



National Library
of Canada

Bibliothèque nationale
du Canada

Canadian Theses Service

Service des thèses canadiennes

Ottawa, Canada
K1A 0N4

NOTICE

The quality of this microform is heavily dependent upon the quality of the original thesis submitted for microfilming. Every effort has been made to ensure the highest quality of reproduction possible.

If pages are missing, contact the university which granted the degree.

Some pages may have indistinct print especially if the original pages were typed with a poor typewriter ribbon or if the university sent us an inferior photocopy.

Previously copyrighted materials (journal articles, published tests, etc.) are not filmed.

Reproduction in full or in part of this microform is governed by the Canadian Copyright Act, R.S.C. 1970, c. C-30.

AVIS

La qualité de cette microforme dépend grandement de la qualité de la thèse soumise au microfilmage. Nous avons tout fait pour assurer une qualité supérieure de reproduction.

S'il manque des pages, veuillez communiquer avec l'université qui a conféré le grade.

La qualité d'impression de certaines pages peut laisser à désirer, surtout si les pages originales ont été dactylographiées à l'aide d'un ruban usé ou si l'université nous a fait parvenir une photocopie de qualité inférieure.

Les documents qui font déjà l'objet d'un droit d'auteur (articles de revue, tests publiés, etc.) ne sont pas microfilmés.

La reproduction, même partielle, de cette microforme est soumise à la Loi canadienne sur le droit d'auteur, SRC 1970, c. C-30.

THE UNIVERSITY OF ALBERTA

LIVING WITH CHEMOTHERAPY: PERCEPTIONS OF HUSBANDS

by



PATRICIA SHARON WILSON

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH
IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE
OF MASTER OF NURSING

FACULTY OF NURSING

EDMONTON, ALBERTA

FALL, 1988

Permission has been granted to the National Library of Canada to microfilm this thesis and to lend or sell copies of the film.

The author (copyright owner) has reserved other publication rights, and neither the thesis nor extensive extracts from it may be printed or otherwise reproduced without his/her written permission.

L'autorisation a été accordée à la Bibliothèque nationale du Canada de microfilmer cette thèse et de prêter ou de vendre des exemplaires du film.

L'auteur (titulaire du droit d'auteur) se réserve les autres droits de publication; ni la thèse ni de longs extraits de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation écrite.

ISBN 0-315-45577-2

THE UNIVERSITY OF ALBERTA

RELEASE FORM

NAME OF AUTHOR: PATRICIA SHARON WILSON

TITLE OF THESIS: LIVING WITH CHEMOTHERAPY:

PERCEPTIONS OF HUSBANDS

DEGREE: MASTER OF NURSING

YEAR THIS DEGREE GRANTED: FALL, 1988

Permission is hereby granted to THE UNIVERSITY OF ALBERTA LIBRARY to reproduce single copies of this thesis and to lend or sell such copies for private, scholarly or scientific research purposes only.

The author reserves other publication rights, and neither the thesis nor extensive extracts from it may be printed or otherwise reproduced without the author's written permission.

Sharon Wilson

(Student's signature)

2077 BARSUDA DR., UNIT 9

MISSISSAUGA, ONTARIO

L5T 1V6

(Student's permanent address)

Date: Sept 1 1988

I was angry at [my husband]. I knew I shouldn't be, but I was. I knew it was awful for him too. I knew that the relatives of sick or dying people have their own hell, and that sometimes it is a more barren, lonely place than the hell of the person directly hit. I was perfectly aware that [my husband] shared the horror of my illness without sharing any of the rewards. He suffered and he was afraid, but no one pitied him, visited him, brought him presents, or made him a star. Stardom in a hospital bed was small compensation for having [breast] cancer, but it was, as they say, better than nothing. At least it gave me the right to be tempermental.

excerpt from Rollins, B. (1976). *First, You Cry*, New York: J.B. Lippincott, p. 111.

THE UNIVERSITY OF ALBERTA
FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research, for acceptance, a thesis entitled LIVING WITH CHEMOTHERAPY: PERCEPTIONS OF HUSBANDS submitted by PATRICIA SHARON WILSON in partial fulfillment of the requirements for the degree of MASTER OF NURSING.

Janice M. Hare
.....
Supervisor

John Forest
.....
Co-supervisor

W. G. K. King
.....

Date: *September 1* 1988

ABSTRACT

Chemotherapy, one of several methods used to treat cancer, has the potential for causing distressing and uncomfortable side effects. This study explores and describes the experience of living with a wife undergoing chemotherapy from the emic perspective of the husband. Unstructured, open-ended face-to-face or telephone interviews with fourteen informants were utilized to collect qualitative data. Data was also obtained from the diary of one informant. The use of grounded theory facilitated the generation of a three stage theory: the threat, the fight and the veteran. These three stages depict the process through which a husband experiences his wife's chemotherapy treatment. Recurrence of the disease begins the process again. Buffering is the process by which husbands protect, simplify and reduce the stress of day-to-day life for their wives, and it involves two active components: constant vigilance and cognitive action. Husbands experience fear, stress and anxiety in response to the unpredictable effects of chemotherapy and the changes that occur within the marital dyad. Their experience is influenced by repetitive paradoxical responses in which self-contradictions, such as, guarded optimism, prevail. The husbands' coping strategies depend upon perceived control, hope, the degree of responsibility assumed for the side effects suffered by their wives and their ability to be an advocate for their wives.

Additional study is needed to explore the meaning of fear and the expression of anger. Both are paramount for understanding the coping strategies of husbands during their wives' chemotherapy. It is also essential that health care providers understand how husbands perceive control and how the lack of communication affects their coping strategies. As a result, more supportive measures might then be implemented for husbands during their wives' chemotherapy treatment for cancer.

Acknowledgements

I would like to thank the members of my thesis committee, Dr. Janice Morse, Dr. Darlene Forrest and Dr. Al MacKay, for their warmth, interest and support throughout this study. In particular, I would like to extend a special thank you to Dr. Janice Morse who was so generous with her own unique brand of encouragement, humor and caring, as well as, with her inspiring depth of knowledge about qualitative research.

I would also like to thank my peers and colleagues who made me feel welcome to the University of Alberta, and with whom I have shared many happy moments. In particular, I want to thank my colleagues on the fifth floor who shared my ups and downs and provided me with many insights toward those very important "hunches." Talking with them always helped me to clarify my own thoughts.

I would especially like to thank Anne and Brian for their love of laughter and fun and for their hospitality. They have been treasured friends to me, and I am deeply grateful for their caring, especially when I was a stranger to Albertan ways.

I would sincerely like to acknowledge the husbands who participated in this study. Each of these men has made a remarkable contribution to my understanding of health, illness, life and death which would not have been possible without their willingness to share personal and often stressful experiences with chemotherapy.

Finally, I want to thank my family who have been consistent long-distance supporters of my endeavour to survive graduate studies.

This research study was supported in part by grants from the Alberta Foundation of Nursing Research and the Alberta Association of Registered Nurses.

TABLE OF CONTENTS

| CHAPTER | <i>page</i> |
|------------------------------------|-------------|
| I. INTRODUCTION _____ | 1 |
| Statement of the Problem _____ | 1 |
| Purpose and Rationale _____ | 4 |
| II. REVIEW OF THE LITERATURE _____ | 5 |
| Selected Concepts _____ | 6 |
| Coping _____ | 6 |
| Social Support as a Buffer _____ | 8 |
| Chronicity _____ | 9 |
| Normalization _____ | 10 |
| Anticipatory Grief _____ | 11 |
| Stage of the Disease _____ | 11 |
| Diagnostic Stage _____ | 12 |
| Recurrent Stage _____ | 13 |
| Terminal Stage _____ | 13 |
| Site of the Disease _____ | 16 |
| Treatment of the Disease _____ | 19 |
| Surgery _____ | 19 |
| Chemotherapy _____ | 21 |
| Radiotherapy _____ | 22 |
| Side Effects of Chemotherapy _____ | 23 |
| Summary _____ | 25 |
| Research Questions _____ | 25 |

| | |
|---------------------------------------|----|
| III. METHOD | 26 |
| Grounded Theory | 26 |
| Sample Selection | 27 |
| Data Collection | 29 |
| Reliability and Validity | 31 |
| Data Analysis | 31 |
| Ethical Considerations | 32 |
| IV. RESULTS: THE THREAT AND THE FIGHT | 34 |
| The Threat | 37 |
| Suspecting | 37 |
| Becoming Aware | 37 |
| Worrying | 39 |
| Beginning to Act | 40 |
| Finding Out | 40 |
| Becoming Informed | 41 |
| Facing the Fact | 43 |
| The Fight | 46 |
| Resolving To "Take On" | 47 |
| Inducting | 49 |
| Initiating | 49 |
| Orienting | 52 |
| Anticipating Chemotherapy | 52 |
| Going to Chemotherapy | 53 |
| Following Chemotherapy | 54 |

| | |
|---|----|
| V. RESULTS: ENDURING AND FINALIZING THE FIGHT | 57 |
| Enduring | 57 |
| Struggling with Suffering | 58 |
| Apprehending the Struggle | 58 |
| Evaluating Wife's Response | 59 |
| <i>Examining Beliefs</i> | 59 |
| <i>Grieving</i> | 59 |
| <i>Second-guessing</i> | 59 |
| <i>Changing in Response to Chemotherapy</i> | 60 |
| <i>The "Chemo Crazy's"</i> | 60 |
| <i>Losing Hair</i> | 61 |
| <i>Fatigue</i> | 62 |
| <i>Nausea</i> | 63 |
| <i>Fighting</i> | 64 |
| <i>Supporting</i> | 64 |
| Recognizing His Own Response | 66 |
| <i>Expressing Love</i> | 66 |
| <i>Expressing Suffering</i> | 66 |
| <i>Creating Emotional Turmoil</i> | 67 |
| <i>Changing Lifestyle</i> | 69 |
| <i>Relating to Others</i> | 72 |
| <i>Maintaining Health</i> | 73 |
| <i>Being Informed</i> | 73 |
| <i>Orienting to the Future</i> | 74 |
| Waiting | 77 |
| Committing | 79 |

| | |
|--|-----|
| Implementing Strategies _____ | 80 |
| Softening the Blow _____ | 81 |
| <i>Being There</i> _____ | 81 |
| <i>Cherishing</i> _____ | 84 |
| <i>Normalizing</i> _____ | 86 |
| <i>Taking Charge</i> _____ | 87 |
| <i>Being Positive</i> _____ | 88 |
| <i>Adding On</i> _____ | 90 |
| Resisting Disruption _____ | 91 |
| <i>Disguising One's Feelings</i> _____ | 92 |
| <i>Treading Lightly</i> _____ | 93 |
| <i>Omitting the Truth</i> _____ | 94 |
| Preserving Self _____ | 95 |
| <i>Conserving Energy</i> _____ | 95 |
| <i>Keeping Busy</i> _____ | 96 |
| <i>Healthiness</i> _____ | 97 |
| <i>Seeking Out</i> _____ | 97 |
| <i>Maintaining Motivation</i> _____ | 99 |
| <i>Sharpening Helping Skills</i> _____ | 101 |
| Finalizing _____ | 102 |
| VI. RESULTS: THE VETERAN _____ | 104 |
| Making It Through _____ | 104 |
| Recognizing Changes _____ | 106 |
| Marking Time _____ | 109 |

| | |
|---|---------|
| Recurrence | 112 |
| Initial Recurrence | 112 |
| Multiple Recurrence | 114 |
| Summary | 119 |
| The Threat | 119 |
| The Fight | 120 |
| The Veteran | 122 |
| Recurrence | 123 |
| Hypotheses for Further Research | 124 |
| VII. DISCUSSION | 125 |
| Evaluation of Method | 125 |
| Grounded Theory | 125 |
| Interview Method | 126 |
| Face-to-Face | 126 |
| Telephone | 128 |
| Critique of Findings | 129 |
| Buffering and the Changing Marital Dyad | 129 |
| The Fight | 131 |
| Powerlessness | 132 |
| Hope | 133 |
| Advocacy | 135 |
| Victimization | 136 |

| | |
|---|-----|
| Implications for Nursing Practice _____ | 137 |
| The Threat _____ | 137 |
| The Fight _____ | 138 |
| The Veteran _____ | 139 |
| Implications for Nursing Research _____ | 142 |
| Summary of the Study _____ | 144 |
| REFERENCES _____ | 150 |
| APPENDIX A: Informed Consent for Face-to-Face Interview Method ____ | 162 |
| APPENDIX B: Informed Consent for Telephone Interview Method ____ | 163 |

