	C
7. To feel there is hope	3.96	3.90	E
8. To know what symptoms the treatment or disease can cause	3.96	4.00	C
9. To know when to expect symptoms to occur	3.96	4.00	C
10. To feel that the clinic personnel care about the patient	3.92	3.90	E
11. To know the name of your doctor in the clinic	3.92	3.80	C
12. To know what treatment the patient is receiving	3.89	4.00	C
13. To be told about changes in treatment plans while they are being made	3.89	3.90	C
14. To know why things are done for the patient	3.85	3.80	C

TABLE 7 (continued)

Need	Iversen's Mean	Tringali's Mean	Category**
15. To have a specific person to call at the clinic if problems arise at home	3.85	3.50	C
16. To have booklets that explain my family member's disease and treatment	3.85	3.50	C
17. To know the probable outcome of the patient's illness	3.84	3.90	C
18. To feel accepted by clinic staff	3.82	3.40	E
19. To have directions about what to do for the patient at home	3.82	3.80	C
20. To know what types of staff members are taking care of the patient	3.75	3.10	C
21. To know at the time you leave the clinic when you are to return	3.75	3.90	C
22. To talk about the possibility of the patient's death	3.67	3.60	E
23. To receive information about the patient at each visit	3.67	3.20	C
24. To talk with the doctor at each visit	3.61	2.90	E
25. To know which staff members could give what type information	3.60	3.40	C
26. To be told about other people who could help with problems	3.57	3.40	C
27. To have a bathroom near waiting room	3.57	3.20	P

*Receiving a Mean Score of 3.50 to 4.00

**C = Cognitive, E = Emotional, P = Physical

compared with thirty (56%) in Tringali's (1986) study. Again, many of the needs ranked as "important" were similar between the two studies. In this study, there were two needs in this category that were not in Tringali's. These needs were to have food and beverages available in the clinic. Tringali's study had six needs in the "important" category which this study did not. It should be noted that the subjects in this study had rated all six of these needs as belonging in the "most important" category. These needs were: to know what staff members could give what type of information; to be told about other people to help with problems; to receive information about the patient at each visit; to have a bathroom near the waiting room; to know what types of staff members are taking care of the patient; and to talk with the doctor at each visit. In this study, four (15%) of these needs were in the cognitive category, fourteen (56%) were in the emotional category, and seven (28%) were in the physical category. In Tringali's study, eight (27%) needs were in the cognitive category, 16 (53%) of the needs were from the emotional category, and six (20%) were from the physical category. Table 8 contains the comparison of the need statements in the "important" category from both studies.

There were few items in the physical need category. In both studies, the same need statement was ranked as "not important." The item was concerned with being allowed to

TABLE 8

**Mean Ranking of Family Members' Important Needs
in Iversen's and Tringali's Studies***

Need	Iversen's Mean	Tringali's Mean	Category**
1. To know the name of your nurse in the clinic	3.46	3.30	C
2. To have someone concerned with my health	3.42	3.00	E
3. To be able to call the nurse at any time	3.39	3.20	E
4. To have friends nearby for support	3.32	3.10	E
5. To visit the clinic at any time	3.32	2.40	P
6. To be allowed to cry	3.28	2.80	E
7. To be told about someone to help with family problems	3.25	2.60	C
8. To be assured that it is all right to leave the house for a while	3.25	3.00	E
9. To have explanations about the environment before going into the clinic for the first time	3.21	2.90	C
10. To have appointment times changed for special conditions	3.18	2.50	E
11. To have the waiting room near the patient examination room	3.14	2.60	P
12. To talk to the same nurse every visit	3.11	2.70	E
13. To be in the examining room with the patient	3.03	3.10	E
14. To talk about feelings such as anger or guilt	3.03	2.70	E

TABLE 8 (continued)

Item	Iversen's Mean	Tringali's Mean	Category**
15. To have comfortable furniture in the waiting room	2.82	2.80	P
16. To be able to be alone at any time	2.67	2.80	E
17. To have someone to help with financial problems	2.57	2.50	C
18. To have a telephone near the waiting room	2.53	2.20	P
19. To have a short waiting period before being seen	2.52	3.40	E
20. To have someone with me when visiting the clinic	2.50	2.00	E
21. To have interesting magazines available at the clinic to read while visiting	2.28	2.60	E
22. To have my pastor or rabbi visit at home	2.25	2.30	E
23. To have a place to be alone while waiting at the clinic	1.92	1.60	P
24. To have beverages, such as coffee, available at the clinic	1.75	1.50	P
25. To have food available in the clinic	1.67	1.30	P

*Receiving a Mean Score of 1.51 to 3.49

**C = Cognitive, E = Emotional, P = Physical

smoke in the waiting room. Tringali (1986) had two other needs in this category: to have food and beverages available in the clinic.

