

LIVING WITH CANCER: HUSBANDS' VIEW
OF LIFE STYLE CHANGES

by

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ABSTRACT

Cancer is one of the major chronic illnesses that brings about change in the family life style. A descriptive study was undertaken to determine the life style changes in 20 subjects whose wives were in the adjuvant, recurrent, or advanced treatment phase with gynecological cancer. The interview consisted of questions regarding changes in the husband's daily routine, changes in his relationship with others, and changes in his relationship with his wife. Results from questions regarding changes in daily routine and changes in the relationship with others revealed that the husbands experienced slight to moderate change with the greatest change occurring in eating patterns, sleeping patterns, overall daily routine, management of stress, daily work routine, time spent with children, activities around the home, other people's behavior, and time spent with others. The husbands experienced a moderate to great deal of change in their relationship with their wives with the greatest change occurring in activities shared with their wives, in their sexual relationship, and in their overall relationship with their wives. The study also revealed that the changes were not always for the worse; some changes were for the better and some neither for the better or for the worse. These findings offer direction for clinical nursing practice.

CHAPTER 1

INTRODUCTION

Cancer is one of the major chronic illnesses that brings about changes in family life style. The Random House Dictionary defines change as making the nature of something different from what it is and as becoming altered or modified. Any chronic illness, such as cancer, has a profound effect on both the patient and family. Since chronic illness is "an impairment of health that requires an extended period of medical treatment" (Leonard, 1972:687), it can disrupt the patient and family's sense of security, ability to carry out daily activities and responsibilities, and social roles.

Because the health of the cancer patient affects the functioning and activities of the family, a change in one member results in a change in the entire system (Menke, 1980; Olsen, 1970). The extent of change resulting from cancer and the way the family reorganizes itself to re-establish homeostasis can differ drastically among members. Since the "marital dyad lasts longer and is more intimate than any other family relationship," any physical illness that affects the husband or wife has some impact on the marital relationship (Vincent, 1970:350).

The cancer experience consists of the following periods: (1) prediagnostic, (2) diagnostic, (3) treatment, and (4) end of life (Marino and Kooser, 1981). The prediagnostic and diagnostic stages are

the periods when the patient first notices symptoms, seeks consultation with a physician, undergoes diagnostic procedures, receives confirmation of the diagnosis, and agrees to treatment. The treatment period is divided into five phases: definitive therapy, initial hospital discharge, adjuvant therapy, time of first tumor recurrence, and advanced disease state. During the definitive therapy phase, the patient is usually hospitalized and initial treatment is accomplished. At the time of the second phase, the patient is discharged from the hospital. He may or may not be cured and may require additional treatment. After the definitive therapy phase, adjuvant therapy may be given to kill any microscopic remnants of cancer in patients who are at a high-risk for recurrence. During the time of first tumor recurrence, the fourth phase, the threat of death becomes more real. The patient fears becoming a burden on his family. Communication and social relationships are more difficult and may become disrupted. Metastasis is documented during the advanced disease phase. Treatment is aimed at slowing the future spread of the cancer and the patient and family spend more time on symptom control and treatments. Social relationships become more unstable and the patient's family and friends assume more of his responsibilities. During the adjuvant, first tumor recurrence, and advanced disease state, the emphasis is on day-to-day living with the illness as it affects the family/home environment. The final period, the end of life, focuses on facilitating a dignified death. The length of each period varies with the disease, the patient, and the family.

Statement of the Problem

What are the life style changes reported by the husband during the treatment phase (adjuvant, tumor recurrence, advanced disease state) of his wife's experience with gynecological cancer?

Purpose

The purpose of this study was to describe the life style changes perceived by a husband whose wife is undergoing treatment and care for gynecological cancer.

Significance of the Problem

According to Cancer Facts and Figures (1979), approximately 18 percent of all cancer diagnosed in females involves the ovary and uterus. These cancers account for 12 percent of the deaths in women due to cancer.

Since treatment may represent mutilation, disfigurement, sexual dysfunction, and disability, chronic illness of the wife may be the greatest single source of danger that can disrupt family functioning (Parsons and Fox, 1952; Litman, 1971; Litman, 1974). Therefore, it may be difficult for her to maintain her normal role and responsibilities and to fulfill her obligations to the other family members (Litman, 1974). One of the primary roles of the wife is supportive strength to the nuclear family. This function may be diminished at a time when the nuclear family is asked to meet unexpected demands (Parsons and Fox, 1952).

The family may view the wife as being invulnerable and her activities too important to be disrupted. This poses a serious threat to family functioning resulting in disorganized family life, interpersonal problems, and increased role tension. The more prolonged and complicated the wife's illness, the greater the threat to family functioning. As a result of prolonged illness, other family members may need to assume new duties and responsibilities, especially within the home (Litman, 1974). The fewer the roles within the nuclear family, the harder it is to assume the duties and responsibilities of the chronically ill person. Therefore, illness of the wife may result in the husband assuming the roles of nursemaid and housewife (Wilson, 1971; Koos, 1946).

In summary, it can be seen that the health of the cancer patient affects the functioning and activities of the family. Chronic illness in one of the spouses results in increased role tension, role conflict, role accentuation, and role alterations (Larter, 1974; Klein, Dean, and Bogdonoff, 1967; Goldstein, Regnery, and Wellin, 1981). Klein and others (1967:243) reported the following effects upon the spouse as a result of illness in their mate: jumpiness; easily angered; easily depressed, blue, or sad; easily excited; feelings easily hurt; more apt to hide feelings; and a decrease in work activity. Goldstein and others (1981) described the effects of chronic illness on the caretaker (the person who assumes the responsibility for the care of the chronically ill person) as being dependent upon the patient's degree of disability and dependence, the caretaker's health and functional mobility, the amount of assistance available within and outside the home, and the

roles and responsibilities of the caretaker. Therefore, the husband whose wife is chronically ill may experience restricted mobility on activities outside the home and conflict between the new demands and his normal role responsibilities.

Conceptual Framework

The conceptual framework is based on chronic illness as a stressor and an individual's adaptation to the stressor (Figure 1).

Chronic illness produces stress within the family system. Lazarus (as cited in Miller, Denner, and Richardson, 1976:162), described stress as "the extreme disturbance of biological and psychological functioning brought about by unusually threatening, demanding, or damaging life conditions." Stress causes disequilibrium within the system; family functioning is less efficient and less effective (Miller et al., 1976; Glasser and Glasser, 1970). Present family roles and rules may be ineffectual in maintaining homeostasis when a family member becomes ill.

Lazarus (as cited in Miller et al., 1976) identified the event (stimulus) producing change in the family system as a stressor. Chronic illness is a type of a stressor that brings about change within the family. This change disrupts the family's homeostatic balance resulting in complex adjustments and alterations with each family member. The family faces the prospect of chronic, enduring changes in its standard roles, relationships, and sense of unity. As a result, the family must regroup in order to regain its homeostatic balance. As the ill member

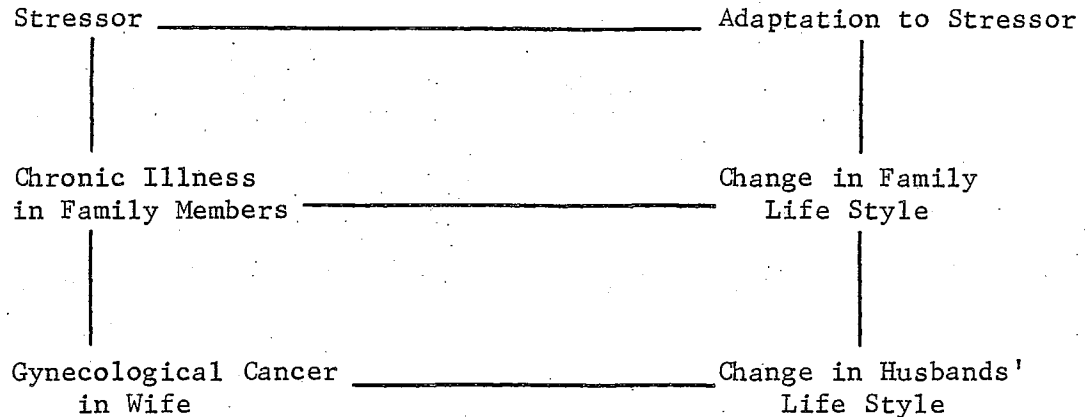


Figure 1. Conceptual Framework

moves into the sick role, the family reconstructs its roles and functions to accommodate to the new situation (Cassileth and Hamilton, 1979; Olsen, 1970; Cameron, 1977). Through modifications and reorganization, the family seeks to reestablish homeostasis in the new framework of chronic illness. The reorganized family may function better or worse than it did before the chronic illness (Olsen, 1970; Glasser and Glasser, 1970; Cassileth and Hamilton, 1979).

The degree of disorganization and reorganization depends on many aspects of the family and its individual members prior to the illness. Family cohesiveness, its ability to withstand stress, the hardship of chronic illness, and the definition each family member makes in regard to the seriousness of the changes are factors related to the adjustment (Cassileth and Hamilton, 1979; Cameron, 1977).

Glasser and Glasser (1970) described changes that aid in reestablishing equilibrium within the family. These adaptations include: (1) changes in present family functioning, (2) alterations in group

structure and processes, (3) shifts in family power structure, (4) changes in communication, (5) changes in tasks assigned family members, and (6) changes in problem-solving methods. Without these adaptations, disequilibrium will continue.

Therefore, gynecological cancer in the wife is an example of a chronic illness which brings about change in the husband. When the wife assumes the sick role, expectations and role behavior change. The wife may not be able to fulfill the role of partner, homemaker, caretaker, and financial source. As the family reorganizes, changes occur in the family's structure and function. Thus, by definition, the wife's illness due to cancer is a stressor event. The reorganized family may function as well as, better, or worse than it did before. The husband's description of the changes that occur can provide information regarding his reorganization and functioning. Therefore, this study focused on the husband's view of the changes affecting his activities and relationships when his wife's cancer experience acts as a stressor.