LIST OF TABLES

| Table | Description | Page |
|-------|---|------|
| 1. | Method of Interview and Characteristics of Informants | 28 |

LIST OF FIGURES

| Figure | Description | <i>Page</i> |
|--------|--|-------------|
| 1. | The Process of Living with Chemotherapy: Experiences of Husbands | 35 |
| 2. | The Process of Buffering | 36 |
| 3. | The Process of the Threat Experienced by Husbands Whose Wives Receive Chemotherapy Treatment for Cancer | 38 |
| 4. | The Process of the Fight Experienced by Husbands Whose Wives Receive Chemotherapy Treatment for Cancer | 48 |
| 5. | Typology Illustrating the Relationship Between Quality of Marital Relationship and the Strategy for Enduring | 57 |
| 6. | Typology Illustrating the Relationship Between the Husband's Ability to Resolve Anger and the Ability to Assist His Wife Endure Chemotherapy | 80 |
| 7. | The Process of Emerging as a Veteran and Potential Recurrence Experienced by Husbands Whose Wives Receive Chemotherapy Treatment for Cancer | 105 |

I. INTRODUCTION

Statement of the Problem

Cancer is a feared, life-threatening illness (Abrams, 1966). One in three Canadians will develop cancer during their life and will have a 40% chance of a five-year survival (Canadian Cancer Society, 1987). Although the response rate to treatment (i.e., chances of a cure) is improving, the diagnosis of cancer continues to convey a threat of intractable pain, hopelessness and a prolonged period of wasting away before death occurs (Klagsbrum, 1983). It is likely this negative connotation of diagnosis reflects the lack of control over the disease and the fact that one cannot alter the course of the disease by changing personal behavior (Abrams, 1966; Quint, 1963). This image persists even though more advanced and successful forms of treatment, such as, chemotherapy, have prolonged survival. We often assume that longevity is always a desirable goal and that newer methods of treatment are "good" and "desirable." However, the reality is that newer treatment modalities carry many adverse and sometimes unrelenting side effects over which the patient has very little control. It becomes imperative that ways be found to help patients and their families live with the side effects of treatment in order to enhance the quality of life for the patient.

Chemotherapy is one of several methods used to treat cancer. Chemotherapy is advantageous for the patient because it is most often given in an outpatient department and the patient can remain in their home environment and still retain control over the decision to continue working (King & Taylor, 1987). Chemotherapy is advantageous for the health care system in that health care costs are reduced (King & Taylor, 1987). When chemotherapy is given as a treatment for cancer, the illness is characterized by relatively stable, non-symptomatic periods between treatments and acute symptomatic episodes during the period of time the chemotherapy treatment is administered. While

symptomatic periods necessitate immediate action, nonsymptomatic periods frequently exhibit residual effects left over from acute symptomatic episodes. Therefore, cancer meets the criteria for chronic illness (Epp, 1986). For health care providers trying to meet the needs of the patient and family, the impact and co-existence of both the acute and chronic aspects of chemotherapy treatment for cancer represents a challenge.

Chemotherapy is mostly administered during the intermediate stage of advancing cancer. This stage of life with cancer involves integrating one's lifestyle with the illness and has not been adequately researched by nurses. Most of the research regarding psychosocial responses to chemotherapy reflects the traditional medical model and focuses on the sick person. Recently, more investigators have begun to focus on the needs of the family. The intermediate stage represents a period of time when social relationships, family relationships and one's perspectives on life and health change (Parsons, 1977). It can be a very disrupting time for the patient and the members of the family (Weisman, 1979). For example, altered communication patterns may occur which interfere with the family's ability to exchange information and resources with each other (Lewis, 1986). Increased role tension and interpersonal conflict and tension have been reported by the marital dyad, and an increase in the patient's symptoms increases the emotional tension for other family members (Klein, Dean, & Bogdonoff, 1967).

Increasing numbers of patients receive chemotherapy on an outpatient basis and return to their home environment after receiving treatment. Patients and their families organize their day-to-day lifestyle around chemotherapy treatments. The altered pattern in the organization of family life is especially important when one considers the length of time over which chemotherapy is given. Although the important role of the family in meeting the needs of the patient with cancer has received considerable attention in the research literature (Giacquinta, 1977; Hampe, 1975; Kristjanson, 1986), the needs of

the family as they experience the chemotherapy treatment for cancer has received very little attention. Family concerns are primarily for the comfort of the patient, and these concerns reveal that health care providers need more information about the family role in supporting cancer patients as well as approaching the family with a caring attitude. Families rank their own needs as inferior and less important than patients. Very little is known about how chemotherapy affects the day-to-day lifestyle of family members or how family members affect the impact of the illness for the patient.

Chemotherapy has the potential for distressing and uncomfortable side effects because it is destructive to normal cells as well as cancer cells. Indeed, patients have indicated that minimizing the side effects is the most problematic area of treatment (Lauer, Murphy, & Powers, 1982). Weisman and Worden (1975, 1976) found that patients who can express their concerns and accept support from others are more able to cope with their illness trajectory. The spouse is often the most important person influencing the patient's response to the cancer and the side effects of treatment (Fernsler, 1986; Giacquinta, 1977; King & Taylor, 1987). Patients also derive support from spousal communication (Chekryn, 1984). For the female patient, her husband is frequently an active participant in caregiving (Wellisch, Jamison, & Pasnau, 1978). Thus, a woman will be more likely to turn to her husband for assistance in maintaining her physical and emotional well-being during chemotherapy treatment. Husbands place a high priority on their wives' adjustment to mastectomy and adopt a protective guardian role (Sabo, Brown, & Smith, 1986). The husband becomes the most important pivotal source for maintaining family life within the home, especially during periods when side effects disrupt the wife's role within the family. The cancer experience is stressful not only for the patient but for the spouse who is attempting to provide support for the patient (Goldberg, Wool, Tull, & Boor, 1984; Sabo, Brown, & Smith, 1986). Because a husband is such an important influence affecting the

responses of the patient, it is important to discover how the family, and in particular, the husband, copes with the chemotherapy process. The ultimate outcome is to enhance the quality of life for the patient and the family as they learn to live within the limitations imposed by the cancer and the effects of the treatment for cancer.

Purpose and Rationale

The purpose of this research is to explore the husband's experience during his wife's chemotherapy treatment. The described experiences will be developed into patterns of behaviors which can then be assessed by nurses. In order to provide effective nursing care, nurses must clearly understand the husband's experience and the factors which influence the husband's experience during his wife's chemotherapy treatment. This study provides a basis for understanding the experiences of the husband whose wife is receiving chemotherapy treatment for cancer from the emic perspective of the husband. The significance of this research is to provide information that will enable nurses to effectively plan and implement nursing care strategies that will assist husbands in developing coping strategies while their wives are undergoing chemotherapy treatment for cancer.

II. REVIEW OF THE LITERATURE

Cancer represents an abrupt and feared assault on the well-being of the patient and the family. As a result, the diagnosis of cancer disrupts and alters family life. The purpose of this review is to augment and elaborate on the husband's experience of his wife's chemotherapy treatment for cancer using empirical documentation of spousal response to the diagnosis and treatment of cancer. Most of the literature dealing with spousal response to cancer was non-research based, and although the literature identifies personal coping strategies dealing with the effects of cancer, the lack of systematic rigor in problem definition and research methods represents a gap between the anecdotal and the research literature. In this chapter, research literature from nursing, family, chronic care and other health related fields are reviewed while the anecdotal accounts are excluded.

The presence or absence of social support for the patient is a crucial factor in the patient's adaptation to cancer. Patients who lived longer tend to maintain cooperative and mutually responsive relationships, especially during the terminal stage of disease (Weisman & Worden, 1975). The spouse must not be overlooked as the potential primary social support for the patient (Cherkyn, 1984; Smith, Redman, Burns, & Sagert, 1985). The pattern of the patient's adaptation to cancer is not independent of the marital relationship, and the spouse is often the key to the patient's success or failure to adapt (Dyk & Sutherland, 1956). It is this researcher's contention that the spouse faces tremendous difficulty when attempting to provide support for the patient.

Several deficiencies were noted in the research literature. Often the sex differences of spouses were not reported. When investigators examine spousal response, this lack of rigor leaves one assuming the experience is the same for both the husband and the wife. Therefore, unless sex differences in spousal response are reported specifically,

these findings indicate that the spousal response for husbands and wives are interchangeable. Investigators who focus on the husband's experience and the non-patient experience do not clarify the interviewing techniques utilized for data collection. Those who interviewed the couple as a unit do not discuss the limitations of this approach. For example, one partner may be fearful of disclosing too much in front of the other partner, or one partner may assume control and speak for the other. If and when this occurs, the investigator fails to understand the experiential meaning of the experience for each of the partners involved. Many of the reported findings are based on small sample sizes using tools of undemonstrated reliability and validity.

For the purpose of this discussion, the research studies under review are divided into categories according to the stage of illness, site of cancer, treatment of cancer and side effects of chemotherapy treatment. Selected concepts inherent in the spousal response pattern are also reviewed.

Selected Concepts Inherent in the Spouse Response Process

Many of the concepts associated with experiencing cancer originate in the literature on chronic illness which focuses on the interaction of the individual, family and environment. Cancer has been considered a chronic illness, and as such, these concepts are important for understanding the cancer experience.

Coping

Coping has been defined as any effort to manage demands or conflicts that tax or exceed the internal or external available resources a person has at hand (Folkman & Lazarus, 1980). Coping strategies are multidimensional in that they occur over time and are affected by salient variables such as stress, the environment and individual personal characteristics (Panzarine, 1985). Clearly, stress is an important criterion influencing coping ability. Wives of cancer patients have been shown to experience

greater stress, helplessness and physical health problems. They neglect their own health more than wives of myocardial infarction patients (Vachon, Friedman, Formo, Rogers, Lydall, & Freeman, 1977). Family members report difficulty with concealment of feelings, acquiring information and coping with helplessness (Northouse & Northouse, 1987).

Stress is a complex process involving constant change (Lazarus & Folkman, 1986). The acknowledgement of stress depends on repeatedly observing the interaction of the environment and the person, over time (Lazarus & Folkman, 1986). In a stressful encounter, both problem-focused and emotion-focused coping are used, and conceptualizing coping solely in terms of defensive or problem-solving actions is inadequate (Folkman & Lazarus, 1980). Problem-focused coping includes seeking information or help and inhibiting or taking direct action. Emotion-focused coping includes using humor, avoidance, detachment or blaming behavior (Folkman & Lazarus, 1980). Men persevere in more problem-focused coping longer than women, but they do not differ from women in using emotion-focused coping within similar situations (Folkman & Lazarus, 1980). Family members focus their attention on the needs of the patient and deny their own needs as well as thoughts of the future (Parkes, 1975).

Marital relationships are important for harmony in the family life. Marital tension creates illness and somatic symptoms in the well spouse and is exemplified by nervousness, fatigue, role tension, anger and depression (Klein, Dean, & Bogdonoff, 1967; Schmidt, 1978). Spouses of myocardial patients demonstrate role tension with covert anger and bitterness because expression of resentment of increased role demands is perceived as being harmful to the patient. Spouses become overly protective, anxious and depressed (Stern & Pascale, 1979). Tension in the marital dyad is stressful for the well spouse (Klein, Dean, & Bogdonoff, 1967; Schmidt, 1978; Stern

& Pascale, 1979). Marital difficulties found to occur before illness escalate during convalescence (Flor, Turk, & Scholz, 1987). Well spouses fear talking about the fatal aspect of the illness and cope by decreasing communication with the patient (Stern & Pascale, 1979). Two indicators of social support, perception of family cohesiveness and the amount of social contact, have direct effects on coping and indirect effects on adjustment of the patient to breast cancer (Bloom, 1982). Bloom (1982) concludes that the coping mediates the relationship between social support and adjustment for patients with breast cancer.

Social Support As A Buffer

Lazarus (1966) identifies a threat as the crucial variable affecting psychological stress. A threat is any situation which a person evaluates as being harmful or potentially harmful. This paradigm focuses on the individual's perception of the situation. Thus, the individual who perceives a lack of control, such as, when a harmful situation is perceived, experiences greater degrees of psychological stress. The model developed by Lazarus (1966) describes coping behaviors for dealing with stress which are aimed at reducing or eliminating the threat or altering the perception of the harmful situation.