Summary

This study was a replication of one on the needs of family members of cancer patients conducted by Tringali (1986). Twenty-eight family members of cancer patients in a military outpatient clinic participated. The findings of the two studies were similar, many of the same needs being ranked in the same way.

In this study, 27 (51%) of the 53 need statements were ranked as "most important" while in Tringali's (1986) study, 20 (38%) needs were in the same category. In both studies, the majority of the needs were from the cognitive category followed by emotional needs. Only one physical need in this study and none in Tringali's were in the "most important" category.

The findings were again similar in the "important" category. The family members in this study ranked 25 (40%) of the 53 needs in the "important" category compared to 30 (56%) needs in Tringali's (1986) study. Most of the needs in both studies were from the emotional category, with cognitive and physical needs being almost the same.

Few needs were ranked in the "not important" category; only one from this study and three from Tringali's (1986). The needs from both studies were from the physical category.

CHAPTER V

Discussion of Findings, Implications and Recommendations

Discussion of Findings

The findings of this study supported those of Hampe (1975), Molter (1979), Welch (1981), O'Brien (1983), Wright and Dyck (1984), and Tringali (1986), which were reviewed in the conceptual framework. All of these studies demonstrated that family members of patients with a life-threatening disease can identify and prioritize their needs. The family members in these studies believed their most important needs were for: honest, understandable information about the patient's condition, treatment, and prognosis; to know that the best care was being given by personnel that cared about the patient; and that there was emotional support for the family.

In comparing the results of this (n=28) study with Tringali (n=10) (1986), cognitive needs were more important overall than emotional or physical needs to the family members. The family members in this study rated 19 out of 23 cognitive needs in the "most important" category, compared to seven of the 21 emotional needs, and one of the nine physical needs. Since this study only looked at family members of cancer patients receiving initial treatment, that was also the group used to compare results

with in Tringali's study even though she also studied family members of cancer patients in recurrent and follow-up treatment. In Tringali's study, the family members of cancer patients in the initial stage rated 15 out of 23 cognitive needs as "most important," compared with eight out of 21 emotional needs, and zero physical needs. The findings were similar between the two studies.

In the "most important" category, the subjects from this study placed 27 (54%) of 53 needs in this category compared to 20 (38%) needs in Tringali's (1986) study. The needs included in this category from both studies were very similar, with the majority of needs being cognitive. Weisman and Worden (1976) have identified information seeking as one of the general coping strategies used by people which would help explain why family members of cancer patients chose the cognitive category of needs as most important. When a family member of a cancer patient has the needed information about the disease, treatment, and prognosis, s/he is able to meet their own needs and then to go on to function as a source of support for the cancer patient.

There were seven needs in the "most important" category from this study that were rated as "important" in Tringali's study (1986). The subjects in this study may have felt that knowing appointment times, who to talk with about problems and the patient's possible death, and which

staff members give what type of information was more important than subjects in Tringali's study did because they may have been referred to this hospital from a smaller military hospital. They were now in an unfamiliar environment and unsure how to find resources to meet their needs. A possible reason for the needs to see the doctor and receive information at every visit as being so important could have been if the family members perceived that they could not go in with the patient to see the doctor and get answers to their questions. The need to have a bathroom near the waiting room may have been important due to the layout of the hospital which consisted of long halls and long walks to the bathroom. In Tringali's study, there was one need in the "most important" category that was in the "important" category in this study. It is not known why family members in Tringali's study viewed directions about how to care for the patient at home as "most important" when this study's subjects did not. It could be that patients in her study were at a different stage of illness or had a different disease site than subjects in this study.

Family members in this study rated 25 (47%) of 53 needs in the "important" category compared to 30 (56%) needs in Tringali's study. Of the 25 needs in this study, 14 needs were from the emotional category, seven from the physical category, and four needs from the cognitive

category. In Tringali's study, 16 of the 30 needs in the "important" category were from the emotional category, eight needs were from the cognitive category, and six needs were from the physical category. The preponderance of emotional needs in this category may be due, as was stated before, to the families' overwhelming needs for information. Until the information needs are met and the family feels more in control, the emotional needs cannot be dealt with, causing the family to perceive them to be of less importance.