Definition of Terms

Adaptation: Adjustment to different circumstances or conditions (The Random House Dictionary of the English Language, 1966).

Chronic Illness: "An impairment of health that requires an extended period of medical treatment" (Leonard, 1972:687).

Family: Persons who are directly related to the patient or who represent a significant support group (Marino and Kooser, 1981).

Gynecological Cancer: Cancer involving the female reproductive system.

Life Style: Those activities and roles that are an individual's way of living.

Stressor: The event (stimulus) producing change (Lazarus as cited in Miller et al., 1976).

CHAPTER 2

SELECTED REVIEW OF THE LITERATURE

Much of the literature deals with how cancer in a family member produces life style changes in the cancer patient and any or all family members. The review of the literature deals first with these changes in the family, second with the changes that occur in the cancer patient (wife), and third with the effects of the wife's cancer on the husband.

Effects of Chronic Illness and Cancer on Family Life Style

The family can be depicted as a unit or system. Olsen (1970) defined a system as a whole which is greater than the sum of its parts. The family is more than just a group of people living together; it is a dynamic entity with a structure of its own. The family develops homeostatic mechanisms in order to preserve stability within the system. The nuclear family consists of a husband, wife, children, and/or other relatives living in the home (Olsen, 1970). The extended family includes all the other relatives. The nuclear family guides the family's structure and function. It is the framework for teaching children the values, norms, and beliefs of their culture. Each family has its own set of goals and rules of behavior. Each member occupies and functions in generally stabilized roles, relationships, and expectations with one another. These roles, relationships, and expectations exist in dyads (wife-mother,

husband-father, etc.). Rules exist within the family which define and govern these relationships and maintain the family's stability (Olsen, 1970; Cassileth and Hamilton, 1979; Cameron, 1977).

The modern American family is not totally seen as a small, isolated, nuclear unit. Litman (1974) stated that a major form of assistance is provided by members of kin-related families. In cases of chronic illness, the family can count on help from the extended family. Litman (1974) reported that 43.2 percent felt that it would be fairly difficult for them to take care of a sick family member for a prolonged period of time. Effects of chronic illness on the nuclear family may be inversely related to family size. Large families of five or more members seem to have less problems with role relations. Families of two to four members are more likely to experience role revision and inconvenience (Litman, 1974).

Many people view cancer as an "insidious, debilitating, painful, drawn-out process" (Pilsecker, 1979:369) and as "unclean, painful, and dehumanizing" disease (Watson, 1978:45). They may associate cancer with a chronic endless disability accompanied by mutilation, helplessness, suffering, and death. In addition, there are fears of abandonment, job loss, and financial crisis (Watson, 1978). Therefore, the diagnosis of cancer is perceived as a tremendous attack to the family system.

Health workers need to identify the meaning that the illness of cancer has for the family. Menke (1980:10) cited the following factors influencing the family system towards cancer as: the family's value orientation, cultural background, values toward health and illness,

perception of health care delivery systems, previous experiences with illness and hospitalization, and understanding of the patient's illness and therapy.

How the patient plays the sick role and the family's response to the illness may influence the patient's condition and the health and happiness of the family. The roles within the family, the available emotional support, and the family's financial stability affect the family's response to the chronic illness of one of its members. Patterns and attitudes within the home influence the ability to treat illness. There may be difficulties in coordinating the goals of medicine with those of the family. Family behavior patterns and attitudes may not fit into the treatment program resulting in broken appointments and medication regimens. Therefore, the family should be involved in decisions made regarding the patient's illness (Litman, 1974; Mabrey, 1970).

Uncertainty may exist in the home since the cancer patient spends much of his illness in this environment. There is sometimes a long period between diagnosis and death or cure. The patient straddles the line between the world of the sick and the world of the well. If the patient is physically able he may resume part of his pre-illness responsibilities within the home or job. At other times, the focus of family function is on the care of the ill member (Cassileth and Hamilton, 1979).

Both the patient and family must make ongoing adjustments to the pain, discomfort, loss of control, and changes in body image

experienced by the patient. The family must deal with its feelings; its sense of powerlessness; its ambivalence, anger, and guilt; and its fear. In order to give the needed care required by the ill member and meet the needs of other family members, the family must learn how to manage the demands made upon them and the role shifts that accompany the illness.

As a result, there is the probability that the family members may overreact to the illness. This further intensifies the stress experienced by the patient and other family members (Craven and Sharp, 1972). The extent the family is affected by the chronic illness depends on the nature of the illness itself. The more prolonged and complicated the illness, the more effect it has on family functioning (Litman, 1974).

Gynecological Cancer of the Wife

Gynecological cancer strikes females at any age. This may mean that the patient is under severe stress. The patient may face the threat of a disabling illness or death. Also, the patient may express and experience fears regarding the unknown, mutilating surgery, frightening treatments, dependency, altered body image, role dysfunction, abandonment, disturbances of interpersonal relationships, loss of self-esteem, and physical symptoms (Welch, 1979; Leonard, 1972; Ehlke, 1978). These fears are usually ongoing as there may be a long time between diagnosis and death, or cure. The patient may live for months and years with a diagnosis of cancer. In addition, there are numerous disruptions in the patient's routine due to hospitalizations,

doctors visits, rehabilitative efforts at home, physical limitations, and emotional stress (Cassileth and Hamilton, 1979).

Treatment for gynecological cancer includes surgery which is often extensive, involving wide excision of the tumor and adjacent lymph nodes. Sometimes functioning body parts, such as the uterus, ovaries, sections of colon, or bladder, must be removed. Surgery may represent changes in body image, sexual dysfunction, and disability. These cancers are also treated with radiation therapy and chemotherapy. These modes of treatment affect the normal cells as well as the cancer cells. The side effects may include weakness, fatigue, hair loss, skin changes, nausea and vomiting, diarrhea, and stomatitis (Watson, 1978; Saunders, 1981).

Also, a diagnosis of gynecological cancer may affect a woman's view of her sexuality. The removal of the uterus forces one to deal with the loss of an internal organ involved in reproduction, symbolic of femininity, and associated with maintaining one's youth and attractiveness. The woman may fear the loss of sexual desire and attractiveness with the subsequent loss of her husband's interest and fidelity. In addition to the psychological reactions that may disrupt sexual responsiveness, there are physical reasons for sexual dysfunction. There is loss of hormones with oophorectomy which results in decreased lubrication and thinning of the vaginal walls. Radiation therapy for carcinoma of the cervix may result in pelvic fibrosis, and vaginal narrowing. Chemotherapy may cause masculinizing and/or feminizing effects (Burkhalter, 1978; Woods, 1979; Watson, 1978). Also, the

disease and treatment may cause fatigue or malaise which may have an effect on the patient's feelings of sexual desire and/or on the patient's ability to express sexual feelings into physical expression. Pain, limited mobility, and vascular interference that impair blood flow to the genitalia may limit the patient's sexual expression. In addition, the patient may not be able to integrate the sick role and sexual role (Lamb and Woods, 1981).

In summary, a diagnosis of cancer causes changes in the patient. First, the patient may be unable to care for himself physically. Second, the patient may be unable to fulfill normal social roles, such as one's sex role, occupational role, and family role. Third, it may impair the patient's ability to fulfill his normal responsibilities to others (Thomas, 1970). Therefore, if the wife is ill, she may have to relinquish her homemaking and child-care activities. As a result of these changes, the family member may feel hindered and have to alter vacation, recreational, and social opportunities.

Effects of the Wife's Cancer on the Husband's Life Style

Within the marital relationship, cancer in one partner produces life style changes in the spouse. One area of the husband's life style that undergoes change is the interruption of daily routines, such as eating and sleeping patterns (Breu and Dracup, 1978). The husband also experiences changes in his self-image. In addition, the wife's cancer experience may result in increased tension, problems, and stress in the husband as his life style undergoes change (Cassileth and Hamilton, 1979; Malick, 1972; Craven and Sharp, 1972).

Another area of the husband's life style that undergoes change is his external reference groups. Members of the extended family, occupational, and friendship circle serve as sources of interpersonal contacts, references for family behavior, and a framework for measuring attitudes, aspirations, and behaviors. Due to the cancer, a prime reference group for the husband's thinking is the outpatient clinic, physicians, nurses, hospital, treatments, and other patients and families in the waiting room (Cassileth and Hamilton, 1979). The husband's recreational role and function may be altered. Social contacts are interrupted. Also, the husband's relationship with other family members may be affected by life style changes (Malick, 1972; Craven and Sharp, 1972; Breu and Dracup, 1978). Even though most of the direct expenses related to cancer treatment are covered by third-party payment, financial strain may result from the indirect expenses by family members who take off work to care for, visit, and accompany the patient to the physician (Cassileth and Hamilton, 1979).

A third area of the husband's life style that undergoes change is the interpersonal relationship with his wife. Patterns of interaction are disrupted or threatened. Both short-term and long-term family objectives, plans, and orientations may be temporarily or permanently disrupted. Some of these goals involve educational, occupational, financial, social plans, and child care. The external reference groups that the husband-wife interacts with are altered (Cassileth and Hamilton, 1979). Other functions and roles that are subject to change due to illness are as follows: housekeeper, child care, child

socializer, sexual, emotional, autonomy and authority (Malick, 1972; Craven and Sharp, 1972). There is role reversal, forced autonomy, and the loss of financial stability. Also, the spouses personal reward system is interrupted. All of these changes in functions and roles result in life style changes that affect the husband-wife relationship by producing tension, problems, and emotional strains (Breu and Dracup, 1978; Cassileth and Hamilton, 1979)..