Social support, a characteristic of the social situation, buffers the effect of stress (Revenson, Wollman, & Felton, 1983). Social support acts as a buffer by changing the perception an individual has of a situation, by enhancing the individual's coping abilities or by reducing the individual's degree of reaction to the situation (House, 1981). Social support acts as a buffer for depression (Woods & Earp, 1978) and the fear of recurrence (Northouse, 1981) in cancer patients. On the other hand, women who experience mastectomy assert that the social support extended to them is inappropriate due to the mistaken assumption that her most salient concern is the loss of her breast rather than the fact that she has cancer (Peters-Golden, 1982). Social

support, in the form of a planned counselling and information program enhance the adjustment of patients after breast surgery (Bloom, Ross, & Burnell, 1978).

Husbands with higher levels of social support have fewer adjustment difficulties coping with their wives' mastectomy, particularly during the immediate postoperative period (Northouse, 1988). Husbands of cancer patients receive less support from health care providers than patients and gain more support from their wives than from family or friends (Bell, 1986; Northouse, 1988). The success of marital adjustment to cancer was better for those who expressed satisfaction with their relationship before the cancer episode (Lichtman, Taylor & Wood, 1988). The relationship between the breast cancer patient and her husband seems to be especially important to the patient's emotional adjustment (Jamison, Wellisch & Pasnau, 1978; Lichtman, Taylor & Wood, 1988; Vess, Moreland & Schwebel, 1985a, 1985b; Weisman, 1979; Weisman & Worden, 1976). The most frequently expressed need of families caring for the patient with cancer in the home is the desire for a place they could go outside the home to discuss their fears. This clearly indicates the family's need for social support outside the home environment (Hinds, 1985). Spouses often deal with double anxiety as they listen to the patient while experiencing their own anxiety and their own increasing sense of aloneness (Welch-McCaffrey, 1985).

Chronicity

If one defines a chronic illness as one requiring prolonged adaptation and having lifestyle limitations, then receiving chemotherapy constitutes a chronic situation. Chronic illness in one partner increases the responsibilities in the home for the other (Ekberg, Griffith, & Foxall, 1986). Couples who are able to work together collaboratively to manage chronic illness are able to prevent, resolve or circumvent problems associated with the illness (Corbin & Strauss, 1984). Spouses do experience symptoms of depression, anxiety, fatigue and role tension during the patient's illness.

Thus, illness exerts a changing effect on family members who do not have the illness (Goldstein, Regnery, & Wellin, 1981; Klein, Dean, & Bogdonoff, 1967). In spite of being together with their wives almost constantly, spouse burnout in husbands produces feelings of uselessness, wanting to leave home, loneliness and social isolation (Ekberg, Griffith & Foxall, 1986).

Chronic pain also impacts on family members. When examining the effect of chronic pain on the spouse, Rowat and Knafl (1985) found increased symptomatology, feelings of aloneness, helplessness and uncertainty as to what to do for fear of causing harm to the patient. Spouses with high distress scores describe environmental changes, such as, keeping the stress level down, as coping strategies designed to protect the patient from undue stress and to decrease potential pain. Husbands who have been dealing with the chronic pain for a longer time period and whose wives continue to work exhibit lower distress scores. Spouses with lower distress scores report using avoidance or ignoring behaviors to cope with the patient's pain. Foxall, Ekberg and Griffith (1985) found spouses who live with chronic illness of longer duration with partial or total disability do not adjust well. Loneliness and social isolation are found to be attributes of the lower adjustment process. Chronic pain produces considerable change in marital and sexual satisfaction (Flor, Turk, & Scholz, 1987). The dysphoric mood of spouses is directly related to their perceived negative appraisal of the patient's pain, lack of life control and marital dissatisfaction (Flor, Turk, & Scholz, 1987). The central theme of the chronicity literature is that of uncertainty in relation to the adjustment to chronic pain and the implications for family life.

Normalization

Normalization is a term used to describe how families attempt to manage their family life when one member is ill (Knafl & Deatrick, 1986). Normalization can be defined using four characteristic behaviors: 1) acknowledging the existence of the

impairment; 2) defining the family life as essentially normal; 3) defining the social consequences of their situation as minimal; and 4) engaging in behaviors designed to demonstrate the essential normalcy of the family to others.

Thorne (1985) interviewed families coping with cancer and found they focus on normalcy. They value normalcy and perceive themselves as maintaining it through strategic choices. Families articulated a shared belief system or philosophy, a coping style and a successful "positive attitude" which together merged to develop their unique sense of normalcy and dignity when adapting to and managing the cancer experience.

Anticipatory Grief

Anticipatory grief is a process which provides a means by which an individual relinquishes a key person and fills the void created by that person's death even though a bereavement has not been experienced (Averill, 1968; Lindemann, 1944; Weisman, 1979). Anticipatory grief is either a positive or negative adaptive response to impending loss and provides a rehearsal for the bereavement role (Siegel & Weinstein, 1983). It is cited as a normal and expected component of coping; however, the process of how it manifests itself in family members is not described (McCorkle & Donaldson, 1986; Welch, 1982). One investigator utilizes a sample of adults from all stages of cancer progression and finds anticipatory grieving begins at diagnosis and remains throughout life (Welch, 1982). Factors affecting anticipatory grief in families include hospitalization on a specialized oncology unit or past experience with death of an immediate family member (Welch, 1982). A limitation of the anticipatory grief research is found in the consistent sampling of elderly and bereaved who do not constitute the experience for other populations.

Stage of the Disease

Cancer is described as having three distinct stages: the diagnostic stage, the

intermediate or middle stage and the terminal stage (Edstrom & Miller, 1981). The emphasis of research is on the initial, late and recurrent stages. There is a scarcity of documentation concerning spousal response during the intermediate stage of cancer progression when chemotherapy is commonly administered. Research focuses on spousal response to treatment rather than on the coping strategies of spouses or the management of daily activities in the home. The stage of disease affects the degree to which the spouse assumes the patient's role and the amount of tension created between the marital couple (Jamison, Wellisch, & Pasnau, 1978; Silberfarb, Maurer, & Crouthamel, 1980; Wellisch, Jamison, & Pasnau, 1978). Families of cancer patients perceive cognitive needs such as information giving to be the most important in all phases of the cancer illness (Tringali, 1986).

Diagnostic Stage

During the diagnostic stage, spousal depression is reflected in their lack of social interest outside the nuclear family (Goldberg, Wool, Glicksman, & Tull, 1984). Uncertainty over the patient's readiness to die, existential concerns, personal restlessness and anxiety are also described (Germino, 1984). Existential concerns encompass those aspects of personal vulnerability associated with the purpose and meaning of life, death and the dying process (Lewis, 1986). Spouses express fear about the uncertainty of the disease progression, specifically during the early and late stages, fear about the future and fear associated with the uncertainty of waiting (Gotay, 1984; Wright & Dyck, 1984). Waiting is described as a lack of control (Bell, 1986).

Hospitalization produces family responses of fear, anxiety, distress at observing symptoms, absorption with getting information and waiting (Welch, 1981b; Wright & Dyck, 1984). Lovejoy (1986) found the specific responses of shock, uncertainty, accommodation, immersion and awareness. Uncertainty evokes helplessness and negative emotions, such as, guilt, fear or anxiety. Accommodation represents changing

priorities and activating coping strategies. Immersion represents a process of heightened sensitivity and fusion with the patient which results in the family member neglecting himself. Awareness is an awakening when preparation for the future begins and control of the reality of the situation is regained.

Recurrent Stage

Spouses whose ill partners are dealing with recurring disease are uncertain about the future, have existential concerns, express anger and feelings of injustice and experience anticipatory grief (Cherkyn, 1984). The primary concern is fear of recurrence (Bell, 1986). When these feelings become part of the spousal reality, they produce tension concerning the future disease trajectory, even though many feel recurrence fosters marital closeness (Cherkyn, 1984). As the disease progresses watching someone suffer from pain, fatigue, weight loss or nausea is difficult (Wright & Dyck, 1984). Spouses need to be kept informed of changes in the patient's condition and to be reassured of the patient's comfort (Wright & Dyck, 1984). The need to be with the patient, talk to the patient and be helpful to the patient dominates the actions of the spouse (Wright & Dyck, 1984). Patients find it difficult to talk to their spouse when they do not share the same meaning concerning recurrence of the disease. In spite of this and even though they are unable to openly share feelings about having cancer or about bereavement issues with their spouse, patients do recognize the important role of spousal support. Patients readily talked with the interviewer, and this exemplifies their need to communicate with someone (Cherkyn, 1984). Patients with recurrent cancer are equally distressed at the times of initial diagnosis and diagnosis of recurrence. They do not find recurrence to be more distressing than the initial diagnosis (Weisman & Worden, 1985).

Terminal Stage

Several investigators interviewed spouses during the terminal stage of illness

(Dracup & Breu, 1978; Hampe, 1975; Howell, 1986; Stetz, 1987). The terminal illness of a partner is the most stressful life event for spouses. They need to be with their partner and to be kept informed of their partner's condition (Hampe, 1975; Howell, 1986). Spouses experience decreased health and disturbed thought processes which progress to feelings of helplessness, fear and a need for personal emotional support (Grobe, Ahmann, & Ilstrup, 1982; Howell, 1986; Krant & Johnson, 1978; Stetz, 1987). Spouses are often told of the gravity of the illness before the patient, and although the patient should be told, telling the patient is dependent on the spouse (Hinton, 1981). This added responsibility constitutes an added stressor for the spouse.

Spouse caregivers in the home experience the personal demands of standing by and managing the household, finances and physical care of the patient (Stetz, 1987). Husbands are reluctant to get involved with the physical care of their wives and cope poorly with physical care because of their fear of causing harm (Dracup & Breu, 1978; Hinds, 1985). The responses to observing the patient and standing by helplessly make spouses realize the need to find a way to cope with their inability to alter the patient's illness (Germino, 1984; Krant & Johnson, 1978; Stetz, 1987). When patients are hospitalized, spousal concerns relate to the unmet comfort needs of the patient and to lifestyle changes, such as, concern about being alone (Hampe, 1975; Howell, 1986).

Conflicting research findings regarding communication between husband and wife raise questions about the need to discuss and share thoughts about dying between partners. Spouses share in giving and receiving emotional support to the exclusion of other family members (Hampe, 1975). Hinton (1981, 1980) reports that communication about impending death made no difference in the closeness of the couple's relationship. Evidence suggests spouses have been unable to vent their feelings with health professionals, and this lack of opportunity to talk with someone outside the family impedes their grieving process (Hampe, 1975).

Bereavement issues are reported in several studies. Krant and Johnson (1978) found that while a majority of family members think of the possibility of the patient dying most have not discussed this with the patient. The discussion with the patient is influenced by whether the patient believes dying is imminent and whether the patient and the family member understand what is happening. No published data were found to demonstrate that the inability to discuss these issues with the patient alters the quality of life for either the patient or for the family member. Families who have poorer communication patterns between family members and the patient, do not want the patient to die at home. The family members want the health care system to be responsible for patient care. Hinds (1985) reports that family members express fears related to dying and dealing with the patient's fear of dying. Although they seldom seek assistance family members need assistance to deal with their own and the patient's fear of dying. Giacquinta (1977) found that family responses in the terminal stage of disease include impact, functional disruption, search for meaning, informing others, engaging emotions, reorganization and framing memories. These findings suggest a process of reminiscing and reframing of thoughts about the person who was ill.

Throughout all of the stages of cancer progression, the fear of death and uncertainty prevail (Germino, 1984; Gotay, 1984; Krant & Johnson, 1978; Welch, 1981a). This review of the literature indicates that frequently patient and spousal needs are non-convergent or out-of-phase with each other (Germino, 1984; Gotay, 1984; Lewis, 1986; Northouse & Swain, 1987). Unfortunately, the literature dealing with the spouse is based on patient information obtained with questionnaires. It appears the researchers have been using the wrong data to represent spousal experiences. This is relevant for nursing assessment and nursing intervention with families of cancer patients because the target and scope of most intervention is focused on the patient's needs and not on those of family members, such as, the husband. Stetz (1987) was the

first to report a distinction between the difficulties experienced by husband versus wife caregivers and found husbands are most concerned with the day-to-day management of the household and finances. The lack of research concerning the experience of the well husband and the existence and differentiation of the husband's or wife's response to cancer represents a gap in the theoretical literature. Without specific research concerning the husband's response, effective nursing interventions designed to help the husband cope with his wife's cancer and chemotherapy experience cannot be rigorously tested or utilized in clinical practice.