Again, many of the needs were similar between the two studies in the "important" category. This study had two needs in this category which Tringali's study did not. These were to have food and beverages available in the clinic. Tringali's study had six needs in the "important" category which this study did not. All six of these needs were ranked as "most important" in this study. These needs were: to know which staff give what type of information; to be told about others to help with problems; to talk with the doctor at each visit; to know what staff members are taking care of the patient; and to have a bathroom near the waiting room. It is not known why this study's subjects felt it was important to have food and beverages in the clinic while Tringali's subjects did not. The six needs in this category from Tringali's study that were not in the same category in this study may not have been as important

to Tringali's subjects if they were being included in visits and given information about the patient and available services.

An interesting finding was that in both studies it was deemed more important by family members to know the name of their doctor than to know the name of the nurse. Tringali (1986) has put forth the idea that families may believe that the nurse works for the doctor and not with the family or may be due to inconsistent nurse/family interactions. The author would agree with the former idea that patients and families do not have a clear idea of the nurse's role in the clinic and what they are doing for the patient and family. This is consistent with studies of other patients.

There are problems in the design of the questionnaire. One problem is that the need statements were derived from a review of the literature and not from what family members said their needs were. If the need statements are going to help in determining what needs are most important to family members, then families should determine what their needs are, not health professionals.

Another design problem was that there were unequal numbers of need statements in each category, especially the physical. The physical needs statements were also a problem as they did not deal with the physical needs that could be expected of family members of cancer patients but

instead looked at the physical layout of the clinic and having food available in the clinic.

The placement of the need statements in the various categories needs to be examined. There are questions about the placement of the items in the particular categories, especially the cognitive and emotional. Tringali (1986) did not explain how the needs were placed in each category.

A further criticism of the tool is the scale used to determine the importance of the needs. The categories "most important" needs and "not important" needs each had a difference of 0.5 in their scales. The scale for the "important" needs was from 1.51 to 3.49 or a difference of 1.98. This scale does not discriminate enough on importance. A large number of the needs (n=27) in this study were placed in the "most important" category which makes it difficult to determine what are the most important needs. The middle category for "important" is so large that it becomes difficult to determine what needs are important and which needs are really not that important or are all these needs really important. Again, a tool developed with patient and family input may help with this.

In spite of all the comments about the weakness of the tool, in the two studies in which the tool has been used; in different parts of the country and in different samples; the findings are similar. That says something about the

tool. Families of cancer patients do have needs and many of them are very important.

Implications for Nursing

This study has implications for nurses working with cancer patients and their families. Recent nursing literature has emphasized the importance of family-centered nursing care. Instead of only treating the patient, the literature has recommended that the patient be viewed as part of a complex unit, the family. This study has provided further support of that concept. The results showed the families, as well as patients, are affected by the diagnosis and treatment of one of its members of cancer. Nurses must learn to be family-oriented in their practice in order to insure that the family will have its needs met and thus be better able to support the ill family member.

It is evident from this study and others that the family members can identify and prioritize their needs. It is within the scope of nursing practice to assess these needs, develop, and implement interventions to meet these needs. An additional implication for oncology nurses is for them to realize that family members desire information before they need emotional support. The family members want information about the patient, his disease, treatment, prognosis, complications, where to get help, and so on.

These enormous needs for information were demonstrated in both this study and the one conducted by Tringali (1986). Nurses need to develop and implement plans to make sure that family members are getting the information that they need. So far the emphasis in cancer nursing has been on emotional support and then information.

Recommendations for Further Research

The following are recommendations for future studies.

1. A tool should be developed with needs based on input from family members of cancer patients. It should have equal numbers of cognitive, emotional, and physical needs. Reliability should be tested.
2. A similar study with a larger sample and control of variables.
3. A similar study but the questionnaire would be given several times over the illness trajectory to determine how needs change.
4. A study which looks at nurses' and patients' perceptions of the role of the nurse in working with the family and in meeting the needs of families.
5. A study which looks at the needs of family members of hospitalized cancer patients to see if the needs differ from the ones documented for an outpatient clinic.
6. A similar study which also examines if the needs are being met and by whom or what.