Also, the physical and psychological sexual feelings of the cancer patient have potential effects on the husband. He may be unable to cope with his feelings of sexuality. He may fear contracting the disease or inflicting pain and harm (Wasow, 1977). The husband may not have any other acceptable outlet for expressing his sexual feelings. The husband may experience decreased sexual desire or sexual dysfunction secondary to fatigue from caring for his wife. The husband may be hesitant to initiate sexual relations with his wife, because he may see her as fragile, feel guilty about making demands on her, and/or for being interested in sex when his wife may not be (Lamb and Woods, 1981).

CHAPTER 3

METHODOLOGY

This chapter presents the research design, the sample, and the measurement tool for data collection.

Research Design

This was a descriptive study designed to describe the life style changes reported by the husband during the treatment phase of the wife's experience with gynecological cancer. This design enables one to gain insights regarding husband's life style changes. A structured interview was used to collect the data from husbands whose spouses have gynecological cancer.

Setting and Sample

This study was conducted in a large southwestern cancer center. A convenience sample consisting of the first 20 subjects was selected according to the following criteria: (1) married to or living in a common-law relationship with a woman diagnosed with gynecological cancer; (2) living with their spouses from the time of her diagnosis with gynecological cancer through completion of the interview; (3) spouse is in the adjuvant, recurrent, or advanced disease phase of her cancer experience; (4) spouse is currently undergoing treatment or care for her cancer; (5) read and write English; and (6) agree to participate in the study.

Potential subjects for this study were obtained by direct contact with the husband and patient in the gynecologic oncology outpatient clinics and medical inpatient units. If the subject agreed to participate, an appointment was made for an interview to take place in the clinic or subject's home.

Human Subjects' Approval

This study was not subject to Human Subjects' approval (Appendix A). The objectives and risks of the study were explained both verbally and in a disclaimer form to each subject and patient who volunteered to participate in the study (Appendix B).

A letter describing the objectives of the study and a copy of the interview guide were submitted to the attending medical oncologist, gynecologic oncologist, and radiation oncologist (Appendix C). The study proceeded after permission was granted from the various physicians.

Measurement Tool

An interview guide (Appendix D) was developed to elicit the husband's view of perceived life style changes. The structured interview guide was divided into the following categories: (A) demographic data, (B) changes in daily routine, (C) changes in husband's relationship with others, (D) changes in husband's relationship with his wife, and (E) diagnosis and treatment data on the spouse. There are a total of 39 questions (section A, 6; section B, 6; section C, 10; section D, 8; section E, 1; and section F, 8).

The content of the structured interview guide was based on the review of the literature. Changes occurring in daily routine were discussed by Breu and Dracup (1978) and Thomas (1970). In addition to these authors, the question on managing stress was also based on Weisman's (1979) coping strategies. Changes occurring in the husband's relationship with others were discussed by Craven and Sharp (1972), Cassileth and Hamilton (1979), Breu and Dracup (1978), Litman (1974), and Goldstein and others (1981). Changes occurring in the husband's relationship with his wife were discussed by Cassileth and Hamilton (1979), Craven and Sharp (1972), Klein and others (1967), Litman (1974), Wilson (1971), and Koos (1946). Face validity was obtained by having all questions reviewed by two oncology clinical nurse specialists, two oncology social workers, four nurses with oncology nursing experience, and one cancer patient.

Questions regarding change in sleeping patterns, change in daily routine as a result of fitting treatments in with regular routines, change in amount of time spent with the children, changes in activities with the wife, and how comfortable the husband feels in discussing his wife's illness with her were modified from Cameron's study (1977) regarding life style changes in mothers who had a child with chronic disease. Questions regarding people who have offered help, the type of help received, and changes in expressing feelings were modified from Larter's study (1975) regarding life style changes in women whose husbands had experienced a myocardial infarction. Also, a scale modified from Young and Longman (1980) was used for most of the questions to

determine the amount of change which had occurred in the husband's life as a result of his wife's cancer experience. The husband was asked to circle the place on the scale that best described these changes. For example, the scale for question (D-1) regarding the changes that have occurred in decision making appeared as:

no change	1	2	3	4	5	very great deal of change
		Slight	Moderate	great change		

change for better

change for worse

neither

Similar scales are presented for questions regarding changes associated with overall change in daily routine (B-5), changes in managing stress (B-6), changes in time spent with children (C-4), changes in activities around the home (C-5), changes in activities outside the home (C-6), changes in others' behavior (C-7), and changes in amount of time spent with friends (C-8). Scales presented regarding the husband-wife relationship include changes in social/recreational activities (D-2), changes in expression of feelings (D-3), changes in sexual and psychological closeness (D-6, 7), and overall changes in the husband's relationship with his wife (D-8).

Pilot Study

A pilot study was completed on five subjects to determine whether the interview guide was understandable, to establish the time necessary to complete the interview, and to determine the best way to conduct the interview. Suggestions from the subjects for improvement of the questions and method of conducting the interview were used for further structuring of the interview guide.

Method of Data Collection

Each subject who agreed to participate in the study was interviewed and questions from the measurement tool were asked. The interviews took place in the outpatient clinics, the inpatient units, or in the home. The wife was not present at the time of the interview. The diagnosis and treatment data of the wife were collected by chart review.

Data Analysis

Statistical analysis was selected according to the nature of the data. The type of analysis used for nominal and ordinal data was frequencies, modes, and means.

CHAPTER 4

ANALYSIS OF THE DATA

This chapter includes the results of data collection according to the characteristics of the sample and the findings regarding changes in the husband's daily routine, changes in the husband's relationship with others, and changes in the husband's relationship with his wife.

Characteristics of the Sample

The sample population consisted of 20 subjects whose wives were receiving treatment at a cancer center in a large southwestern city. The characteristics discussed are the subjects' age, marital status, education, and ethnic background. The age range of the sample was 30 to 73 years with the mode of 60 to 69 years. All subjects were married at the time of their wives' diagnosis and all were currently living with their spouse. The mean number of years in the marital relationship was 26.5 with a range of 1 to 50 years. The formal education of the subjects were the following: five had less than a high school education, four finished high school, one completed business/vocational school, six attended some college, and four had a college degree. Fifteen of the subjects were Anglo-American, two were Mexican-American, and three were of other ethnic backgrounds. Seven of the subjects had children living at home with them ranging in age from four months to 43 years.

Twelve of the subjects lived alone with their wives, while one subject and wife lived with one of their children (Table 1).

The characteristics regarding the treatment data of the wife included age, diagnosis, number of years since diagnosis, past and current treatment, treatment stage, medical problems, and type of therapy taken at home. The age range of the wives was 25 to 75 years with a mean of 51.8 years. The main cancer diagnosis was ovarian and uterine carcinoma. Also, included were carcinoma of the cervix, carcinoma of the vulva, choriocarcinoma, and fallopian tube carcinoma. Eleven of the wives had been diagnosed with cancer less than two years, while nine had been diagnosed more than two years. Six were in the adjuvant treatment stage, six in treatment for recurrent disease, and eight in treatment for advanced disease (Table 2). The past treatment modalities that the wives received were surgery, chemotherapy, and radiation therapy. Chemotherapy was the current treatment modality most often received. Sixteen of the wives had no other medical problems. One of the wives had another primary cancer, two had complications related to surgery, and two had hypertension. Only one of the wives did not take any form of therapy at home. The most frequently mentioned therapies taken at home were anti-nausea medication, vitamins, oral chemotherapy, and pain analgesics.

Changes in the Husband's Daily Routine

Presented in this section are the findings regarding changes in eating habits and weight, personal appearance, sleeping patterns, overall changes in daily routine, and ability to manage stress.

Table 1. Demographic Characteristics of the Husbands

Characteristics	Number
Age	
30 - 39	4
40 - 49	3
50 - 59	1
60 - 69	10
70 - 79	2
Total	<u>20</u>
Years in Marital Relationship	
1 - 9	4
10 - 19	4
20 - 29	2
30 - 39	5
40 - 49	4
50 - 59	1
Total	<u>20</u>
Education	
Less than high school diploma	5
High school diploma	4
Business/vocational school	1
Some college	6
College degree	4
Total	<u>20</u>
Ethnic Background	
Anglo-American	15
Mexican-American	2
Other	3
Total	<u>20</u>
Members of Household	
Husband-wife lived alone	12
Children lived in home	7
Husband-wife lived with children	1
Total	<u>20</u>

Table 2. Characteristics: Age and Treatment Data of Wives

Characteristics	Number
Age	
20 - 29	3
30 - 39	2
40 - 49	1
50 - 59	6
60 - 69	7
70 - 79	<u>1</u>
Total	20
Diagnosis	
Cervix	2
Ovarian	9
Uterine	6
Other	<u>3</u>
Total	20
Time Since Diagnosis	
Less than 2 years	11
Greater than 2 years	<u>9</u>
Total	20
Treatment Stage	
Adjuvant	6
Recurrent	6
Advanced	<u>8</u>
Total	20

Table 3 presents the frequency for changes in the husband's daily routine according to eating habits, weight, personal appearance, sleeping patterns, and stress. Sixteen of the husbands experienced a change in eating habits. Even though there were little differences in the reasons for this change, the most frequent answers were eating out more frequently (N=7) and eating more irregularly (N=6). Only six of the husbands experienced a weight change; the maximum weight gain or loss was 20 pounds. There was little change reported in personal appearance. Only four of the husbands stated that some change had occurred. The answer most frequently checked as the reason for the change was a decrease in time to care for themselves (N=2). One subject stated that his grooming had improved since his wife's diagnosis. Ten of the husbands reported a change in sleeping patterns. The change reported was attributed to a decrease in the amount of sleep received per night (N=6) and awakening or getting up more frequently during the night (N=8). The reasons for awakening or getting up more frequently were to use the bathroom (N=3) and to assist their wives (N=3). Thirteen of the husbands stated they felt rested with the amount of sleep received while six stated they did not and one stated that he occasionally felt rested.