Site of the Disease

The major thrust of previous research focuses on the psychosocial impact and coping responses of husbands when their wives have breast cancer (Asken, 1975; Klein, 1971; Lewis & Bloom, 1979; Wellisch, Jamison, & Pasnau, 1978). The effect of breast cancer on marital relationships has been studied extensively, with inconclusive findings. For example, the longer, more stable marriage may show less strain (Jamison, Wellisch, & Pasnau, 1978), greater strain (Wellisch, 1985) or may improve after breast cancer (Bell, 1986; Gates, 1980; Grandstaff, 1976; Leiber, Plumb, Gerstenzang, & Holland, 1976). Couples who have an unsatisfactory marital relationship before surgery are more vulnerable to problems after surgery (Wellisch, 1981). Lichtman (1982) found that when marital discord occurs it was due to differing views regarding adjustment and coping strategies. In one study, wives notice either no change in their husbands following surgery or a positive change, such as, being more considerate, affectionate and supportive (Bell, 1986). There is no evidence in the literature of any negative changes in husbands' behavior from the wives' perspective.

An interesting phenomenon in the communication pattern of spouses is illustrated by the double bind situation (Gates, 1980). This no win situation is one in which the

husband is given contradictory messages concerning sexual contact. The husband is thwarted in an attempt to provide reassurance to his wife through sexual contact and becomes frustrated and feels rejected and victimized. The husband distances himself from his wife in order to defend himself. This results in the husband becoming distressed and the wife losing her support system.

Only one longitudinal study was found which interviewed husbands of cancer patients who had undergone mastectomy (Pfefferbaum, Pasnau, Jamison, & Wellisch, 1977; Wellisch, 1981; Wellisch, Jamison, & Pasnau, 1978). Most husbands are not included in the decision-making regarding surgery and wish they could be more involved. Husbands who are involved in decision-making are more supportive and resolve the emotional impact of mastectomy faster than their wives (Wellisch, 1981). A disturbing finding is that most of the husbands suffer from some form of psychosomatic reaction, such as, changes in their appetite, sleep pattern, weight, fatigue or some form of work related difficulty (i.e., lack of concentration). Unable to adjust, some husbands find their marital relationship deteriorating. A large number of husbands report their sexual response is affected. Maguire (1981) found periods of stress to be highest for husbands during hospitalization and surgery. Another stressful time for husbands is when viewing their wives' nude body for the first time after mastectomy, and many never see their wives unclothed after the mastectomy (Wellisch, 1981). Husbands are reported to be as distressed as their wives following mastectomy (Baider & De-Nour, 1984; Northouse & Swain, 1987). For families, better adjustment is predicted by more expressiveness and less conflict and moral-religious orientation (Spiegel, Bloom, & Gottheil, 1983). Families cope with metastatic breast cancer with conspiracies of silence often found to be more harmful than beneficial (Spiegel, Bloom, & Gottheil, 1983).

Oberst and James (1985) interviewed couples where one spouse had surgery for

bowel or genitourinary cancer. Well spouses report exhaustion and disruption in lifestyle brought about by the need to take the patient to hospital for further treatment. Well spouses report being uncertain about the efficacy of treatment, especially when improvement is not dramatic. Rarely helpful with physical caregiving for long periods, spouses are found to be most helpful during initial homecoming from the hospital. Husbands express a need to be constantly cheerful and hopeful for the patient, which escalates their anxiety and interferes with their ability to cope with daily activities. As a result, husbands experience ambivalent feelings of anger and guilt. For example, they respond with anger because often they have actual physical symptoms of distress of which their wives are virtually unaware. Guilt is evident when husbands think of themselves rather than concentrating all their energy on the patient, and some question their own self-image as a good person. Well spouses perceive a lack of support from all sources, including health professionals.

Spouses of patients who have undergone abdominoperineal resection with colostomy react in a manner similar to that described above (Dyk & Sutherland, 1956). Spouses conceal their fears, minimize the danger of disease progression and encourage hope for the patient. The needs of the patient dominate and the goal of maintaining the patient's self-esteem is expressed. Many spouses have not seen the colostomy due to the patient's shame and modesty and become annoyed at the social seclusiveness of their wives. Husbands who see the ostomy are not as repelled as their wives are of themselves.

Cooper (1984) interviewed couples experiencing lung cancer and found spouses do not share their fears with patients, report increased signs of stress and do not share the patient's perception of closeness in the marital relationship since diagnosis. Spouses experience loneliness, helplessness, anger, hopelessness, vulnerability and guilt. Hope is important to spouses because it indicates the disease is treatable. Helplessness is

associated with "empty-handedness" or the lack of control over the disease progression. When considering social support, spouses and not patients, are more apt to reach out to others outside the nuclear family for support and/or someone to talk with. Quinn, Fontana & Reznikoff (1986) found spouses of lung cancer patients coped by using wish-fulfilling fantasy, self-blaming denial and emotional expression.

These findings suggest the needs of spouses may be unmet and overlooked by health professionals. Most of the literature focuses on the patient as an isolated individual and overlooks the concurrent response of family members. The revealed vulnerability of the spouse is in direct opposition to the key role of supporter and provider which health care providers expect him to take within the marital dyad and within the family system.

Treatment of the Disease

Surgery

The most common treatment modality in the research literature is surgery. Surgery represents a physical assault on the body which may not necessarily have a successful outcome. Husbands involved in decision-making about the choice of surgery offered for breast cancer are less anxious and depressed both pre-operatively and postoperatively (Morris & Royle, 1988). Therefore, involvement in the treatment produces less stress for husbands. Husbands find the hospitalization period to be most stressful due to feelings of exhaustion and role strain as they struggle to fulfill work, home and visitation responsibilities (Oberst & James, 1985; Northouse & Swain, 1987) or due to the emotional shock of the possibility of their wives' death (Grandstaff, 1976).

After hospitalization, Oberst and James (1985) found the disruption in lifestyle and the role change needed to deal with the disruption is accompanied by increasing anger

and resentment. Incidences of illness and somatic complaints escalate from fatigue to a multitude of physical problems. A significant finding is that spouses expend energy worrying about their wives' symptoms while wives are unaware of the distress husbands experience. Many husbands hide their distress, while others want to be noticed; but they also feel they cannot burden their wives with their own problems. When considering the efficacy of surgery as a modality of treatment for cancer, Oberst and James (1985) found that uncertainty begins to increase as postoperative time increases. Baider, Rizer and De-Nour (1986) found that husbands are less satisfied than wives with the surgical treatment during the hospitalization.

While the emotional distress of patients decreases, spouses experience increasing emotional distress as postoperative time progresses (Oberst & James, 1985). Although wives had bowel surgery with resultant ostomy, spouses have no feelings of stigmatization toward the ostomy although they report a reluctance to tell others because of feelings of stigmatization toward the cancer (Oberst & James, 1985). The spouse is of prime importance to the ostomy patient coping with an altered body image. This is particularly evident in relation to resumption of normal sexual activity (Dyk & Sutherland, 1956; Gloeckner, 1983). A substantial number of spouses react with fear of injuring or causing pain to the stoma after surgery, and this affects resumption of sexual activity. These findings indicate the need for further research to identify variables affecting the husband's response postoperatively so that effective nursing interventions can be planned to decrease the emotional distress experienced.

The double bind situation described by Gates (1980) is reflected in the findings of Oberst and James (1985). Husbands feel increasing emotional distress and become angry at their wives for being so egocentric and not perceiving the distress experienced by their husbands. Once angry, husbands become overcome with guilt feelings, which in turn make them more attentive to their wives in order to absolve the guilt. Grandstaff

(1976) defines a pattern of husband response which includes denial, anger or frustration, depression, a sense of grieving or mourning and fear in which the responses are intermittent and often cyclic in nature.

While wives are hospitalized, husbands feel they are well informed (Oberst & James, 1985). However, unless they accompany their wives to follow-up appointments, they have no access to the physician, and their only source of information is through their wives. Spouses experience distress, anger and frustration at the lack of support, especially from health professionals.

Chemotherapy

Chemotherapy may be used as adjuvant therapy or as a primary treatment modality for cancer. Marital relationships, particularly in relation to communication and adjustment to receiving chemotherapy, have been the subject of research investigation. There is a paucity of research exploring the experience of either the patient or spouse during chemotherapy, and response to chemotherapy is described entirely from a health provider perspective.

Hart (1987) found family members describe the need to change the types of activities they share with the patient due to side effects experienced as a result of chemotherapy. The greatest stress for family members is associated with the initial diagnosis, and the least amount of stress is experienced by those who have been living with the diagnosis more than twenty months. Spouses want more information about the chemotherapy and the probable course of disease progression, and they look to the physician for this information. Once a physician is chosen by a couple, spouses report they believe that they must trust the physician. This implies spouses feel chemotherapy is a situation in which they have little control (Cooper, 1984). Physicians inform family members of the diagnosis and the family responds with feelings of helplessness in dealing with the prognosis. Family coping responses are aimed at eliminating or

reducing the anticipated threat, and only 2% of the coping responses are behaviors aimed at altering the perception of the threat (Cooper, 1984). Family members consciously advocate actual behavioral responses based on the reality of the threat rather than denying or ignoring the existence of the threat. When chemotherapy patients are depressed, they seek out nonfamily significant others (i.e., a friend) to share their feelings with, and Hart (1987) hypothesizes that patients are trying to protect family members from the feelings they are experiencing.

Patients and spouses of both sexes are reported to have an increased desire for physical closeness and a decreased desire for sexual intercourse while receiving chemotherapy (Leiber, Plumb, Gerstenzang, & Holland, 1976). Female patients have the highest levels of depression. They are also more likely to have their affectional needs met by their husbands, while the needs of husbands whose wives are receiving chemotherapy are poorly met and infrequently expressed (Lieber, Plumb, Gerstenzang, & Holland, 1976).

Radiotherapy

The patient receiving radiotherapy is ambulatory and usually responsible for self-care. However, undesirable side effects develop as the treatment progresses and depending on the degree and type of cell damage, the patient becomes quite incapacitated. The research literature focuses on the patient response (Christman, 1987; Dodd, 1984a; Eardley, 1985a, 1985b, 1985c, 1985d; Forester, Kornfeld, & Fleiss, 1978; Karlsson & Anderson, 1986; King, Nail, Dreamor, Strohl, & Johnson, 1985; Kubricht, 1984; Peck & Boland, 1977), while the family response is not investigated. This investigator found no relevant studies regarding the experience of either the patient or the spouse during radiotherapy.

Side Effects of Chemotherapy

Chemotherapy produces very unpleasant side effects, such as, hair loss or excessive nausea and vomiting. Research literature focuses on the patient, with studies on visual physiological symptom management (Cline, 1984; Coons, Leventhal, Nerenz, Love, & Larson, 1987; Cotanch & Strum, 1987; Duigon, 1986; Kennedy, Packard, Grant, & Padilla, 1981; Rhodes, Watson, Johnson, Madsen, & Beck, 1987; Rhodes, Watson, & Johnson, 1986; Rhodes, Watson, & Johnson, 1985), body image (Baxley, Erdman, Henry, & Roof, 1984) and self-care (Dodd & Moon, 1981; Dodd, 1982a; 1982b; 1983; 1984a; 1984b; 1988; Fernsler, 1986). Unfortunately the literature excludes the psychological disturbances accompanying chemotherapy. This investigator found no relevant studies regarding the experience of either the patient or the spouse during chemotherapy, and the research literature focuses entirely on the caregiver perspective.

Hart (1987) found that fatigue is the side effect causing the highest level of stress for family members during chemotherapy, with the nausea and vomiting second. Thomas (1978) found that when chemotherapy is used as adjuvant therapy the family shares a feeling of ambivalence about the efficacy of chemotherapy due to the demoralizing effect it has on their lifestyle.

Of particular interest to this researcher is the experience of the husband when his wife is undergoing chemotherapy treatment for cancer. The lack of research utilizing a sample of patients receiving chemotherapy is representative of the scarcity of information regarding the non-medical problems, the invisible scars of chemotherapy, for both the patient and the spouse. Although interventions for the side effects of chemotherapy are offered, there is a gap in the research representing studies to validate the interventions.

Summary

Although cancer is a heterogeneous disease of multiple stages and types, most research does not address the changes inherent in the disease transitions. Frequently, data collection is based on one interview at one particular stage rather than continuing data collection over time. The one-shot approach ignores the changing nature of the disease progression and the husband's experience with this change. The review of the literature indicates that aspects of daily life and the marital relationship can be affected by chemotherapy, yet the impact on the spouse is unclear.