BIBLIOGRAPHY

- Abrams, R.D. (1966). The patient with cancer--his changing pattern of communication. New England Journal of Medicine, 274(6), 317-322.
- Aguilera, D.C., & Messick, J.M. (1986). Crisis intervention: theory and methodology (5th ed.). St. Louis: C.V. Mosby.
- American Cancer Society. (1987). Cancer facts and figures-1987. New York: Author.
- Auger, J. (1976). General systems theory. In D. Johnson (Ed.), Behavior systems and nursing. New Jersey: Prentice-Hall, pp. 19-29.
- Bertalanffy, L.V. (1968). General systems theory: foundations, development, and applications. New York: George Braziller.
- Bertrand, A. (1972). Social organization: a general system and role theory perspective. Philadelphia: F.A. Davis, pp. 95-106.
- Blum, D.S. (1984). Crisis intervention techniques. In Proceedings of the National Conference on Practice, Education, and Research in Oncology Social Work. New York: American Cancer Society, pp. 39-41.
- Bullough, B. (1982). Emotional support for the patient with breast cancer. Health Values: Achieving High Level Wellness, 6(2), 19-22.
- Burr, W. (1973). Theory construction and the sociology of the family. New York: John Wiley & Sons.
- Caplan, G. (1974). Support systems in community mental health. New York: Behavioral Publications, pp. 1-40.
- Caplan, G. (1983). The family as a support system. In H.I. McCubbin, A.E. Cauble, & J.M. Patterson (Eds.), Family stress, coping, and social support. Springfield: Charles C. Thomas, pp. 200-221.
- Cassileth, B.R., & Hamilton, J.N. (1979). The family with cancer. In B.R. Cassileth (Ed.), The cancer patient: social and medical aspects of care. Philadelphia: Lea and Febinger, pp. 233-247.

- Chekryn, J. (1984). Cancer recurrence: personal meaning, communication, and marital adjustment. Cancer Nursing, 7(6), 491-498.
- Cobb, S. (1976). Social support as a moderator of life stress. Psychosomatic Medicine, 38(5), 300-314.
- Cobb, S. (1983). Social support and health throughout the life course. In H.I. McCubbin, A.E. Cauble, & J.M. Patterson (Eds.), Family stress, coping, and social support. Springfield: Charles C. Thomas, pp. 189-199.
- Cohen, F., & Lazarus, R.S. (1980). Coping with the stresses of illness. In G.L. Stone, F. Cohen, & N. Adler (Eds.), Health psychology--a handbook. San Francisco: Josey-Bass, pp. 217-254.
- Cohen, M.M., & Wellisch, D.K. (1978). Living in limbo: psychosocial interventions in families with a cancer patient. American Journal of Psychotherapy, 32(4), 561-571.
- Craven, R.F., & Sharp, B.H. (1972). The effects of illness on family functions. Nursing Forum, 11(2), 187-193.
- Dean, A., & Lin, N. (1977). The stress-buffering role of social support. The Journal of Nervous and Mental Disease, 165(6), 403-417.
- Dunkel-Schetter, C., & Wortman, C.B. (1982). The interpersonal dynamics of cancer--problems in social relationships and their impact on the patient. In H.S. Friedman, & M.R. DiMatteo (Eds.), Interpersonal issues in health care. New York: Academic Press, pp. 69-101.
- Dyck, S., & Wright, K. (1985). Family perceptions: the role of the nurse throughout an adult's cancer experience. Oncology Nursing Forum, 12(5), 53-56.
- Duvall, E.M. (1977). Marriage and family development (5th ed). Philadelphia: J.B. Lippincott, pp. 111-116.
- Farkas, S.W. (1980). Impact of chronic illness on the patient's spouse. Health and Social Work, 5(4), 39-57.
- Gardener, K.G., & Wheeler, E.C. (1987). Patient's perception of support. Western Journal of Nursing Research, 9(1), 115-131.

- Germino, B.B. (1984). Family members' concerns after cancer diagnosis. Unpublished doctoral dissertation, University of Washington, Seattle.
- Giaquinta, B. (1977). Helping families to face the crisis of cancer. American Journal of Nursing, 77(10), 1585-1588.
- Gillis, C. (1983). The family as a unit of analysis: strategies for the nurse researcher. Advances in Nursing Science, 5, 50-59.
- Glasser, P.H., & Glasser, L.N. (1970). Adequate family functioning. In P.H. Glasser, & L.N. Glasser (Eds.), Families in crisis. New York: Harper and Row, pp. 291-301.
- Googe, M.C., & Varricchio, C.G. (1981). A pilot investigation of home health care needs of cancer patients and their families. Oncology Nursing Forum, 8(4), 24-28.
- Gotay, C.C. (1984). The experience of cancer during early and advanced stages: The views of patients and their mates. Social Science Medicine, 18(7), 605-613.
- Grandstaff, N.W. (1976). The impact of breast cancer on the family. Frontiers of Radiation Therapeutic Oncology, 11, 146-156.
- Grobe, M.E., Ahmann, D.C., & Ilstrup, D.M. (1982). Needs assessment for advanced cancer patients and their families. Oncology Nursing Forum, 9(2), 26-30.
- Hampe, S. (1975). Needs of the grieving spouse in a hospital setting. Nursing Research, 24(2), 26-30.
- Hill, R. (1949). Families under stress: adjustment to the crisis of war, separation and reunion. New York: Harper & Brothers, 3-21.
- Hinds, C. (1985). The needs of families who care for patients with cancer at home: are we meeting them? Journal of Advanced Nursing, 10, 575-581.
- Holing, E.V. (1983). A descriptive study of the dying trajectory; the primary caregiver's impressions. Unpublished master's thesis, University of Washington, Seattle.
- House, J.S. (1981). Work, stress, and social support. Philippines: Addison Wesley.