The ways in which the husbands managed stress varied. The most frequently checked answers were the following: seek more information (N=9), talking it out with others (N=7), do other things for distraction (N=7), take firm action based on present understanding (N=7), and try to forget (N=5). Ten of the husbands responded that there had been

Table 3. Frequencies of Change in Husbands' Daily Routine

Characteristics	Number
Eating Habits	
Change	16
No change	<u>4</u>
Total	20
Weight	
Change	6
No change	<u>14</u>
Total	20
Personal Appearance	
Change	4
No change	<u>16</u>
Total	20
Sleeping Patterns	
Change	10
No change	<u>10</u>
Total	20
Stress	
Change	10
No change	<u>10</u>
Total	20

changes in their ability to manage stress. Of those husbands who experienced a change, the mean reported change was 2.6 (slight to moderate change). Five of the husbands stated the change was for the better, three for the worse, and two neither. Every husband gave different reasons for the change.

Figure 2 summarizes the changes that occurred overall in the husbands' daily routine in the areas of eating, personal appearance, and sleeping patterns. Thirteen of the husbands stated there was an overall change in their daily routine. Of those who reported a change, the mean change was 2.8 (slight to moderate). Seven of the 13 reported the change was for the worse, three for the better, and three neither.

Changes in Husband's Relationship with Others

This section presents the findings regarding changes in work routines, time spent with children, activities around and outside the home, others' behavior, amount of time spent with friends, and the kinds of assistance the husband had received.

Table 4 presents the frequency for changes in the husbands' relationship with others according to employment, work routines, time spent with children, activities within and outside the home, other people's behavior, and amount of time spent with friends.

Six of the husbands were retired and 14 of the husbands were employed with 11 working outside the home and three working independently. Five of the husbands were employed over 40 hours per week, four at 40 hours per week, and five less than 40 hours per week. Five of the husbands reported a change in employment. One husband decreased his

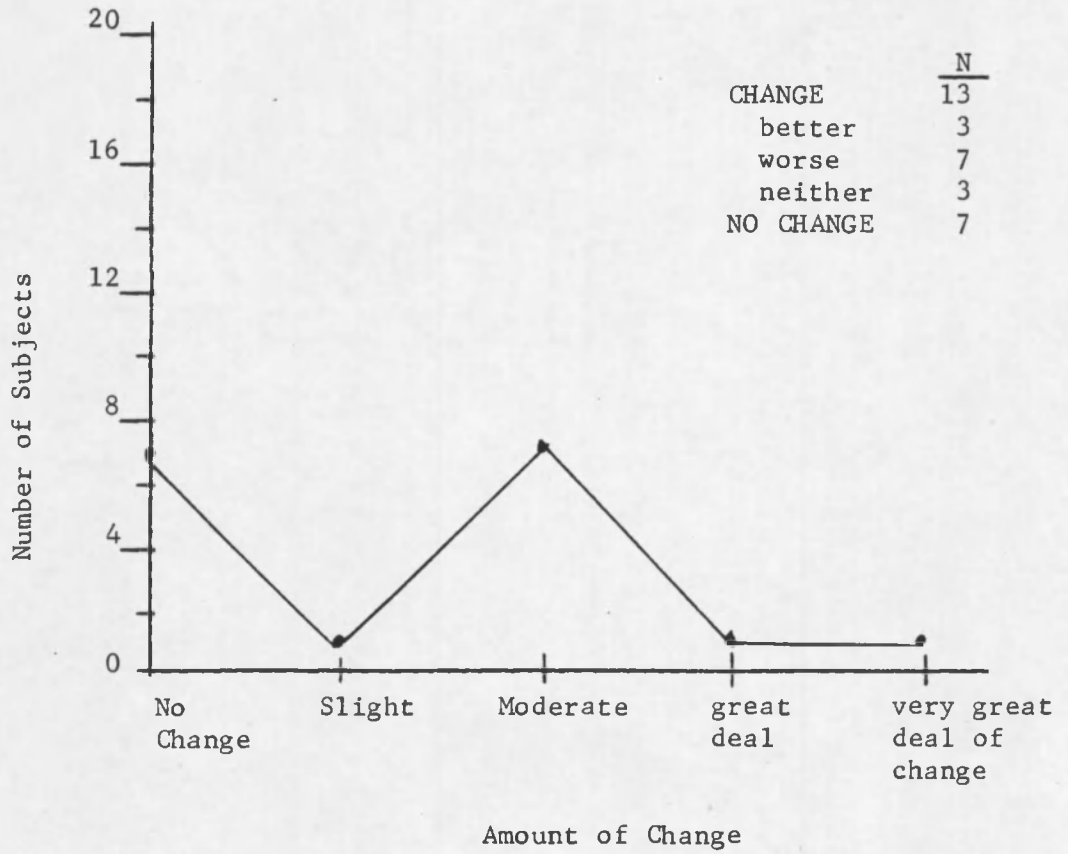


Figure 2. Overall Changes in Daily Routine of Husbands

Table 4. Frequencies of Change in Husbands' Relationship with Others

Characteristics	Number
Employment	
Change	5
No change	9
Total	<u>14</u>
Work Routines	
Change	9
No change	5
Total	<u>14</u>
Time Spent with Children	
Change	14
No change	3
Total	<u>17</u>
Activities Within Home	
Change	10
No change	10
Total	<u>20</u>
Activities Outside Home	
Change	7
No change	13
Total	<u>20</u>
Other People's Behavior	
Change	14
No change	6
Total	<u>20</u>
Amount of Time Spent with Friends	
Change	12
No change	8
Total	<u>20</u>

work hours and another one experienced a change in jobs as a result of moving for his wife's medical treatment. Two of the husbands gave no reason for the change and one retired at 65 years of age. Nine of the 14 husbands who were employed would leave work in order to assist their wives. The most common reasons given for leaving work were to accompany the wife to the doctor (N=8), accompany her for treatments (N=7), and to visit her in the hospital (N=7). The frequency of leaving work was dependent on the wife's appointment and/or treatment schedule.

The amount of time spent with the children changed in 14 out of 17 subjects with only one person experiencing a decrease in time. Of those husbands who reported a change, the mean was 2.7 (slight to moderate change). The most frequent reasons given for the change were the children calling or visiting more often (N=8) and the husband spending more time with the children (N=4).

The main types of activities participated in around the home were watching television (N=15), reading (N=12), maintenance work on the house (N=11), hobbies/crafts (N=8), listening to music (N=8), and gardening (N=8). Of the 10 husbands who reported a change in these activities, the mean change was 2.4 (slight to moderate change). Three of the husbands stated the change was for the better, three for the worse, and four neither. A decrease in the amount of time available for these activities (N=6) was the most frequent reason given for the change.

The types of activities participated in outside the home varied. Some of the activities mentioned were walking (N=5), fishing (N=5),

swimming (N=3), golf (N=3), and other (N=6). Five of the husbands stated they did not participate in any outdoor activities. Seven husbands responded that there was a change in their outdoor activities mainly due to a decrease in time (N=4). Of those who reported a change, the mean change was 3.0 (moderate). One stated the change was for the better, one for the worse, and five neither.

Fourteen of the husbands responded that other people's behavior toward them had changed with eight feeling the change was for the better, two for the worse, and four neither. The mean reported change was 2.7 (slight to moderate). The main reasons given for the change were that others showed more concern (N=5) and that there was more contact by others (N=4). Also, the amount of time the husband spent with friends underwent change. Of the 12 husbands who reported a change, the mean was 2.7 (slight to moderate). Eight of the husbands described the change as a decrease in the amount of time spent with friends with four stating there was an increase.

Children (N=15), other relatives (N=13), and friends (N=11) were the three people most often mentioned as the people offering help to the husbands. The types of assistance that the husband received since his wife's diagnosis were supportive visits from friends (N=11) and help with home management (N=7). Four of the husbands stated they had received no assistance.

Changes in the Husband's Relationship with His Wife

This section presents the findings regarding changes in decision making, social/recreational activities, expressing feelings, assisting

the wife with household activities, communication regarding the illness, sexuality, and overall change in the husband-wife relationship.

Table 5 presents the frequency for changes that occurred in the husbands' relationship with their wives since diagnosis in the areas of decision making, social/recreational activities, expressing feelings, assistance with household activities, and physical/psychological sexual activity. In the area of decision making, decisions regarding money, childcare, medical care, and future plans/goals were shared between the husband and wife. Decisions regarding home management were either shared or made by the wife. Four of the husbands responded that he and his wife were unable to make decisions regarding future goals/plans due to the uncertainty of the future. Seven of the husbands stated there had been a change in decision making since their wives' diagnosis. Of the husbands who reported a change, the mean was 3.1 (moderate). Two of the husbands stated the change was for the better, one for the worse, and three neither. The reasons given for the change were a change in the person making the decisions (N=4), change in the type of decisions made (N=3), and change in the complexity of decisions (N=3).

The most frequent activities shared by the husband and wife were dining out (N=17), social get-togethers (N=15), and music (N=8). Two husbands stated that he and his wife shared no social/recreational activities. Of the 12 husbands who reported a change, six stated the change was for the worse, two for the better, and four neither. The mean reported change was 3.1 (moderate). The reasons most frequently given for the change were a decrease in the frequency of activities

Table 5. Frequencies of Change in the Husbands' Relationship
with Their Wives Since Diagnosis

Characteristics	Number
Decision Making	
Change	7
No change	13
Total	<u>20</u>
Social/Recreational Activities	
Change	12
No change	8
Total	<u>20</u>
Expressing Feelings	
Change	9
No change	11
Total	<u>20</u>
Assistance with Household Activities	
Change	10
No change	10
Total	<u>20</u>
Physical Sexual Activity	
Change	13
No change	7
Total	<u>20</u>
Psychological Sexual Activity	
Change	12
No change	8
Total	<u>20</u>

(N=6), doing more things alone (N=4), and doing things with different friends (N=3).