Clearly there is a need to study the husband's response to his wife's long-term, outpatient chemotherapy treatment for cancer. The husband traditionally works outside the home and is not present in a caring role for the majority of the day. In order to do so, he has to assume an adaptive role change. The prolonged nature of chemotherapy treatment, with its accompanying disabling side effects, makes this an important topic for investigation. Although the side effects of the chemicals used for chemotherapy vary according to the drug and the individual's response, the effects are always evident in some form, and the reality of the husband's emotional involvement cannot be ignored. From this review of this literature it is apparent that the husband is at risk for problems of health and adjustment.

Research Questions

The following research questions investigate the husband's experience during his wife's chemotherapy:

1. How does the husband describe his experience of living with a wife who undergoes chemotherapy treatment for cancer?
2. What appears to influence the husband's response to his wife's situation?
3. What personal strategies does the husband describe as most helpful in responding to his wife's situation?

III. METHOD

In this study, the research questions were most appropriately addressed using qualitative methods of data collection and analysis. A qualitative research method was designed to describe the experience of living with a wife undergoing chemotherapy from the emic perspective of the husband. The subjective nature of the husband's experience along with a lack of knowledge about the experience of husbands whose wives are undergoing chemotherapy, indicated the need for an inductive approach.

Grounded Theory

Exploring the experience and discovering what is important to the husband whose wife is undergoing chemotherapy was obtained through the use of grounded theory methods and working with inductive and deductive reasoning in a systematic way (Glaser, 1978; Glaser & Strauss, 1967). Grounded theory was used because little is known about this subject area and quantitative analysis is unrealistic since variables relevant to the concepts have not been identified (Stern, 1980). Grounded theory methods enabled the researcher to discover the dominant patterns of behaviors relative to the specific context under study and encouraged the use of creative thinking in the process of generating potential hypotheses (Field & Morse, 1985). The method allowed for the collection of data to be modified as interviews progressed, and this facilitated the clarification of potential hypotheses evolving from the data.

Sample Selection

The selection of a purposeful nonprobability sample of husbands whose wives were experiencing new and/or recurring treatment situations requiring chemotherapy for any kind of cancer was determined by the research questions. A nonprobability sample

allowed the selection of informants who were eager to be good informants and who were willing to talk and share experiences. In order to be included in this study, informants had to have a wife or partner in a permanent relationship who had undergone chemotherapy and were able to speak on the telephone without incurring long-distance charges. Informants determined the nature of their personal relationship with the woman receiving chemotherapy. A strength of the sample was that the population was not limited to a strict or legal definition of a marital relationship. This factor strengthened the variability of responses while facilitating and enriching the data analysis.

Informants were deliberately sought from the community by advertising for volunteers. Direct contact with husbands, as opposed to referral from a physician or a spouse, was preferable to reduce potential bias. Newspaper articles and circulars describing the purpose of the study and requesting volunteers were published and available in places, such as, wig shops, where potential informants might see them. Volunteers were requested to initiate a telephone contact with the investigator to indicate their interest in participating in the research. Previous to initial contact, informants were randomized to either interview method so that appointments for interviews could be mutually agreed upon. Consent requesting permission to conduct the interviews and to tape-record the content of the interviews was obtained. Fifteen informants met the inclusion criteria and were deemed sufficient to obtain an appropriate and adequate amount of information to saturate the categories evolving from data. The biographical characteristics of the informants are presented in Table 1. A total of forty-eight interviews, ranging from twenty minutes to two hours, and one diary were included for data analysis. The diary was included because of the appropriateness of the data and the inability to verbally interview the informant due to geographical distance from the interviewer. The average age of informants was forty-seven years, the average length

TABLE 1
INTERVIEW METHOD AND
CHARACTERISTICS OF INFORMANTS

| Informant | Characteristics | | | Interview Method | |
|-----------|-----------------|-------------------|------------------------------|-------------------------|------------------|
| | Age in Years | Years of Marriage | Total Months of Chemotherapy | Undergoing Chemotherapy | Interview Method |
| 1 | 46 | 20 | 90 | Currently | Telephone |
| 2 | 32 | 12 | 15 | Currently | Telephone |
| 3 | 46 | 12 | 3 | Currently | Telephone |
| 4 | 44 | 12 | 3 | Currently | Face-to-face |
| 5 | 46 | 20 | 8 | Currently | Telephone |
| 6 | 32 | 1 | 3 | Currently | Face-to-face |
| 7 | 60 | 4 | 16 | Completed | Telephone |
| 8 | 65 | 37 | 14 | Completed | Face-to-face |
| 9 | 54 | 37 | 24 | Completed | Face-to-face |
| 10 | 48 | 14 | 11 | Completed | Telephone |
| 11 | 50 | 26 | 4 | Completed | Telephone |
| 12 | 43 | 22 | 10 | Completed | Telephone |
| 13 | 49 | 25 | 26 | Completed | Face-to-face |
| 14 | 46 | 10 | 9 | Completed | Telephone |
| 15 | nk ¹ | 9 | 11 | Completed | Diary |

¹Not Known

of marriage was seventeen years, and the average length of time living with a wife receiving chemotherapy was seventeen months. Of the fifteen informants' wives, six were currently undergoing chemotherapy and nine had completed chemotherapy. Six of the nine wives who had completed chemotherapy were deceased at the time of study completion.

Data Collection

Unstructured, open-ended interviews facilitated sharing the husband's experience of living with a wife enduring the chemotherapy process and enabled the investigator to explore the meaning of the experience for the husband. Unstructured, open-ended interviews were chosen because they allow the interviewer to proceed from the general to the specific as directed by information the informant deems important. Open-ended interviews are particularly useful when conducting exploratory research (Field and Morse, 1985). The researcher asked descriptive questions following the ethnographic interview process. Fieldnotes and memos further supplemented data collection.

Two methods of interviewing were chosen to expand the richness of data obtained by the interviewer. The telephone method was chosen because informants were accustomed to speaking on the telephone and could choose the time and physical setting in which the telephone conversation would occur. Telephone interviews have been found to have responses consistent with face-to-face interviews (Janofsky, 1971; Kegeles, Fink, & Kirscht, 1969). Interviews were tape-recorded to facilitate later transcription. However, the predominant reason for choosing telephone interviews was to provide the informant with anonymity. Norris (1986) describes the appropriateness of telephone interviews for providing the context of anonymity. Anonymity facilitates the private and unseen release of emotion along with the sharing of private feelings and thoughts about a sensitive topic (Warwick & Lininger, 1975). Colombotos (1969) found informants are more willing to admit to socially undesirable

behaviors and are less likely to overstate socially desirable behaviors on the telephone than during face-to-face interviews. This researcher recognized telephone interviews negated the feedback obtained from the nonverbal behavior accompanying the informant's verbal response. The possibility that face-to-face interviews would reflect data of a different content or a different emphasis due to the nonverbal cues picked up by the interviewer during the conversation led to the use of the face-to-face interview method. Informants were randomized to an interview method by tossing a coin prior to beginning the study. The investigator introduced the predetermined interview method during the initial contact with the informant.

Informants were not eager to participate, and the investigator actively sought informants for a period of seven months before the ongoing data analysis indicated saturation of categories. As data collection progressed, it was necessary to examine the inclusion criteria for the sample population. As the search for informants continued, three informants refused to participate in the research due to the randomized interview method, and two informants refused to be tape-recorded. Of those who refused on the basis of the interview method, their decision not to participate was made because they did not want to have to meet with the investigator and preferred to remain anonymous. Another informant was reluctant to be interviewed on the telephone and preferred to meet personally. On evaluation of the need for randomizing the interview method, the investigator decided to offer informants their choice of either telephone or face-to-face interview method rather than lose a potential informant. Of the five informants offered their choice of interview method, four chose the telephone interview method and one chose the face-to-face interview method. As data analysis continued, informants indicated their reluctance and personal difficulty talking about their experience of their wives undergoing chemotherapy. They felt others would be more willing and able to share their experience with the investigator retrospectively. Therefore, the investigator

expanded the selection criteria to include those husbands who had experienced their wives' chemotherapy.

Reliability and Validity

Reliability was enhanced by deliberately selecting informants according to research needs and having the researcher consistently conduct all interviews. This process enabled the researcher to more accurately probe inconsistencies in data collection and to clarify vague or ambiguous meanings expressed by informants during interviews. The nonprobability sample ensured optimal reliability and validity. The assumption that all informants were not equally able to share information relevant to the purpose of the study enabled the researcher to choose informants who were more motivated, interested, knowledgeable and willing to be interviewed over time (Morse, 1986). The informants were able to supply copious amounts of comprehensive and relevant information which was appropriate to the research. This data saturated the categories so that no new information added to further understanding the patterns and themes of information inherent in the categories. The nonprobability method of sampling ensured the information was accurate, precise and complete (Morse, 1986). Internal validity was ensured through grounding the data in the reality of the context dependent situation. The use of methods, such as actively seeking negative cases, which were inconsistent with the evolving patterns and themes of data and utilizing theoretical sampling of the literature further strengthened the internal validity of the findings. Repeated interviews over time were used to corroborate recurrent or changing data.

Data Analysis

Tape recordings of interviews were transcribed verbatim. As interviews progressed, the researcher developed questions based on previous interviews. These

questions reflected the ongoing, constant comparative analysis between informants. Interviews became semi-structured in an attempt to validate comments made by informants in earlier interviews. The systematic analysis of the transcripts involved initially coding behavioral responses of husbands and using constant comparison to look for commonalities or negative cases across all of the interviews. A negative case was representative of the husband whose experience would clearly refute the theme or pattern of behavior emerging from the majority of the interviews (Field & Morse, 1985). The understanding of the husband's behavior which evolved from the data represented the reality of living with a wife undergoing chemotherapy.

As the data collection continued, similar data were coded and grouped to form categories. Categories were linked among themselves and compared to existing theory in order to form potential hypotheses. Data collection continued until categories were saturated and new data did not add to the current understanding. Secondary informants were not used to confirm evolving patterns of husbands' responses as the use of constant comparison adequately validated the ongoing analysis.

Eventually, a core variable called *Buffering* evolved. Grounded in the data, *buffering* explained the major behaviors of husbands. This core variable represents the pattern of behavior of husbands relevant to the context of the marital dyad and forms the basis of a grounded theory.

Ethical Considerations

The purpose of the study was explained during the initial telephone conversation initiated by the informant. The investigator established a research relationship with the informant by explaining that the focus of the study was on the individual informant and not on the wife receiving chemotherapy. Informed consent for either face-to-face or telephone interview was obtained at the time of the first interview (Appendix A and

Appendix B). The consent form clarified the right to withdraw from the study and the right to terminate an interview or to refuse to discuss a topic if the informant so desired. Informant confidentiality was ensured through coding informants' names so that only the codes appeared on transcripts of the interviews or in reported findings. Specific details concerning each informant were changed in written reports so as not to identify the informant in any manner. Original tapes were kept in a locked cupboard during the progress of the study. It was anticipated that the process of expressing one's experiences with chemotherapy would be beneficial to the informant. In order to decrease the likelihood of potential risk, harm or emotional trauma for the informant, information regarding counselling and professional services was available to the informants at the discretion of the investigator.

IV. RESULTS: THE THREAT AND THE FIGHT

The purpose of this research is to describe the experience of living with a wife undergoing chemotherapy from the emic perspective of the husband. This experience is a process (figure 1) of three essential components: the threat, the fight and the emergence as a veteran. All informants did not proceed to the fourth component of recurrence, but those who did began the process again. Thus, the process is cyclical and repetitive in nature.

In human experience there is usually a core variable that explains the meaning of the data (Glaser, 1978) and it has three essential characteristics: it occurs frequently and it links and explains the variation of data (Hutchinson, 1986). The basic social structural process (BSSP) described by Glaser (1978) and Glaser and Strauss (1967) is a type of core variable as it explains the variation in behavior evident over time in the data. The BSSP that emerged in this study is *buffering*. *Buffering* is a process by which husbands are able to set up a protection surrounding their wives which acts to simplify and reduce the stress of day-to-day life during the wife's chemotherapy treatment for cancer. The buffering process (figure 2) is a very delicate one, (e. g., similar to walking a tightrope) and husbands have to be constantly reassessing their strategies of buffering and developing new ones. The assumption underlying the buffering process is that when one has a positive attitude toward the outcome of chemotherapy treatment it will be less stressful for the wife and influence her length and quality of life.