- Janosik, E.H. (1984). Crisis counseling: a contemporary approach. Monterey, CA: Wadsworth Health Sciences Division, 3-22.
- Kaplan, D.M., Smith, A., Grobstein, R., & Fischman, S.E. (1973). Family mediation of stress. Social Work, 18(4), 60-69.
- Kirschling, J.M. (1986). The experience of terminal illness on adult family members. Public Health Nursing, 3(4), 121-138.
- Klein, R.F., Dean, A., & Bogdonoff, M.D. (1967). The impact of illness upon the spouse. The Journal of Chronic Disease, 20, 241-248.
- Krant, M.J., & Johnston, C. (1978). Family members' perceptions of communications in late stage cancer. International Journal of Psychiatry in Medicine, 8(2), 203-216.
- Leavitt, M. (1982). Families at risk: primary prevention in nursing practice. Boston: Little, Brown, pp. 3-15.
- Lewis, F.M. (1983). Family level services for the cancer patient: critical distinctions, fallacies, and assessment. Cancer Nursing, 5(3), 193-200.
- Lewis, F.M. (1986). The impact of cancer on the family: a critical analysis of the research literature. Patient Education and Counseling, 8, 269-289.
- Lewis, F.M., Ellison, E.S., & Woods, N.F. (1985). The impact of breast cancer on the family. Seminars in Oncology Nursing, 1(3), 206-213.
- Lindsey, A.M., Norbeck, J.S., Carrieri, V.L., & Perry, E. (1981). Social support and health outcomes in post-mastectomy women: a review. Cancer Nursing, 4(5), 377-384.
- Longman, A.J., & Graham, K.Y. (1986). Living with melanoma: content analysis of interviews. Oncology Nursing Forum, 13(4), 58-64.
- Lovejoy, N.C. (1986). Family responses to cancer hospitalization. Oncology Nursing Forum, 13(2), 33-37.

- MacVicar, M.G. (1986). A conceptual framework for family-centered cancer care. In B. Flynn, & M. Miller (Eds.), Current perspectives in nursing: social issues and trends. St. Louis: C.V. Mosby, pp. 35-43.
- Mailick, M. (1979). The impact of severe illness on the individual and family: an overview. Social Work in Health Care, 5(2), 117-128.
- Maxwell, M.B. (1982). The use of social networks to help cancer patients maximize support. Cancer Nursing, 5(4), 275-281.
- McCubbin, H.I., & Patterson, J.M. (1983). Family adaption to crisis. In H.I. McCubbin, A.E. Cauble, & J.M. Patterson (Eds.), Family stress, coping, and social support. Springfield: Charles C. Thomas, pp. 26-47.
- Miller, J.G. (1969). Living systems: basic concepts. In W. Gray, F. Duhl, & N. Rizzo (Eds.), General systems theory and psychiatry. Boston: Little, Brown, pp. 51-133.
- Molter, N. (1979). Needs of relatives of critically ill patients: a descriptive study. Heart Lung, 8(2), 332-339.
- Morrow, G., Hoaglund, A., & Morse, I. (1982). Sources of support perceived by parents of children with cancer: implications for counseling. Patient Counseling and Health Education, 4(1), 36-39.
- Northouse, L.L. (1981). Mastectomy patients and the fear of recurrence. Cancer Nursing, 4(3), 213-220.
- Northouse, L.L. (1984). The impact of cancer on the family: an overview. International Journal of Psychiatry, 14(3), 215-242.
- O'Brien, M.E. (1983). An identification of the needs of family members of terminally ill patients in a hospital setting. Military Medicine, 148, 712-716.
- Pearlin, C.I., & Schooler, C. (1983). The structure of coping. In H.I. McCubbin, A.E. Cauble, & J.M. Patterson (Eds.), Family stress, coping, and social support. Springfield: Charles C. Thomas, pp. 109-135.
- Sexton, D.C., & Munro, B.H. (1985). Impact of a husband's chronic illness (C.O.P.D.) on the spouse's life. Research in Nursing and Health, 8, 83-90.