In response to the question, ". . . which statement best describes how you express your feelings with your wife?", the most frequently checked answers were "I tell her exactly how I feel" (N=15) and "I hold my feelings inside" (N=9). Nine of the husbands stated a change had occurred in expressing their feelings with their wives with four stating the change was for the better, four for the worse, and one neither. The mean reported change was 3.6 (moderate to great deal). One reason given for the change was that it was now harder for them to express their feelings (N=5). All of the husbands assisted their wives with household activities, such as housecleaning, doing dishes, marketing/shopping, cooking, laundry, and budgeting money. Eleven of the husbands helped with four or more of the activities. Ten husbands reported a change in assistance given around the house with the change consisting of an increase in assistance.

The types of physical sexual activity that the husbands participated in since their wives' diagnosis were kissing (N=18), caressing (N=15), intercourse (N=9), and self-stimulation (N=4). Thirteen of the husbands reported a change in physical sexual activity with nine stating the change was for the worse, one for the better, and three neither. The mean reported change was 3.5 (moderate to great deal). The reason most frequently given for the change was a decrease in their physical sexual activity (N=12). The psychological aspects of the sexual relationship consisted of being with and enjoying one another (N=18),

holding and being held (N=15), and sharing and confiding in one another (N=15). Twelve of the husbands stated that this aspect of their sexual relationship had changed with six stating it was for the better, five for the worse, and one neither. The mean change reported was 2.9 (moderate). The change consisted of a decrease in psychological closeness (N=5) and an increase in satisfaction/closeness (N=6).

In response to the question regarding how comfortable the husband feels about discussing his wife's illness with her, the mean reported was 3.7 (moderately to very comfortable). Only two husbands stated they were not comfortable at all while nine husbands were extremely comfortable (Figure 3).

Figure 4 represents the overall changes reported in the husband and wife relationship. Thirteen stated there was a moderate to great deal of change (mean 3.3) with seven reporting a change for the better, four for the worse, and two neither.

Changes According to Number of Years in Relationship and Others Living in Household

In general, few changes were found in the husbands according to the number of years in the relationship. There were eight husbands married one to 19 years, and 12 married 25 to 50 years. More husbands married less than 20 years stated that a change occurred in their sleeping patterns, ability to manage stress, activities within the home, and social/recreational activities shared with their wives than husbands who had been married more than 25 years.

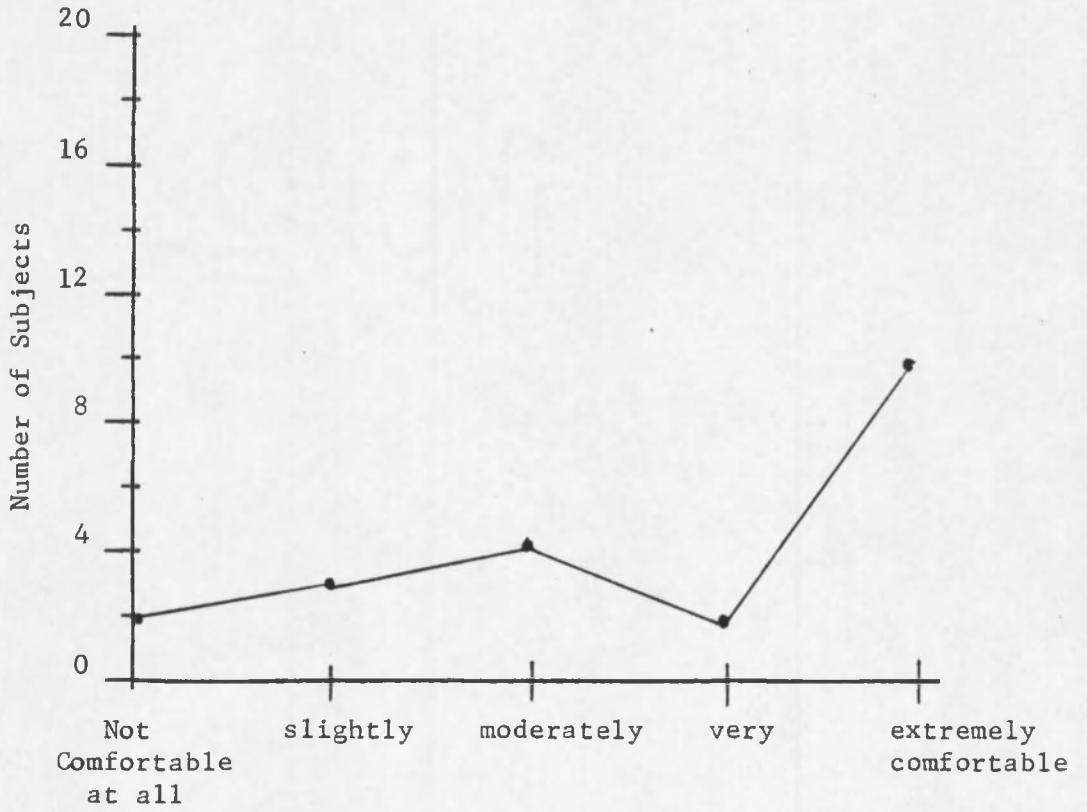


Figure 3. Ability of Husbands to Discuss Their Wives' Illness with Them

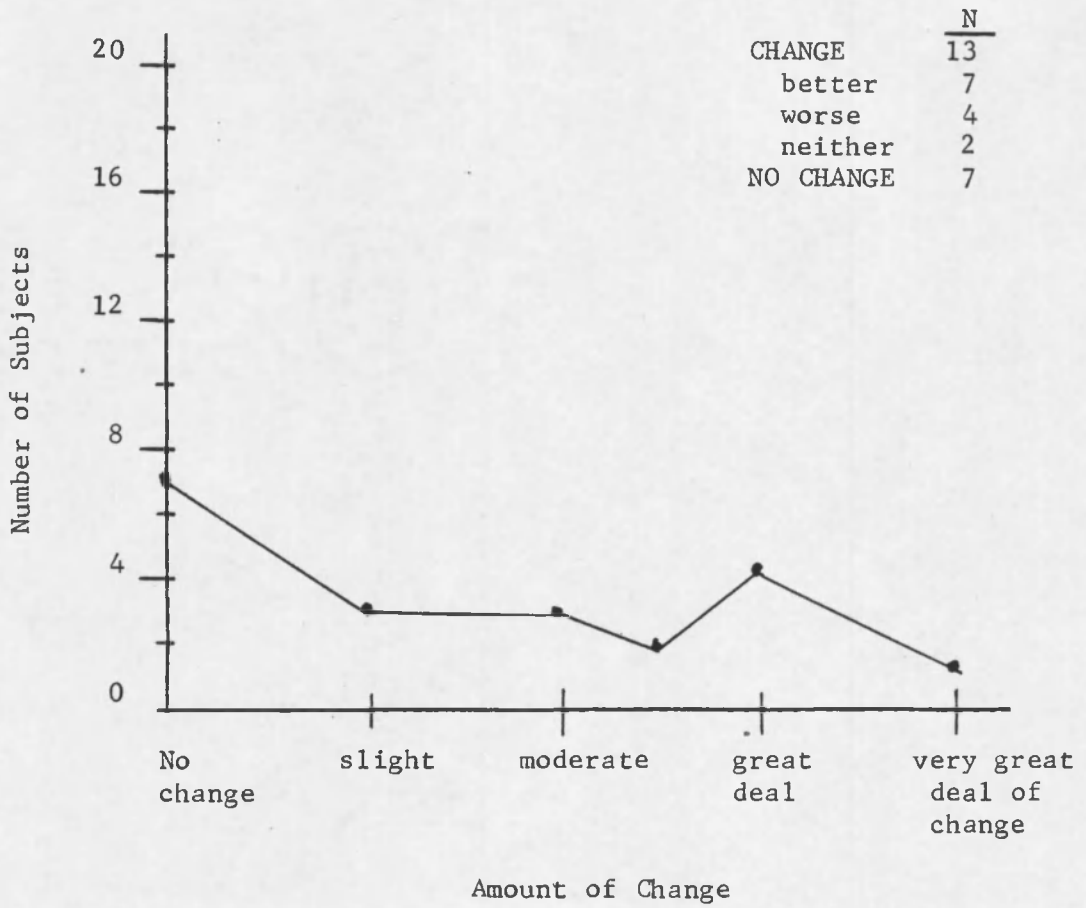


Figure 4. Overall Changes in the Husband-Wife Relationship

In households having children living at home, four or more of the husbands experienced a change in the following areas: weight, sleeping patterns, overall changes in daily routine, stress, activities within and outside the home, decision making, activities shared with wife, expressing one's feelings, and assistance around the house. In households without children less than six of the husbands experienced change in these same categories.

Summary

Responses to the question, "Please add any concerns, recommendations, and/or questions that you feel would better assist your care, your wife's care, and that of others" varied widely. These answers are found in Appendix E. Five husbands did not answer this question.

CHAPTER 5

INTERPRETATION OF FINDINGS

This chapter includes the findings of the study as they relate to the conceptual framework and the review of the literature. Implications of the findings, conclusions, and recommendations for further study are also discussed.

Relationship of Findings to Conceptual Framework and Review of the Literature

The conceptual framework was based on chronic illness as a stressor to the family. This event produces change and adaptation within the family system. Through reorganization, the family seeks to reestablish its homeostasis in the new framework of chronic illness. The areas used in studying change in the husband's life style as a result of gynecological cancer in his wife were:

1. Changes in daily routine.
2. Changes in relationship with others.
3. Changes in relationship with his wife.
4. Changes according to treatment phase.