Buffering requires personal attributes, which include patience, persistence, understanding, compassion and a caring marital relationship. It is not a passive role, but rather involves two active components: constant vigilance and cognitive action. Vigilance consists of watching others and observing the wife's response to chemotherapy and her interactions with others. Cognitive action consists of

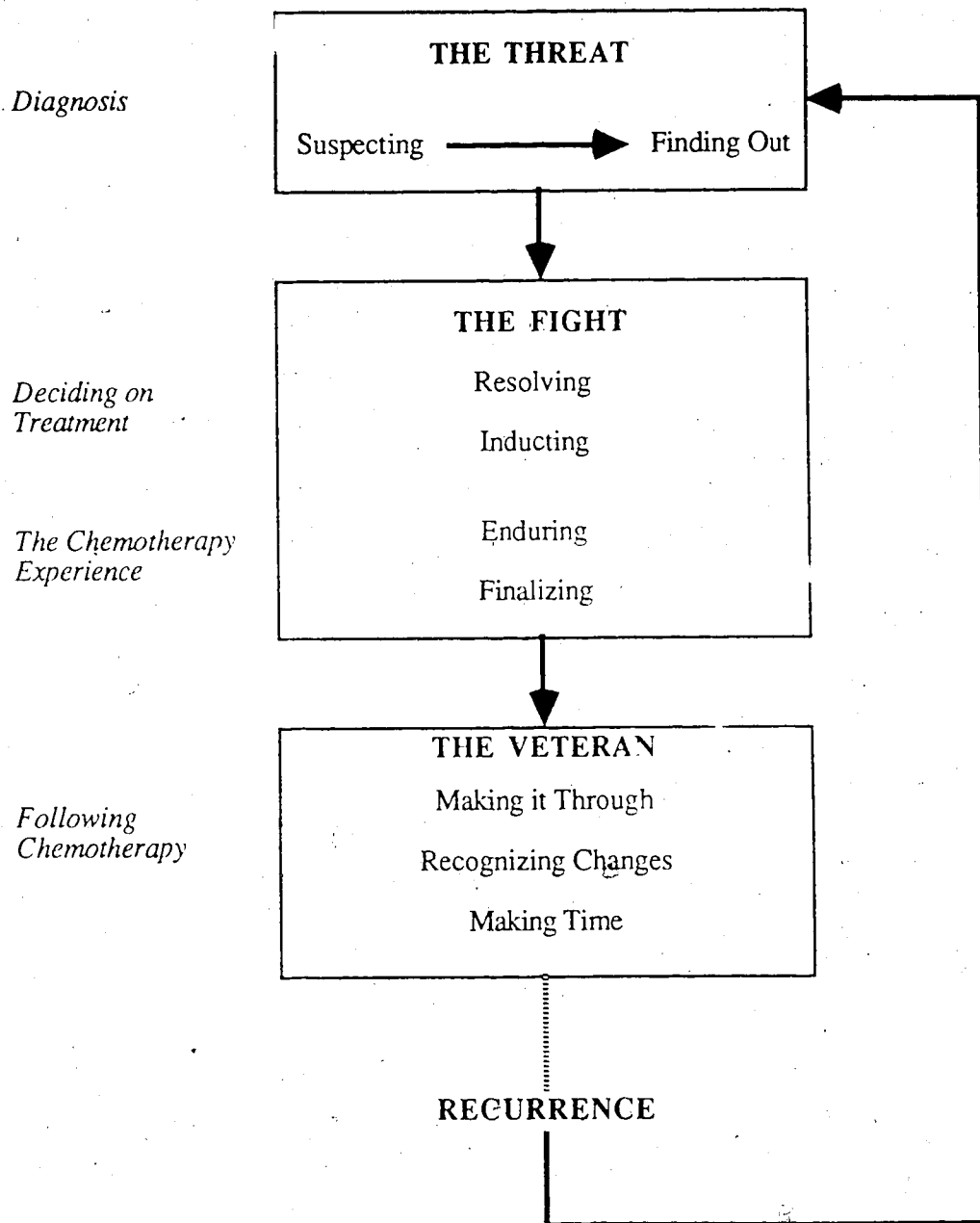
Course of Illness

Figure 1. The Process of Living with Chemotherapy: Experiences of Husbands.

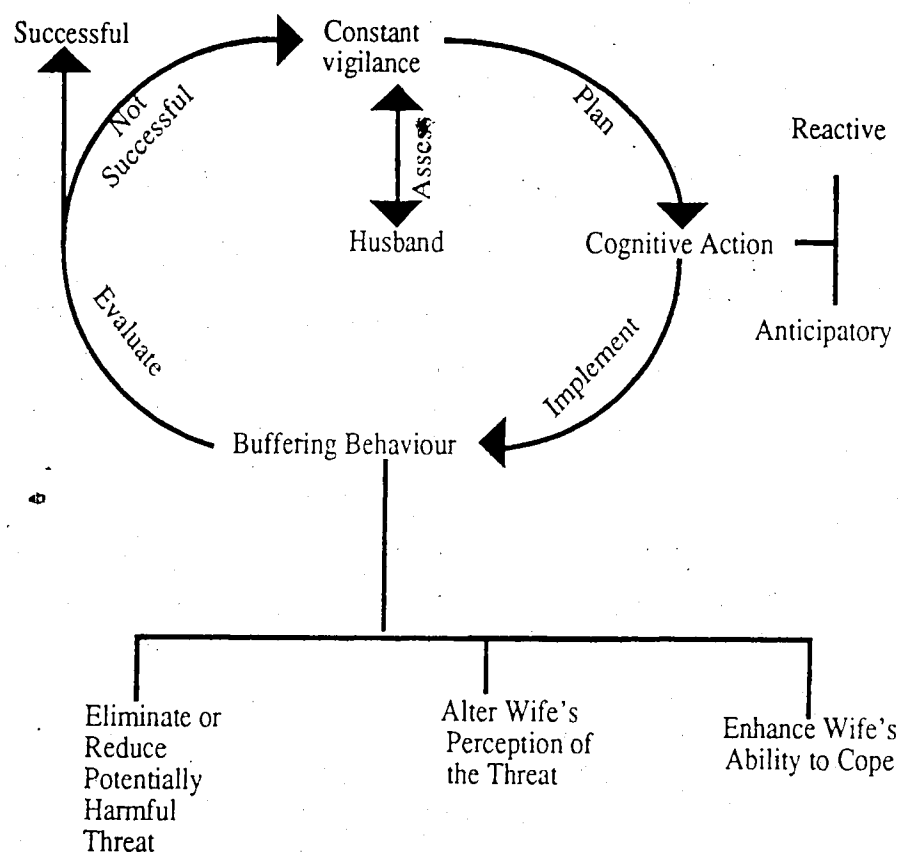


Figure 2. The Process of Buffering.

interpreting these perceptions and then planning an action to *buffer*. Cognitive action involves either anticipating or reacting to a situation perceived as harmful to their wives' well-being.

In order to make the wife's cancer less stressful, husbands use *buffering* behaviors to reduce or eliminate any potentially harmful threat, to enhance the coping abilities of the wife or to alter the wife's perception of the threat thus making it less harmful. Examples of buffering behaviors reducing or eliminating potentially harmful threats were: *guarded optimism, second-guessing, taking charge, resisting disruption, treading lightly, omitting the truth, preserving self and orienting to the future.*

Examples of buffering behaviors enhancing the coping abilities of the wife were: *supporting, cherishing, assuming a passive role, maintaining motivation, using humor and orienting.* Examples of buffering behaviors altering the wife's perception of the threat were: *making sense, being positive, normalizing, being there, adding on and disguising one's feelings.*

THE THREAT

The threat from the suspicion of cancer is ominous and impending but not clearly identifiable. Informants responded to the threat by suspecting and finding out as depicted in figure 3. These responses are emotive and instrumental.

Suspecting

Informants became apprehensive that something was "not right" and worried about the well-being of their spouse. Becoming aware, worrying and beginning to act are inclusive of suspecting.

Becoming Aware

While some informants were unaware of any abnormal change in their wives'

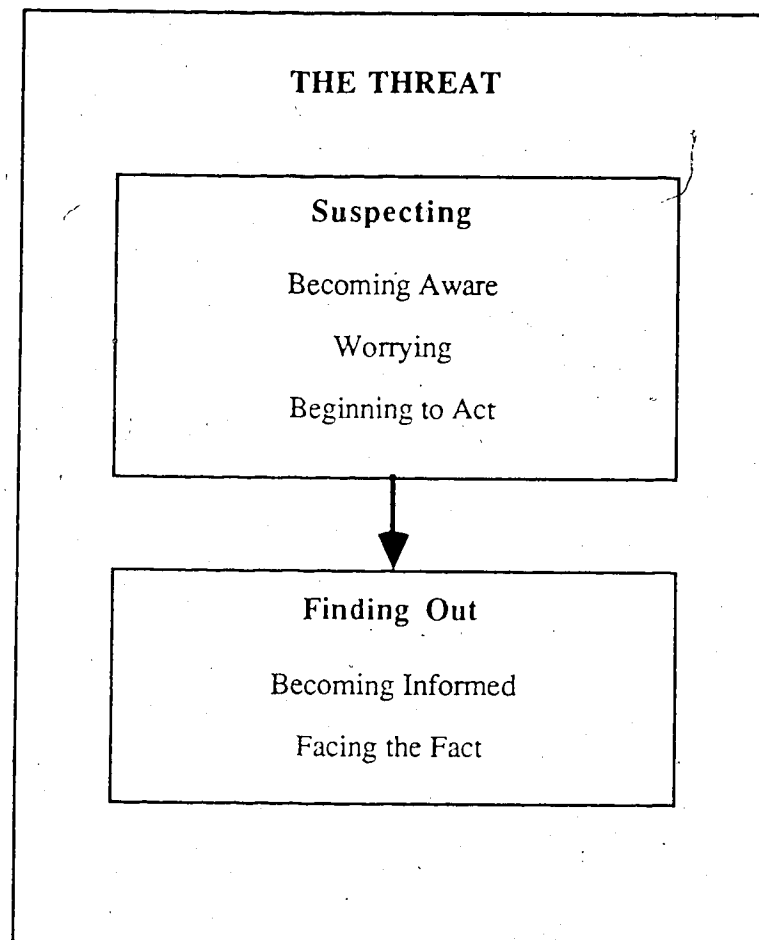


Figure 3. The Process of the Threat Experienced by Husbands Whose Wives Receive Chemotherapy Treatment for Cancer.

bodies, most suspected something was not right. All informants were not advised of a problem by their wives. One wife did not want to tell her husband because of his own prevailing health problem. Although no conclusive evidence supported his suspicion, one informant intuitively suspected his wife's abnormality was cancer. When informants encouraged investigation by a physician, an easy course of treatment was expected.

Worrying

Initially, the attitude of "not worrying" prevailed. Informants were convinced by their wives' responses (particularly when she was a nurse), a previous benign biopsy and the physician's attitude of "nothing to worry about." Often cancer was not considered because it had never been encountered before. Past illnesses were minor and easily cured, and informants assumed that this would be the case again.

Worrying became evident when doubt about the gravity of the problem ensued. Doubt was introduced when the physician stated his need to biopsy. For example, the physician met one informant in the hallway just after his wife was taken to surgery and told him that "it did not look good." In addition, doubt and worry were amplified when the couple received conflicting information about the diagnosis or when the wives were afraid.

An undercurrent of sadness began. Apprehension and doubt increased with waiting. Worrying was particularly evident when it took a prolonged period of time to verify a diagnosis. For example, a four-month wait for a definitive diagnosis occurred for two informants. Other factors aggravated the growing apprehension, such as, the wife's decision to seek another medical opinion(s), the mention of surgery or when family members kept asking for news. One informant worried about cancer as soon as any surgery was mentioned because his grandmother had worried about cancer before her gallbladder surgery. For another, the doubt became overwhelming when his wife

was sent to see a specialist who practiced in a setting devoted to serving people with cancer.

Beginning to Act

Worrying prompted further responses. For example, when a physician advocated a "wait and watch" approach, one couple became angry and increased their attempt to find a surgeon to perform a biopsy. Others phoned the physician's office for feedback when they felt they were waiting too long for the results from tests:

Waiting for results from the lab was really a torture situation. It was extremely stressful when you suspected very strongly, and yet nobody had come out and said this is what it is. When you're waiting for the phone to ring, you're wondering. It was very stressful waiting to hear. You felt so damn helpless. Phoning didn't seem to help. Nothing seemed to help.