- Sills, G.M., & Hall, J.E. (1985). A general systems perspective for nursing. In J. Hall, & B. Weaver (Eds.), Distributive nursing practice: a systems approach to community nursing (2nd ed.). Philadelphia: J.B. Lippincott, pp. 21-29.
- Skorupka, P., & Bohnet, N. (1982). Primary caregivers' perception of nursing behaviors that best meet their needs in a home care hospice setting. Cancer Nursing, 5(5), 371-374.
- Smilkstein, G. (1980). The cycle of family function: a conceptual model for family medicine. Journal of Family Practice, 11(2), 223-232.
- Stuifbergen, A.K. (1987). The impact of chronic illness on families. Family Community Health, 9(4), 43-51.
- Taylor, R. (1979). Family: a systems approach. American Family Physician, 20(5), 101-114.
- Tringali, C. (1986). The needs of family members of cancer patients. Oncology Nursing Forum, 13(4), 65-69.
- Weisman, A.D., & Worden, J.W. (1976). The existential plight in cancer: significance of the first 100 days. International Journal of Psychiatry in Medicine, 7(1), 1-15.
- Welch, D. (1981). Planning nursing interventions for family members of adult cancer patients. Cancer Nursing, 4(5), 365-369.
- Welch-McCaffery, D. (1985). Cancer, anxiety, and quality of life. Cancer Nursing, 8(3), 151-158.
- Wellisch, D.K. (1985). The psychological impact of breast cancer on relationships. Seminars in Oncology Nursing, 1(3), 195-199.
- Wellisch, D.K., Jamison, K.R., & Pasnau, R.O. (1978). Psychological aspects of mastectomy II: the man's perspective. American Journal of Psychiatry, 135(5), 543-546.
- Woods, N.F., & Earp, J.C. (1978). Women with cured breast cancer: a study of mastectomy patients in North Carolina. Nursing Research, 27(5), 279-285.
- Wortman, C.B. (1984). Social support and the cancer patient. Cancer, 53(10), 2339-2360.

Wright, K., & Dyck, S. (1984). Expressed concerns of adult cancer patients' family members. Cancer Nursing, 6(5), 371-375.

APPENDIX A

Researcher's Statement to Subject

My name is Captain Jaime Iversen. I am a graduate student from the University of Washington School of Nursing conducting a research study. The purpose of this study is to determine the needs of family members of patients with cancer. I am specifically interested in what needs family members believe are most important. Families are considered an important source of support for the cancer patient and the family can function more effectively in this capacity when their needs are met. The study will have no benefit to you but will be of value to health professionals in the future.

If you agree to participate in this study, you will be asked to answer some questions about yourself and your relative such as age, sex, occupation, education level, your relationship to the patient, and the patient's disease and treatment. Then you will be asked to read 53 need statements and circle the number in the column which best indicates how important the statement is to you. The form should take about 20 minutes to complete.

There is no risk to you in this study. Anonymity of your study results will be maintained. I will be the only one to see your form. You will not be identified, numbers will be assigned to the forms, and I will always refer to them by that number. The final report will be available in the University of Washington's Health Sciences Library as a part of my thesis.

Your participation is voluntary and you may withdraw from the study at any time. The care of your family member will not be affected if you choose not to participate in the study. I will be happy to answer any questions you have at this time. Thank you for your help with my study.

Signature of Investigator

Jaime S. Iversen

Phone Number: 206-883-8096

This is to certify that Captain Jaime Iversen is a graduate student in the Department of Physiological Nursing at the University of Washington. If you have questions about her or the study, you may call me at the number listed below.

Signature of Advisor

Maxine L. Patrick, D.P.H.

Professor

Dept. of Physiological Nursing

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Seattle, Washington 98195

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APPENDIX B

Data Producing Instrument

Date _____
Code Number _____

Demographic Data:

1. Your age at last birthday: _____ Years
2. Your sex (Circle the number of your answer)
 1. Male
 2. Female
3. Relationship to the patient (Circle the number)
 1. Spouse
 2. Adult Child
4. Are you presently: (Circle as many as apply)

1. Employed Full-Time	5. Retired
2. Employed Part-Time	6. Unable to work because of illness or disability
3. Full-Time Homemaker	7. Unemployed
4. Volunteer Worker	
5. Please describe your usual occupation _____
6. What is the highest level of education you have completed? (Circle the number)

1. No Formal Education	6. Some College or Vocational School
2. Some Grade School	7. Completed College
3. Completed Grade School	8. Some Graduate Work
4. Some High School	9. Completed Graduate School
5. Completed High School	
7. Patient's age at last birthday: _____ Years
8. Patient's sex (Circle number)
 1. Male
 2. Female
9. Date of patient's diagnosis _____
10. What kind of cancer does the patient have? _____
11. What medical treatments has the patient undergone? (Circle as many as apply)

1. Surgery	3. Chemotherapy
2. Radiation	4. Immunotherapy

APPENDIX B (continued)

Self-Perceived Family Needs

Below is a list of statements that describes needs which some family members of cancer patients have experienced. Please read each statement carefully. Then CIRCLE the number in the column to the right of the statement which best indicates how IMPORTANT you feel that statement is to YOU at this time. It is important that you respond to all statements and to do so honestly. Please give only one response to each statement.