Changes in Daily Routine

Comparable changes in eating and sleeping patterns were similar in this study as those suggested by Breu and Dracup (1978). Almost all the husbands experienced some change in eating patterns, and half

experienced a change in sleeping patterns. Findings regarding changes in self-image differed from those suggested by Cassileth and Hamilton (1979), Malick (1972), and Craven and Sharp (1972). Self-image as measured by changes in personal appearance and weight showed very little change. These authors also suggested that a diagnosis of cancer in the wife may result in increased tension, problems, and stress in the husband as his life style changes. Ten of the husbands experienced mild to moderate change in their ability to manage stress. Some of the reasons given were having more things on the mind, taking more energy to manage stress, having to make decisions quicker now, and changes in the way stress is handled.

Changes in Relationship with Others

The husband's relationship with others undergoes change as a result of a cancer diagnosis in his wife. Changes occurred in the husband's occupational role. Although there were only four husbands who experienced a change in employment, over half of those husbands who were working had to take time off from work to care for the wife, visit her in the hospital, and/or accompany her for physician appointments and treatments. Cassileth and Hamilton (1979) stated that this change may affect the family's financial situation in an indirect way.

Changes also occur in the husband's occupational and friendship circles (Cassileth and Hamilton, 1979). There was slight to moderate decrease in the amount of time spent with friends due to the husbands wanting to spend more time with their wives. Also, the husbands stated that others' behavior had changed toward them. Even though the

husbands had less time to spend with friends, the change was described as being for the better. Friends were described as being "more concerned, more understanding, and more helpful." Along with a change in occupational and friendship circles, there were changes with family members (Cassileth and Hamilton, 1979; Malick, 1972; Craven and Sharp, 1972; Breu and Dracup, 1978). The husbands had more contact with children due to increased contact by children and a closer relationship with them.

As the husband's social contacts are interrupted, his recreational role and function may be altered (Malick, 1972; Craven and Sharp, 1972; Breu and Dracup, 1978). A mild to moderate change occurred in activities done around the home in one half of the husbands. This change was mainly due to a decrease in available time. In regards to the husband's activities done outside the home a moderate change occurred in less than half of the husbands. This change was mainly attributed to a decrease in available time and to a change in activities.

Changes in Relationship with Wife

The husband's interpersonal relationship with his wife undergoes change. Patterns of interaction are disrupted. In addition, both short-term and long-term family objectives, plans, and orientations may be disrupted (Cassileth and Hamilton, 1978). Less than half of the husbands experienced a change in decision making. Most of these changes were due to a change in the people making the decision, an increase in the number of decisions, and a change in the type of decisions. Also,

less than half of the husbands experienced a change in expressing their feelings with their wives. The husbands described the changes in decision making and expressing their feelings as being moderate to great deal. Even with these changes in interaction, the husbands were moderately to very comfortable in discussing their wives' illness with her.

Other roles that are subject to change are the couple's social plans and housekeeping duties (Cassileth and Hamilton, 1979; Malick, 1972; and Craven and Sharp, 1972). Over half the husbands experienced a moderate change in activities shared with their wives mainly due to a decrease in time and to a change in the activities shared together. As far as the change that occurred in household activities, half of the husbands helped out more with household activities. The other husbands were already assisting with household duties before their wives' illness.

Another aspect of the husband-wife relationship that undergoes change is their sexual relationship (Malick, 1972; Craven and Sharp, 1972; and Lamb and Woods, 1971). Over half the husbands experienced a moderate to a great deal of change in both the physical and psychological aspects of their sexual relationship. There was mainly a decrease in intercourse, but some husbands also stated there was a decrease in kissing and caressing. Even with a decrease in sexual activity, 18 of the husbands reported that they engaged in kissing, 15 in caressing, and nine in intercourse. Six husbands stated that the psychological aspects of their sexual relationship were better, while five stated there was less desire and less psychological closeness. Over one half

of the husbands stated that their overall relationship had undergone moderate to great deal of change. Many of the husbands described their relationship as being closer.

These changes were the husbands' way of reestablishing homeostasis in the new framework of chronic illness. The husband may function better or worse than he did before the chronic illness (Olsen, 1970; Glasser and Glasser, 1970; Cassileth and Hamilton, 1979). Many of the husbands substantiated this statement. Many of the changes that occurred were not only for the worse, some were for the better, and others were neither.

Changes According to Treatment Phases

The stage of treatment that women are undergoing for gynecological cancer may account for differences in the husband's life style. The husbands whose wives were undergoing adjuvant or advanced treatment experienced slight to moderate changes in most areas while husbands whose wives were undergoing treatment for recurrent disease experienced moderate to great deal of change in most areas. The husbands whose wives were in the adjuvant and advanced treatment group reported that they felt more comfortable discussing their wives' illness with her, while the husbands whose wives were undergoing treatment for recurrence reported they were less comfortable discussing their wives' illness with her. Also, the husbands in the recurrent group experienced more of a change in personal appearance than the other two groups. The husbands in the adjuvant and advanced treatment group reported that the changes in the psychological aspects of the sexual relationship and the

overall changes in the husband-wife relationship were for the better, while the recurrent group felt they were for the worse. The husbands in the adjuvant and recurrent group reported that the changes in others' behavior were for the better and that changes in social-recreational activities shared with the wife were for the worse; while the husbands in the advanced group felt these changes were neither for the better or for the worse. Changes in daily routine were reported to be for the worse in the adjuvant and advanced group, but for the better in the recurrent group. All three groups reported that the changes in the physical aspects of the sexual relationship were for the worse. These findings of the changes that occurred in husbands whose wives were in treatment for adjuvant, recurrent, or advanced therapy differed from those found in the literature. Litman (1974) stated that the more prolonged and complicated the illness the more effect it would have on family functioning. Marino (1981) stated that as the patient progressed through the treatment phases, the family assumes more of the patient's responsibilities, social relationships become more unstable, and communication may be disrupted. Ten or less of the husbands in the advanced group reported that change had occurred in their daily routine, relationship with others, and relationship with their wives, with most of the changes being slight to moderate. The husbands who reported the most change were those in the recurrent group. More than 10 of the husbands reported a moderate to great deal of change in most of the areas. The changes in the sexual relationship reported in this study agreed with those reported by Wasow (1977) and Lamb and Woods (1981). Most of

the husbands reported a change in their sexual relationship. Mainly they reported a decrease in sexual activity due to the wife's discomfort, decreased desire by the husband, wife, or both; or feelings that the cancer had destroyed their sexual relationship. The psychological part of the sexual relationship changed for the better except in the recurrent group.

Implications and Conclusions

Cancer has been previously described as a major chronic illness that brings about change within the family life style. Change brings about a redefinition of one's role and function within the family as adjustment is made to the new framework of chronic illness. The findings of this study indicated that a husband whose wife is undergoing treatment for gynecological cancer experiences change in his life style. Half or more of the husbands experienced mild to moderate change in areas related to daily routine and to his relationship with others. Half or more of the husbands experienced moderate to great deal of change in the areas relating to his relationship with his wife. Not all changes were viewed as being for the better or worse, some were seen as being neither. Also, findings of this study indicated that husbands whose wives are under treatment for a recurrence may be under greater stress than husbands in the adjuvant or advanced treatment group.

Important implications for health professionals can be made from this study. Many health professionals view cancer as a disruptive influence in a family's life style. Cancer may be seen as causing pain, suffering, and death. There is the need for many treatments and

continual medical follow-up. Consequently, when health professionals work with cancer patients and their family, they may have preconceived ideas relating to the changes that a diagnosis of cancer may bring about within a family. Since this study revealed that a diagnosis of cancer in the wife also brings about changes within the husband's life style, it is important for health professionals to realize that the changes are not always devastating. Some of the husbands viewed the changes as having a positive effect on their life style, while some changes were viewed as being neither positive nor negative. Care of the patient and husband must be based on facts rather than the health professional's preconceived ideas regarding an illness.

It is important for health professionals to prepare the husband for changes that may occur in his life style and that not all changes are for the worse. By educating the husband and wife at the time of diagnosis and throughout the treatment period, health professionals can help ease the changes that may occur, so that a diagnosis of cancer may be viewed with a more positive outlook.

Recommendations for Further Study

Based on the findings of this study, the following recommendations are suggested:

1. Reorganizing the interview guide to make the questions more specific to the amount of change that has occurred and the reasons for the change with the specific aim to develop a reliable and valid tool.

2. Conduct a study by interviewing a larger number of husbands in these phases of treatment: adjuvant, time of first tumor recurrence, and advanced disease state.
3. Conduct the study by interviewing separately the husband and wife to compare their perceptions of changes.
4. Conduct a study by doing a longitudinal study of the husband's life style changes as the wife progresses through the treatment phases.

CHAPTER 6

SUMMARY

This was a descriptive study which described the life style changes that occur in a husband whose wife is undergoing treatment and care for gynecological cancer. The amount of change that occurred was also studied.

The significance of the study stems from the fact that the wife is an integral part of family functioning. Chronic illness of the wife may be the greatest single source of danger that can disrupt family functioning. As a result the wife may not be able to maintain her normal role and responsibilities and to fulfill her obligations to other family members.

The conceptual framework of this study was based on chronic illness as a stressor and the adaptation of this stressor. Gynecological cancer in a woman is an example of a chronic illness that requires adaptation by family members. The family faces the prospect of chronic enduring changes in its standard roles, relationship, and sense of unity. The reorganized family may function better or worse than it did before the diagnosis of cancer.

The selected review of the literature focused on the effects of cancer on the family life style, the effects of gynecological cancer on the patient (wife), and the effects of the wife's cancer on

the husband's life style. The literature supported the idea that cancer causes changes within the wife which results in life style changes for the husband.

An interview guide was developed to elicit the husband's view of perceived life style changes in 20 subjects whose wives were in the adjuvant, recurrent, or advanced treatment phase of their experience with gynecological cancer. This interview consisted of questions regarding changes in the husband's daily routine, changes in his relationship with others, and changes in his relationship with his wife.