Self-discipline was important to control the imagination and not think the worst:

It's the unknown, the not knowing, which was the most stressful. It's fear of the unknown; fear of your mind starting to go off in all directions. You imagine all kinds of things. That's where you have to say hold it. You've got to use self-discipline. Say to yourself that you don't know those things, so don't let your imagination start going wild on you. You had to be aware that it was happening in order to control it. It took so long for the diagnosis to be confirmed.

Stress associated with waiting was so great that one informant required increased medication to avoid aggravating an already existing heart condition.

Finding Out

Finding out meant becoming informed of the diagnosis of cancer and facing this fact. The knowledge represented a sudden change from the uncertainty of suspecting:

Now you knew what it was that you had to deal with, you were not guessing. You were not always hoping and at the same time realizing that the hope may be a false hope. You were not going up and down like a yoyo. Now you were in the drink and you damn well had to swim. You were not wondering how you were going to cope with it if you happened to fall in the water. You fell in the water and you found that you were swimming. Now it was a matter of what you had to do to stay afloat and head for shore if you can see it.

Informants were overwhelmed by the speed with which things happened. Once told

about the diagnosis, they were transformed "from the frying pan into the fire pretty quick" and felt the necessity to make decisions about treatment immediately.

Becoming Informed

Informants were advised of the diagnosis of cancer by either their wife or the physician. Although in one instance, the informant had to question his wife to learn of the diagnosis. Sometimes the physician informed the couple together. Being summoned to the physician's office was perceived as an ominous sign. For example, one physician had his nurse telephone the patient and request that she and her husband come to his office that same evening. The situation was frightening because the wife, a nurse, knew this approach usually meant "bad news." When the husband arrived home from work, she was overwrought. He was dismayed and tried to comfort her although he felt "totally unprepared" for what was to come. Another husband had always accompanied his wife to past appointments even though he had never been invited into the physician's office. A sudden request to join them gave him no time to prepare.

When the physician chose to tell the informant alone, it was for the purpose of delegation. Husbands were delegated to either inform their wives of the diagnosis, take them to future appointments or make sure they were admitted for treatment. Two informants met with the physician when their wives were not present. The physician met with one informant as he was coming from his wife's surgery to inform him the extent of the disease and to verify that the diagnosis was cancer. Another physician telephoned an informant asking him to come to the hospital where he personally informed him of his wife's diagnosis.

It was always "horrible and awful" to find out about a diagnosis of cancer or recurring cancer. Informants felt more in control when they had time to "get oneself together." The perception of control was an important factor in how the informants responded. Being informed on the telephone allowed one husband to regain control

faster and facilitated his ability to take advantage of his intuitive ability to comfort his wife. "Telling your wife she has cancer never gets any easier," but one informant felt he could intuitively find better ways to "soften the blow" for her than the physician. For example, privacy was important. The informant could allow his wife to cry while holding her and comforting her in the privacy of their own environment. Informants believed physicians were not at ease with nor knew how to deal with someone who cried.

In order that the wife would not have to relive the shock with each new telling of the story, informing others was an important aspect of the experience. Husbands usually informed children and significant others. The husband's role of informing others helped family and friends get over the initial shock and decreased the energy expenditure for his wife.

The days subsequent to finding out the diagnosis were "the most tense period." Waiting and wondering about the extent of cancer progression produced "emotional wrecks." Determining the extent of disease meant enduring a battery of diagnostic tests. Unrelenting fear, uncertainty and shock converged for what seemed an endless time span. Spouses mirrored each other's anxiety:

I was tense, she was tense. She got tenser from me and I got tenser from her. We just kind of went around in a circle for a while.

Finally, in order to be useful in providing support and strength during the fight, this informant decided that he must stop mirroring his wife's responses.

Surgery often occurred quickly after diagnosis. Surgeries conducted as two episodes: a biopsy followed by more extensive surgery or one episode of major surgery. A biopsy was conducted either in the physician's office or in the hospital. When done in a physician's office, the patient went home afterward to await the result. Informants reported that wives often responded adversely when waiting for results.

When surgery was elective, informants waited during the operation for news from

the physician. They felt confident about the surgeon's ability but waited with *guarded optimism* and dreaded hearing the prognosis. *Guarded optimism* was the paradoxical process of preparing to expect "the worst thing that could happen" but projecting only positive thoughts when with wives. The worst scenario (i.e., the wife's death) always lurked in the back of the informant's mind.

Finding out the results of surgery before wives provided informants with time to get use to the situation. Wives were usually informed by the surgeon, although in one instance the informant was delegated to inform his wife. After hearing the prognosis, informants were forced to acknowledge their own terror, despair and sadness. The intensity of these responses necessitated measures designed to "cover up" the depth of their feelings without trying to hide their response entirely.

Intensive surgery involved hospitalization and offered a reprieve, but this was often very distressing and constituted one of the worst aspects of the experience for many of the informants. The reality of the situation was reinforced by watching their wives incur daily changes of equipment and dressings. Driving from home or work to hospital allowed a quiet period of time which some used to secretly cry and express their despair.

Facing the Fact

Informants described experiencing fear, helplessness and "total shock." They were afraid their wives' death was imminent. They described being thrust into a new situation with no choice: "There was nothing you could do about it." Many were unable to cry and one informant reported he had not cried since. Many described being emotionally numb, "from head to toe":

The first couple weeks was real shock and despair. Just like someone knocked the wind out of you. You're just totally disillusioned and totally thrown for a loop.

A feeling of uncertainty prevailed as informants felt lost and unbalanced, lacked

direction and did not know which way to turn.

Facing the fact heralded changes. One informant changed from someone who was emotionless and never talked about himself to someone able to express feelings more openly, such as, more compassion towards his wife—more than he had for years.

Many reported increased closeness and strengthening of the marital bond.

Questions, such as, what is cancer? and what do I know of cancer? were formulated:

The worst nightmare was her succumbing to the disease. The worst nightmare is cancer not being cured and that it metastasizes somewhere else in your body. That's the worst nightmare. Particularly in the wrong place, it's game over. That's the worst nightmare, without a doubt.

Cancer was closely related to death in many informants' mind:

As soon as you hear cancer, it was immediate, that she may die. Not will she die, or not might she die, but when she dies, or how long is this going to go on before she dies?

These thoughts were reinforced when a physician spoke of statistics for survival or a specific survival time. Suddenly forced to recognize that cancer kills, informants were forced into a life-threatening situation. Never really knowing anybody who had cancer or had survived the disease lent further credence to prevailing thoughts of death. With no idea of what to expect or how to begin to cope with such a crisis, the experience was devastating. Informants were vulnerable because they often cared so much and felt lost in their ability to act maturely. They were overcome with grief, and while recognizing this, they often did not know what to do.

Seeking a cause was one of the first questions an informant asked after the diagnosis of cancer was confirmed. Consideration was given to heredity or family history, diet, stress, smoking, use of the birth control pill, age, previous breast surgery, previous experiences with cancer both within the family and/or within the realm of friendships, excessive use of alcohol or medications and chance. Younger

informants had assumed it was a disease restricted to older people. Many wondered whether they may have caused the cancer. This frightening consideration often prevailed for a long time and, in some cases, was never definitely discarded. Those who had good marriages were most susceptible to the idea of causation and carried a sense of guilt for their presumed role in causing their wives' cancer. How could they legitimately rule themselves out as a causative factor when there was no proof of a definitive cause? For example, "I'd like to think that I didn't have anything to do with it, that it wasn't my fault but I wondered."

Why my wife and not me? Informants saw themselves as the more likely victim:

If I expected anybody to get cancer it would be me because I've consumed enough alcohol, have smoked grass . . . I would be the one that would be more likely to have something like that happen to them.

Informants carried the burden of guilt that it was not their disease. Those who had a good marriage began to absolve themselves of the guilt by sharing ownership of the illness and responsibility for the treatment. For example:

I keep saying we felt, like I guess I feel like this is my disease too. That's because it's so drastic. It's a fight that she has to undertake, so it's partly mine too. It's a psychological thing, the helplessness for the husband. This is not just her disease, it is my disease too.

When analyzing the differences between themselves and their wives, the wife became the "sick one" and the husband the "healthy one." This differentiation was faster when husbands perceived they had less ideal marriages.

What do I do now? reflected a sense of responsibility. Frequently, the couple decided on a plan of action together. When the marriage had not been particularly close, spouses began to re-establish their marital bond. When the marital dyad was not harmonious, their relationship did not grow stronger and, in fact, weakened with the stress of enduring the chemotherapy treatments.

When informed of the diagnosis after major surgery, informants described feeling unstable and inconsolable. On seeing his wife, one informant found himself weak,

dizzy and shaking with the fear that she was going to die. He had no time to pause and reflect because he felt an obligation to inform the family immediately. Making use of different sensory pathways, that is, seeing his wife's condition and hearing himself tell others, helped him face the fact and reinforce the reality of the situation.

Informants also became angry. They had not chosen to have the illness and felt helpless. For some the anger was never resolved:

You feel so damn helpless. You can't buy a cure for her. You can't create a cure for her. It's such a helpless feeling, cancer.

It troubled me a great deal, the anger, resentment. It's a very mixed up time, you don't know what your own emotions are. You are going around in circles. You don't know what the hell to think. You don't know what to feel. A very confusing time.

Several husbands believed earlier treatment may have influenced the extent of the disease, and they were angry at the events, the waiting and the delay prior to diagnosis. The frivolity of a new marriage was "taken away" from one couple. The dilemma was *who could one be angry at?* The physician controlled the treatment and the nurse controlled the caregiving and getting angry at them might affect the care one's wife received. Consequently, they got angry at "things", such as, the disease or the treatment institution.

THE FIGHT

The Canadian Cancer Society widely publicizes the slogan stating that "cancer can be beaten." What might this imply to a person and/or family living with cancer? The suggestion that cancer is an entity one can fight and beat indicates that cancer is something one does not passively want to experience. The implication is that cancer can be overcome. This analogy of battling or fighting is something which must ensue if one is to win. Thus, fighting is equated with winning. A further implication in the

slogan is: *if one fights, then one can be hopeful of beating or curing the cancer*. This fighting process provides hope. Finally, the slogan also places the onus on the person to *do battle* and *win* rather than on the caregivers or the therapy. The demand that one must fight in order to succeed assumes that *if one works hard enough then one will succeed*. When one does not win the fight, the blame is not placed on the caregiver or the therapy because the caregiver and the therapy are not fighting the battle. The only ones left to blame are the patient and the spouse. Husbands feel they are responsible for identifying these "ways" to assist their wives to beat cancer. The outcome is an encompassing sense of responsibility to seek ways to win and an overwhelming sense of guilt when they do not appear to be winning. Thus, as illustrated in figure 4, husbands resolved to help their wives "take on" the fight, were inducted into and endured the chemotherapy and finalized the chemotherapy treatment by completing the last administration of chemicals with their wives.

Resolving to "Take On"

Resolving to take on the fight comprised knowing, achieving a sense of control, crying and taking on guarded optimism:

You've resolved that she has it. You have to take it on, fight it and try to beat it.

The shock happened, and then you kind of resolved yourself into the fact that you're just going to have to fight it. You're just going to have to do whatever's necessary—surgery, chemotherapy, radiation. You just get resolved into saying, we have to do whatever we can to solve the problem here. Let's go for it.