Need	Not Important (1)	Slightly Important (2)	Fairly Important (3)	Very Important (4)
1. To have questions answered honestly (C)	1	2	3	4
2. To know specific facts concerning the patient's progress (C)	1	2	3	4
3. To feel that the clinic personnel care about the patient (E)	1	2	3	4
4. To be informed of changes in the patient's condition (E)	1	2	3	4
5. To know exactly what is being done for the patient (C)	1	2	3	4
6. To know why things are done for the patient (C)	1	2	3	4
7. To know what treatment the patient is receiving (C)	1	2	3	4
8. To have explanations given in terms that are understandable (C)	1	2	3	4
9. To be told about changes in treatment plans while they are being made (C)	1	2	3	4
10. To feel there is hope (E)	1	2	3	4
11. To feel accepted by clinic staff (E)	1	2	3	4
12. To talk to the same nurse every visit (E)	1	2	3	4
13. To have someone with me when visiting the clinic (E)	1	2	3	4
14. To have appointment times changed for special conditions (E)	1	2	3	4
15. To have friends nearby for support (E)	1	2	3	4

APPENDIX B (continued)

Need	Not Important (1)	Slightly Important (2)	Fairly Important (3)	Very Important (4)
16. To be allowed to cry (E)	1	2	3	4
17. To have the waiting room near the patient examination room (P)	1	2	3	4
18. To have a telephone near the waiting room (P)	1	2	3	4
19. To be able to be alone at any time (E)	1	2	3	4
20. To be assured that the best possible care is being given to the patient (E)	1	2	3	4
21. To have explanations about the environment before going into the clinic for the first time (C)	1	2	3	4
22. To know which staff members could give what type information (C)	1	2	3	4
23. To know the name of your nurse in the clinic (C)	1	2	3	4
24. To know the name of your doctor in the clinic (C)	1	2	3	4
25. To talk with the doctor at each visit (E)	1	2	3	4
26. To talk about the possibility of the patient's death (E)	1	2	3	4
27. To have a place to be alone while waiting at the clinic (P)	1	2	3	4
28. To be allowed to smoke in the waiting room (P)	1	2	3	4
29. To have beverages, such as coffee, available at the clinic (P)	1	2	3	4
30. To have interesting magazines available at the clinic to read while waiting (E)	1	2	3	4
31. To have a short waiting period before being seen (E)	1	2	3	4
32. To know what types of staff members are taking care of the patient (C)	1	2	3	4

APPENDIX B (continued)

Need	Not Important (1)	Slightly Important (2)	Fairly Important (3)	Very Important (4)
33. To have a specific person to call at the clinic if problems arise at home (C)	1	2	3	4
34. To know the probable outcome of the patient's illness (C)	1	2	3	4
35. To receive information about the patient at each visit (C)	1	2	3	4
36. To be told about other people who could help with problems (C)	1	2	3	4
37. To be told about someone to help with family problems (C)	1	2	3	4
38. To be assured that it is all right to leave the house for a while (E)	1	2	3	4
39. To have directions about what to do for the patient at home (C)	1	2	3	4
40. To have my pastor or rabbi visit at home (E)	1	2	3	4
41. To have comfortable furniture in the waiting room (P)	1	2	3	4
42. To have food available in the clinic (P)	1	2	3	4
43. To have a bathroom near the waiting room (P)	1	2	3	4
44. To be in the examining room with the patient (E)	1	2	3	4
45. To talk about feelings such as anger or guilt (E)	1	2	3	4
46. To have someone concerned with my health (E)	1	2	3	4
47. To visit the clinic at any time (P)	1	2	3	4
48. To be able to call the nurse at any time (E)	1	2	3	4
49. To know at the time you leave the clinic when you are to return (C)	1	2	3	4

APPENDIX B (continued)

Need	Not Important (1)	Slightly Important (2)	Fairly Important (3)	Very Important (4)
50. To have booklets that explain my family member's disease and treatment (C)	1	2	3	4
51. To know what symptoms the treatment or disease can cause (C)	1	2	3	4
52. To know when to expect symptoms to occur (C)	1	2	3	4
53. To have someone to help with financial problems (C)	1	2	3	4

Thank you for completing the tool. This list may not cover all the needs that you have. Please write in any other needs in the space below.