Results from the questions regarding changes in daily routine and changes in relationship with others revealed that the husbands experienced slight to moderate change with the greatest change occurring in eating patterns, sleeping patterns, management of stress, daily work routines, time spent with children, activities around the home, other people's behavior, and time spent with others. The husbands experienced a moderate to great deal of change in their relationship with their wives, with the greatest change occurring in activities shared with their wives, in their sexual relationship, and their overall relationship with their wives. The study also revealed that the changes were not always for the worse; some changes were for the better and some neither for the better nor for the worse. These findings offer direction for clinical nursing practice. Health professionals need to be aware of the changes that occur in the husband-wife relationship in order to effectively meet the needs of both patient and spouse.

APPENDIX A

HUMAN SUBJECTS' APPROVAL

THE UNIVERSITY OF ARIZONA COLLEGE OF NURSING
MEMORANDUM

TO: Vivian E. Graham
3635 E. Glenn, Apt E1 Tucson 85716

FROM: Ada Sue Hinshaw, R.N., Ph.D. Margarita Kay, R.N., Ph.D.
Director of Research Chairperson, Research Committee

DATE: April 22, 1981

RE: Human Subjects Review: "Living With Cancer: Husbands' View
of Life Style Changes"

Your project has been reviewed and approved as exempt from University review by the College of Nursing Ethical Review Sub-committee of the Research Committee, and the Director of Research. A consent form with subject signature is not required for projects exempt from full University review. Please use only a disclaimer format for subjects to read before giving their oral consent to the research. The Human Subjects Project Approval Form is filed in the office of the Director of Research, if you need access to it.

We wish you a valuable and stimulating experience with your research.

ASH:ss
1981

APPENDIX B

SUBJECTS' DISCLAIMER FORMS

LIVING WITH CANCER: HUSBANDS'
VIEW OF LIFE STYLE CHANGES

The objectives of this study are to describe what changes, if any, occur in your life style as a result of your wife's cancer experience. If you decide to participate, please answer as many of the questions as you are able to answer with confidence. About 45 minutes of your time will be required for completion of this interview and will indicate your consent as a willing participant. There are no known risks from participation. All data will be treated with anonymity and confidentiality. You are free to withdraw from the study at any time without incurring ill will or affecting your wife's medical care.

Investigator

Subject

LIVING WITH CANCER: HUSBANDS'
VIEW OF LIFE STYLE CHANGES

The objectives of this study are to describe what changes, if any, occur in your husband's life style as a result of your cancer experience. Participation in this study includes the review of your chart by the investigator to obtain data regarding diagnosis and treatment. There are no known risks from participation in this study. All data will be treated with anonymity and confidentiality. You are free to withdraw from the study at any time without incurring ill will or affecting your medical care.

Investigator

Subject

APPENDIX C

LETTER TO ATTENDING PHYSICIANS

Vivian E. Graham
3635 E. Glenn #E-1
Tucson, Az. 85716

Dr. David Alberts, M.D.
Hematology-Oncology
University of Arizona Health
Sciences Center
Tucson, Arizona 85724

Dear Dr. Alberts:

I'm a graduate student enrolled in the College of Nursing. Presently, I am conducting a study entitled LIVING WITH CANCER: HUSBANDS' VIEW OF LIFE STYLE CHANGES. The purpose of the study is to describe the life style changes that occur in a husband whose wife is undergoing treatment and care for gynecologic cancer.

A structured interview guide has been developed for collecting the data. The guide includes questions regarding demographic data, the husband's daily routine, the husband's relationship with others, and the husband's relationship with his wife. The wife (patient) will be asked to sign a consent form to enable me to do a chart review for diagnostic and treatment data. A copy of the interview guide is enclosed. The interviews will be conducted in the subject's home or at a designated area of the hospital. The wife will not be present during the interviews.

The research project and interview guide have been reviewed and approved by Karen Redding, M.S.W. I'm requesting your permission to contact subjects and patients in the outpatient oncology clinics. If you have any questions you can contact me at the above address or at 326-5501; my advisor, Dr. Alice Longman, at 626-6656; or Karen Redding, M.S.W.

Sincerely,

Vivian E. Graham, R.N.

Vivian E. Graham, R.N.

Vivian E. Graham
3635 E. Glenn #E-1
Tucson, Az. 85716

Earl A. Surwit, M.D.
Director Gynecologic Oncology
University of Arizona Health
Sciences Center
Tucson, Arizona 85724

Dear Dr. Surwit:

I'm a graduate student enrolled in the College of Nursing. Presently, I am conducting a study entitled LIVING WITH CANCER: HUSBANDS' VIEW OF LIFE STYLE CHANGES. The purpose of the study is to describe the life style changes that occur in a husband whose wife is undergoing treatment and care for gynecologic cancer.

A structured interview guide has been developed for collecting the data. The guide includes questions regarding demographic data, the husband's daily routine, the husband's relationship with others, and the husband's relationship with his wife. The wife (patient) will be asked to sign a consent form to enable me to do a chart review for diagnostic and treatment data. A copy of the interview guide is enclosed. The interviews will be conducted in the subject's home or at a designated area of the hospital. The wife will not be present during the interviews.

The research project and interview guide have been reviewed and approved by Karen Redding, M.S.W. I'm requesting your permission to contact subjects and patients in the outpatient oncology clinics. If you have any questions you can contact me at the above address or at 326-5501; my advisor, Dr. Alice Longman, at 626-6656; or Karen Redding, M.S.W.

Sincerely,

Vivian E. Graham, R.N.

Vivian E. Graham, R.N.

Vivian E. Graham
3635 E. Glenn #E-1
Tucson, Az. 85716

Robert S. Huesinkveld, M.D., Ph.D.
Radiation Oncology
University of Arizona Health
Sciences Center
Tucson, Arizona 85724

Dear Dr. Huesinkveld:

I'm a graduate student enrolled in the College of Nursing. Presently, I am conducting a study entitled LIVING WITH CANCER: HUSBANDS' VIEW OF LIFE STYLE CHANGES. The purpose of the study is to describe the life style changes that occur in a husband whose wife is undergoing treatment and care for gynecologic cancer.

A structured interview guide has been developed for collecting the data. The guide includes questions regarding demographic data, the husband's daily routine, the husband's relationship with others, and the husband's relationship with his wife. The wife (patient) will be asked to sign a consent form to enable me to do a chart review for diagnostic and treatment data. A copy of the interview guide is enclosed. The interviews will be conducted in the subject's home or at a designated area of the hospital. The wife will not be present during the interviews.

The research project and interview guide have been reviewed and approved by Karen Redding, M.S.W. I'm requesting your permission to contact subjects and patients in the outpatient oncology clinics. If you have any questions you can contact me at the above address or at 326-5501; my advisor, Dr. Alice Longman, at 626-6656; or Karen Redding, M.S.W.

Sincerely,

Vivian E. Graham, R.N.

Vivian E. Graham, R.N.

APPENDIX D

INTERVIEW GUIDE AND SELECTED RESPONSES

A. General Information

1. Date: Subject I.D. _____

2. Place of Interview: Hospital-N=15 Subject Age _____
Home - N=15

3. Marital Status:

____ Married, living with spouse

____ Living with someone in a common-law relationship

____ Number of years in relationship

4. Other members of Household:

RelationshipSexAge

5. What is the highest level of education that you obtained?

____ College Degree, _____ degree

____ Some College

____ Business or Vocational School

____ High School

____ Grade School

____ Other, specify _____

6. Ethnic Background:

____ Black

____ Mexican-American

____ Anglo-American

____ Other, specify _____

B. The following questions relate to specific areas in your daily routine. I am interested in learning about any changes that have occurred since your wife's diagnosis.

1. Which of the following statements relate most closely to any changes you have experienced in your eating habits since your wife's diagnosis?

4 eating more frequently

6 eating is more irregular

5 eating different types of food

2 eating more readily prepared foods, such as frozen dinners, easily cooked foods, sandwiches.

7 eating out more frequently

4 skipping meals

4 change in appetite, increase 2 decrease 2

4 no change

4 other, specify _____

2. In what way has your weight changed since your wife's diagnosis?

2 increase, pounds gained range 6-20

4 decrease, pounds lost range 10-20

14 unchanged

3. Which of the following statements relate most closely to any changes you have experienced in your personal appearance since your wife's diagnosis?

1 have less desire to take care of personal appearance

2 have less time to care for self, such as getting haircuts, doing nailcare, have clothes laundered and ironed, etc.

1 wear same clothes more often

16 no change

1 other, specify grooming has improved

4. (a) Which of the following statements relate most closely, to any changes you have experienced in your sleeping patterns since your wife's diagnosis?

6 amount of sleep you get per night, increase 0 decrease 6

0 increase or decrease use of sleeping pills or tranquilizers

8 awakening or getting up more frequently during the night, specify why _____

10 no change

 other, specify _____

4. (b) Do you feel rested with the amount of sleep you receive or with the changes that have occurred in your sleeping pattern?

Yes - 13

No. - 6

Occasionally - 1

5. This question refers to the changes that have occurred overall in your daily routine (eating, personal appearance, sleeping pattern) as a result of fitting your wife's treatments in with your regular routines. Please circle the place which best describes these overall changes.

no					very great deal
change	_____	_____	_____	_____	of change
	1	2	3	4	5
		slight	moderate	great	
				deal	

 change for better

 change for worse

 neither

6. (a) Since your wife's diagnosis, how do you manage stress?

- 9 seek more information
- 7 talking it out with others
- 2 make light of the situation
- 5 try to forget
- 7 do other things for distraction
- 7 take firm action based on present understanding
- 1 withdraw into isolation, get away
- 5 submit to the inevitable
- 1 do something impulsively
- 1 consider or negotiate feasible alternatives
- 2 reduce tension with excessive drink, drugs, eating
- 0 blame yourself
- 1 blame someone/something
- 3 other, specify _____

6. (b) Please circle the place that best describes the changes in your ability to manage stress since your wife's diagnosis.

no change				very great deal of change
1	2	3	4	5
	slight	moderate	great deal	

- _____ change for better
- _____ change for worse
- _____ neither

6. (c) In what way is this a change from before your wife's diagnosis?

2. (a) If employed, do you ever leave work to:

8 accompany wife to doctor

7 accompany wife for treatments

4 take care of wife after treatments

7 visit wife in hospital

3 pick up medication/supplies

1 other, specify _____

11 not applicable

2. (b) How often and when?

3. (a) If employed, do you ever leave work to:

1 run errands for your wife, such as pick up clothes from cleaners, go to bank, etc.

0 pick up kids from school

1 take or pick up kids from babysitter

0 pick up or take home babysitter

1 pick up groceries

0 other, specify _____

18 not applicable

3. (b) How often and when?

If you have children, please answer the following question. If you have no children, proceed to Question 5.

4. (a) This question refers to the changes you might have experienced in the amount of time you spend with your children. Please circle the place which describes these changes.

no						very great
change	1	2	3	4	5	deal of
		slight	moderate	great		change
				deal		

_____ increase of time

_____ decrease of time

4. (b) What do you think the changes in the amount of time spent with children are related to?

5. (a) At the present time, what type of activities do you participate in around your home?

15 T.V.

12 reading

8 hobbies or crafts

11 maintenance work around home

8 gardening

1 other, specify _____

0 none

5. (b) Please circle the place that best describes the changes that have occurred in your activities around the home since your wife's diagnosis?

no	1	2	3	4	5	very great
change		slight	moderate	great		deal of
				deal		change

 change for better

 change for worse

 neither

5. (c) In what way is this change from before your wife's diagnosis (e.g., less or more frequently, doing things more alone, doing things with different friends, etc.)?

6. (a) At the present time, what type of activities do you participate in outside the home?

 0 tennis

 3 swimming

 3 golf

 5 fishing

 5 walking

 6 other, specify _____

 5 none

6. (b) Please circle the place that best describes the changes that have occurred in your activities outside the home since your wife's diagnosis?

no	_____				very great
change 1	2	3	4	5	deal of
	slight	moderate	great		change
			deal		

_____ change for better

_____ change for worse

_____ neither

6. (c) In what way is this a change from before your wife's diagnosis (e.g., less or more frequently, doing things more alone, doing things with different friends, etc.)?

7. (a) Please circle the place that best describes any changes you have experienced in others (your friends, co-workers) behavior toward you since your wife's diagnosis.

no	_____				very great
change 1	2	3	4	5	deal of
	slight	moderate	great		change
			deal		

_____ change for better

_____ change for worse

_____ neither

7. (b) In what way is this a change from before your wife's diagnosis (e.g., less contact, more withdrawn, over-protective, less talkative, etc.)?

D. The following questions relate to your relationship with your wife in the areas of decision-making, social/recreational activities, expressing feelings, helping her with household activities, communication regarding illness, and sexuality. I am interested in learning about change that has occurred since your wife's diagnosis.

1. (a) Since your wife's diagnosis, who makes more of the decisions (shared, husband, wife, or other) in the following areas:

_____ money, such as budgeting, major purchases

_____ child care, such as disciplining, delegating responsibilities, activities that the children can participate in

_____ home management

_____ medical care, such as treatment decisions

_____ future goals/plans, such as retirement and vacations

_____ other, specify _____

1. (b) Please circle the place which best describes the changes that have occurred in decision-making since your wife's diagnosis.

no					very great
change	1	2	3	4	5
		slight	moderate	great deal	deal of change

_____ change for better

_____ change for worse

_____ neither

1. (c) In what way is this a change (e.g., I'm making more of the decisions now, my wife is making more of the decisions now, decisions are shared, decisions are more complicated, there are more or less decisions now, etc.)?

2. (a) Since your wife's diagnosis, what type of social/recreational activities do you and your wife participate in together (excluding children)? (More than one answer is possible).

3 movies, plays

17 dining out

3 dancing

4 participation in sports activities

5 watching sports activities

8 music

5 crafts

15 social get-togethers

6 other, specify _____

2. (b) Please circle the place which describes the changes that have occurred in your social/recreational activities shared with your wife since her diagnosis.

no					very great
change	1	2	3	4	5 deal of
		slight	moderate	great	change
				deal	

_____ change for better

_____ change for worse

_____ neither

2. (c) In what way is this a change (e.g., an increase or decrease, change in types of activities, doing things more alone, doing things with different friends, etc.)?

3. (a) Since your wife's diagnosis, which statement best describes how you express your feelings (anger, annoyance, love, ambivalence, helplessness, depression/sadness, guilt, fear, etc.) with your wife?

15 I tell her exactly how I feel

1 I hint at how I feel

9 I hold my feelings inside

2 I act as if nothing is wrong

 other, specify _____

3. (b) Please circle the place that best describes the changes that have occurred in expressing your feelings with your wife since her diagnosis.

no					very great
change	1	2	3	4	5 deal of
		slight	moderate	great	change
				deal	

 change for better

 change for worse

 neither

3. (c) In what way is this a change?

4. (a) Since your wife's diagnosis, please indicate what kind of assistance you give her around the house? (More than one answer is possible).

11 cooking

15 doing the dishes

11 laundry

17 housecleaning

8 budgeting money

15 marketing/shopping

2 other, specify _____

5. This question refers to how comfortable you feel to discuss your wife's illness with her. Please circle the place which best describes this situation.

not comfortable at all	<u>1</u>	<u>2</u>	<u>3</u>	<u>4</u>	<u>5</u>	extremely comfortable
		slightly	moderately	very		
	N=2	N=3	N=4	N=2	N=9	

The following two questions relate to sexuality. This is a significant area and it has been shown to be an area of concern to husbands and wives. As health professionals, we understand that sexuality includes physical activities such as kissing, touching, intercourse as well as psychological closeness.

6. (a) Since your wife's diagnosis, what are the types of physical sexual activity in which you participate? (More than one answer is possible).

18 kissing

15 caressing

0 oral sex

4 self-stimulation

9 intercourse

0 stimulants, such as vibrators

0 other, specify _____

1 none

7. (c) In what way is this a change (e.g., increase or decrease, change in type, etc.)?
8. This question refers to the overall changes that have occurred in your relationship with your wife since her diagnosis. Please circle the place which best describes these overall changes.

no	1	2	3	4	5	very great
change		slight	moderate	great deal		deal of change

_____ change for better

_____ change for worse

_____ neither

- E. Please add any concerns, recommendations, and/or questions that you feel would better assist your care, your wife's care, and that of others.

F. Treatment Data on the Spouse:

1. Age _____

2. Cancer diagnosis:

3. Date of first diagnosis:

Range - 4 months - 10 years

4. Treatment Modality(ies) received since diagnosis:

Chemotherapy - N=17

Immunotherapy - N=2

Surgery - N=17

Hormonal - N=7

Radiation Therapy - N=12

Hyperthermia - N=3

5. Current Treatment Modality:

Chemotherapy - N=12

Hormonal - N=3

Surgery - N=2

Other - N=1

Radiation Therapy - N=2

6. Treatment Stage:

- Adjuvant Therapy
 Therapy for Recurrent Disease
 Therapy for Advanced Disease

7. Spouse's other medical problems:

- None - N=16
Another Cancer - N=1
Complications related to surgery - N=2
Hypertension - N=2
Diabetes - N=1

8. What type of therapy, if any, does the wife take at home?

- 9 chemotherapy
 8 pain analgesics
 2 steroids
 11 antinausea
 9 vitamins
 0 laetrile
 6 other, specify _____

- 1 none

APPENDIX E

HUSBANDS' RESPONSE TO THE QUESTION "PLEASE ADD ANY
CONCERNS, RECOMMENDATIONS, AND/OR QUESTIONS
THAT YOU FEEL WOULD BETTER ASSIST YOUR CARE,
YOUR WIFE'S CARE, AND THAT OF OTHERS"

HUSBANDRESPONSE

- 1 I practice religious activities more.
- 4 At first, my wife felt that I would leave her. She kept these feelings to herself for four to six weeks. Also, she had a hard time accepting that she couldn't have any more children. I never felt this way. Now, we are communicating better and as a result we have become closer. I wish we had more time between the discussions of chemotherapy and the start of it. There were things we needed to arrange.
- 5 Health professionals should encourage people to live a normal life. They should not be overly sympathetic so the patient feels sorry for themselves and/or feels the loss of value for themselves.
- 6 Concerned about how I'm going to take care of my wife in the future.
- 7 The husband-wife relationship requires more patience by the husband to deal with the reactions and expressions that occur in the wife as a result of the effects of the illness on her (such as denial, anger, why me). I try to understand these emotions and do things for her.
- 9 The husband and wife have to be more understanding. He has to be more understanding of wife's activities since wife is unable to do as much as before.
- 10 Need friends to help.
- 11 I feel very comfortable with the medical care.
- 12 In many ways, I feel much closer to my wife. I like to spend all or as much time as possible with her for whatever reasons. I also try to prove that I don't reject her. We spend more time together, but don't do things with others as we used to. I like the knowledge and ability that makes us feel like we have control over some aspects of the disease and treatment.
- 15 My wife's attitude changed--no self pity, positive attitude. We are very religious and use prayer.
- 16 It's harder for my wife to handle the kids. They get on her nerves more often.

HUSBANDRESPONSE

- 17 I've never been sick so its hard to realize what she is experiencing. She's been chronically sick so much I'm becoming hardened to it or more used to it.
- 18 I feel low at times, but I have great support from the church and friends. They are more than willing to help out and I help them out when I can.
- 19 As soon as the cancer is diagnosed, there should be a program to counsel the husband and wife regarding procedures, length of time, what the family can expect, reactions to medications. I think the hospital should involve the immediate family more in the cancer experience.
- 20 We have tried to improve our faith to help us live a normal way.

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