C = Cognitive Need
E = Emotional Need
P = Physical Need

(These codes did not appear on the tool given to subjects. The codes are for analysis only.)

APPENDIX C

Mean Scores of the Need Statements

Need	Iversen's		Tringali's	
	Mean	S.D.	Mean	Category*
To know specific facts concerning the patient's progress	4.00	0.00	3.90	C
To be informed of changes in the patient's condition	4.00	0.00	4.00	E
To be assured that the best possible care is being given to the patient	4.00	0.00	3.90	E
To have questions answered honestly	3.96	0.18	4.00	C
To know exactly what is being done for the patient	3.96	0.18	3.90	C
To have explanations given in terms that are understandable	3.96	0.18	4.00	C
To feel there is hope	3.96	0.18	3.90	E
To know what symptoms the treatment or disease can cause	3.96	0.18	4.00	C
To know when to expect symptoms to occur	3.96	0.18	4.00	C
To feel that the clinic personnel care about the patient	3.92	0.26	3.90	E
To know the name of your doctor in the clinic	3.92	0.26	3.80	C
To know what treatment the patient is receiving	3.89	0.31	4.00	C
To be told about changes in treatment plans while they are being made	3.89	0.31	3.90	C
To know why things are done for the patient	3.85	0.44	3.80	C
To have a specific person to call at the clinic if problems arise at home	3.85	0.35	3.50	C
To have booklets that explain my family member's disease and treatment	3.85	0.35	3.50	C
To know the probable outcome of the patient's illness	3.84	0.61	3.90	C
To feel accepted by clinic staff	3.82	0.61	3.40	E

APPENDIX C (continued)

Need	Iversen's Mean	S.D.	Tringali's Mean	Category*
To have directions about what to do for the patient at home	3.82	0.61	3.80	C
To know what types of staff members are taking care of the patient	3.75	0.44	3.10	C
To know at the time you leave the clinic when you are to return	3.75	0.51	3.90	C
To talk about the possibility of the patient's death	3.67	0.72	3.60	E
To receive information about the patient at each visit	3.67	0.66	3.20	C
To talk with the doctor at each visit	3.61	0.63	2.90	E
To know which staff members could give what type information	3.60	0.56	3.40	C
To be told about other people who could help with problems	3.57	0.57	3.40	C
To have a bathroom near the waiting room	3.57	0.87	3.20	P
To know the name of your nurse in the clinic	3.46	0.57	3.30	C
To have someone concerned with my health	3.42	0.63	3.00	E
To be able to call the nurse at any time	3.39	0.78	3.20	E
To have friends nearby for support	3.32	0.94	3.10	E
To visit the clinic at any time	3.32	0.72	2.40	P
To be allowed to cry	3.28	0.97	2.80	E
To be told about someone to help with family problems	3.25	0.79	2.60	C
To be assured that it is all right to leave the house for a while	3.25	0.98	3.00	E
To have explanations about the environment before going into the clinic for the first time	3.21	0.87	2.90	C
To have appointment times changed for special conditions	3.18	1.07	2.50	E
To have the waiting room near the patient examination room	3.14	0.65	2.60	P

APPENDIX C (continued)

Need	Iversen's		Tringali's	
	Mean	S.D.	Mean	Category*
To talk to the same nurse every visit	3.11	0.75	2.70	E
To be in the examining room with the patient	3.03	1.07	3.10	E
To talk about feelings such as anger or guilt	3.03	1.07	2.70	E
To have comfortable furniture in the waiting room	2.82	0.90	2.80	P
To be able to be alone at any time	2.67	1.18	2.80	E
To have someone to help with financial problems	2.57	1.16	2.50	C
To have a telephone near the waiting room	2.53	0.92	2.20	P
To have a short waiting period before being seen	2.52	1.13	3.40	E
To have someone with me when visiting the clinic	2.50	1.03	2.00	E
To have interesting magazines available at the clinic to read while waiting	2.28	1.01	2.60	E
To have my pastor or rabbi visit at home	2.25	1.10	2.30	E
To have a place to be alone while waiting at the clinic	1.92	0.97	1.60	P
To have beverages, such as coffee, available at the clinic	1.75	0.92	1.50	P
To have food available in the clinic	1.67	0.86	1.30	P
To be allowed to smoke in the waiting room	1.14	0.52	1.10	P

*C = Cognitive, E = Emotional, P = Physical