Admitting to knowing "she has it" did not imply understanding. Understanding came slowly as informants progressed through the fight and internalized a personal meaning of cancer. Personal differences were influenced by unresolved anger and the type of marital relationship. Those who were possessive of wives vowed to remain loyal to the fight; whereas, those who were angry reacted by being stubborn about

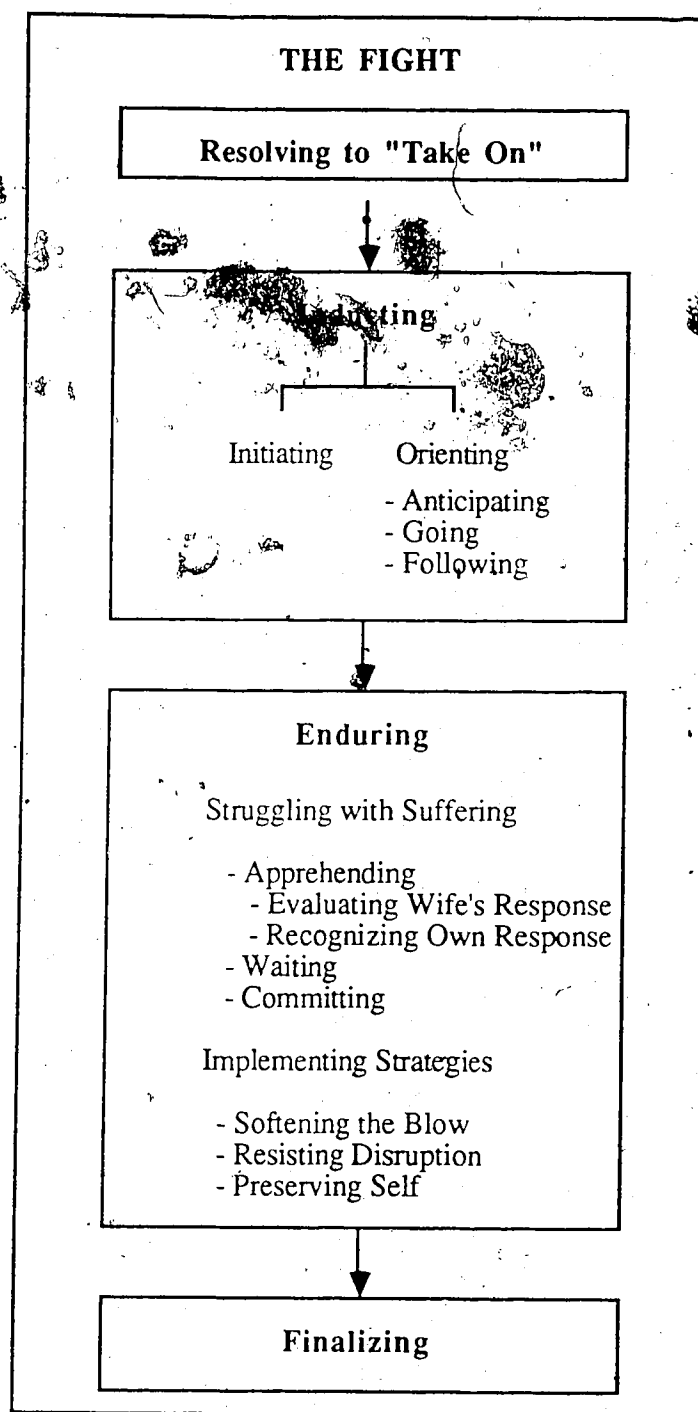


Figure 4. The Process of the Fight Experienced by Husbands Whose Wives Receive Chemotherapy Treatment for Cancer.

giving up as they vowed to help "do whatever's necessary to stay alive."

Realizing the situation was not imminently terminal for their wives provided time and motivation to fight. Resolving to fight provided a sense of control. Participating meant there were things one could do to help even though *guarded optimism* surfaced. "A good cry" often signified initiating the resolution to fight. The initial cry represented a means to relieve shock and express sadness. Afterward, husbands had to "get it together" because they felt a sense of responsibility to act for their wives and family.

Inducting

Inducting represented the period leading up to and experiencing the initial chemotherapy treatment. Inducting is comprised of initiating and orienting.

Initiating

Even though informants were happy to have their wife home with them, *coming home* after surgery was traumatic. Unsure of what was expected, they frequently asked what was the right way to act? One of the biggest hurdles of *coming home* postoperatively was exposing the incisional scar. This was especially true after breast surgery, and the longer it was deferred, the more anxious husbands became. Several informants asked their wives to show them the scar, and many found it was more cosmetically acceptable than expected. One husband described the year following surgery as the hardest for personal stress. Factors affecting this included financial difficulties incurred when changing a job, young children involved in extracurricular activities requiring his parental assistance and his own inability to decline any request for his time and energy.

Sexual relationships did not resume for some time after surgery. The major influencing factor was fear of causing further pain and discomfort in the surgical site. When pain after surgery was severe, the couple did not sleep together in the same bed.

The decision to sleep in another bed was usually made by husbands because they were afraid of unconsciously hurting their wives during the night while asleep. After breast surgery it took time to convince wives that they continued to have sexual attractiveness:

I don't know how long it took her to really believe that I still thought she was beautiful, that I was still sexually attracted to her. That took her a while to get over that part of the shock.

When the cancer was inoperable, husbands reported wives to be devastated and tearful for a long time. Surgery was perceived to be a more efficient treatment than either radiation or chemotherapy. Fear and doubt increased when husbands asked why surgery was not an option and never received a satisfactory answer. Sometimes there was a substantial period of time between surgery and chemotherapy given for a recurrence of cancer. At other times, surgery was immediately followed by chemotherapy, especially when cancer had spread to surrounding lymph nodes or beyond. The treatment of surgery plus chemotherapy was termed a "double whammy." The "double whammy" alluded to the experience of the pain associated with surgery plus the illness associated with chemotherapy.

How was treatment decided? Alternate methods of treatment, other than conservative medical methods, were considered, but the time allotted to learn of alternatives was limited. When the physician and/or specialist suggested conventional treatment, husbands felt compelled to decide and to begin treatment immediately. The lack of knowledge and the inability to "make the problem go away" compounded their feeling of powerless to affect a cure for cancer. The situation offered no choice but to trust the physicians and to orchestrate what was necessary to solve the problem.

The couple decided together or the husband concurred with his wife's decision to acquiesce to the physician's firm suggestions for treatment. Informants usually "played it safe" and did not align with a treatment that opposed either the physician's or the wife's wishes. The furthest informants ventured was to suggest seeking second and

sometimes third opinions from different physicians. One informant wanted his wife to seek a further medical opinion, but she refused. He felt the need to pursue this and approached the physician without her knowledge. In return for his independent action of concern, the informant was severely rebuked by the physician who threatened to withdraw his responsibility for care. The husband learned abruptly that he could not be a participant in his wife's treatment without jeopardizing the care she received from that particular physician. He also learned not to verbalize or question any aspect of his wife's medical treatment with the physician. The lack of information (i.e., being kept *in the dark*) was one of the most punitive states many husbands experienced.

Informants believed chemotherapy had to work to put their wives' cancer "into check" and enable a fairly normal life. Husbands were inundated with information of chemotherapy and "everything was too fuzzy." Making sense of and rationalizing the use of chemotherapy were strategies husbands used to deal with the information overload and establish trust in the efficacy of chemotherapy. Husbands tended to dwell on statistics when they were advantageous and to compare cancer to other diseases that were incurable or more unsightly in order to make their situation less threatening.

Husbands relied heavily on "experts" when deciding to take chemotherapy. Knowledge about what chemotherapy was, how it was given or what effects to expect after the treatment was minimal. When joint decisions were made by the couple, husbands felt their acceptance of chemotherapy was a foregone conclusion. Even when wives were fearful after seeing the effects of chemotherapy with other people, "there was just no two ways about it." One informant, who felt anything was better than the statistics for survival without chemotherapy, described "just living in blissful ignorance" before experiencing the first chemotherapy treatment. Chemotherapy offered as treatment for recurrence of cancer was accepted immediately. Although the impact of recurrence of cancer was as devastating as the initial diagnosis, the

informants had become conditioned to living with the cancer. Chemotherapy represented hope for prolonging life or for curing the disease, and thoughts of "giving up" were intolerable.

Orienting

Orienting to the first chemotherapy treatment influenced coping strategies during subsequent treatments. The first treatment was the time to "learn under fire," and the information gained helped to decrease anxiety concerning the unknown.

Anticipating Chemotherapy

It doesn't compute until you start seeing it happen. You know it just doesn't register. After seeing the first session and seeing everything happen, the [following] ones were a lot easier to cope with because you knew what was going to happen.

Until I actually saw what it was doing, I really didn't have much of an idea.

Chemotherapy was perceived as a kind of radiation which they did not have a "clue" about, but "the name did not sound great." Although the husbands knew the purpose and effects of chemotherapy, they did not know how to respond or what to expect during the first treatment. Powerful or tough drugs were those potent enough to cause hair loss. They wondered, but never asked, why chemotherapy was not begun after surgery (treatment usually began one month after recuperation from surgery). Side effects were expected to appear quickly and were nervously awaited.

The physician was a powerful influence on the husband's outlook, particularly if he was confident chemotherapy would "do the job." *Being positive* did not allow the intrusion of any doubt, and this in turn, enhanced trust and hope in treatment. One informant asked the physician:

How long has she got to live? He said [the physician] don't you ever ask me that question again because I'm not God. Don't you ever ask me that question again.

The physician's punitive response effectively stopped the informant from asking the

question again, even after several recurrences of his wife's cancer. The informant's response was not one of anger but one that accepted the physician's directive.

Going to Chemotherapy

Accompanying their wives to initial chemotherapy treatment was a monumental decision. The decision was influenced by the wife's request, the personal need to understand the treatment, his own health, work commitments and familiarity with the treatment facility. A sense of foreboding and death were associated with cancer and husbands were aware of the need to resolve this attitude before they could be of assistance to their wives.

Initial learning experiences varied because everything was new. Informants looked for the "norm" or "the right thing to do" as they became familiar with the rituals of going to chemotherapy. They asked questions and watched how their wives responded on entering the treatment facility and during treatment, what other husbands did during treatment, how the chemotherapy was given and how the physician and nurses interacted with patients and families. Consciously formulating buffering strategies began. They noted other patients, particularly their ages, skin color and whether they had experienced hair or weight loss. Informants felt alien in a world where their wives belonged. Patients stared at them, nurses did not talk to them and often there were no other husbands present. The experience reinforced their need to align to the reality of their wives' situation and highlighted the life-threatening aspects of the disease.

The response to the treatment facility was varied and often reflected anger toward the disease or previous treatment. Many initially hated the treatment facility while others were pleasantly surprised at finding patients to be friendly, ordinary people. Expectations of patients looking sad, depressed or very ill were not fulfilled. Long periods of inactivity were not uncommon, and husbands began to appreciate waiting as an integral part of chemotherapy.

Following Chemotherapy

Coming home involved filling prescriptions and then waiting for something to happen. Husbands did not respond to the initial chemotherapy experience until their wives were resting in bed. In retrospect, they described a lack of time, energy and mental awareness to absorb everything. In one case, the initial experience was devastating as extreme side effects were experienced immediately; whereas, few symptoms other than fatigue were experienced by other wives. Husbands watched to determine how long their wives were ill, when the illness began and subsided and when their wives began to feel good again. They watched when they perceived their vigilance was not noted by wives. Having no previous experience to fall back on, husbands tried to predict their wives' needs. There was little they could do, and many felt clumsy, helpless and in the way as they hovered over wives. The need to help competed with the need to protect the wives' privacy. In a decision-making role, one informant had to decide whether or not to call the physician when he perceived his wife's illness was too intense.

Informants considered changing work commitments to be with wives during treatment, to learn about the type of cancer their wives had and to spend more time with their wives. Many felt inadequate due to their own lack of knowledge and became frustrated with the questioning of others. In retrospect, informants realized they were giving far more information to others than was expected, and they had unrealistic self-expectations. They were in the bind of trying to please all the people all the time and not wanting to be rude to anyone asking questions out of genuine concern.

Often wives awakened during the night. Informants felt they should be awake with wives and as a result became very tired. Wives read voraciously. Informants tried to keep up with the reading focusing on cancer, which included medical publications, biographical novels and popular magazines. Popular television documentaries and

biographies were also sources of information. Discussion between spouses was ongoing and served to bring the couple closer. Informants read to find a cure.

Whenever the need arose, shopping for a wig was a task during inducting or enduring. It was important for the wig to match the wife's hairstyle and color so that others could not tell if she had experienced hair loss. Maintaining normalcy, particularly to those outside the family, was an ongoing coping strategy. Informants nervously anticipated their own reaction to their wives' hair loss. They expected wives to watch their reaction and tried to prepare for this: "If she can deal with it that well, then I better be able to." The fear of letting wives down and of not being equal to their ability to endure the effects of the chemotherapy created a tremendous strain for husbands.

Increasing amounts of time were spent with wives, often excluding friends and family. Several informants took early retirement or quit their employment. The focus of daily life was the wife's needs, which was particularly difficult for those who continued to work as they had to divide their loyalty between their job and their wives.

Informants began to take on a *doer* role which enabled them to participate even though they were not actually the recipient of chemotherapy. The *doer* role enabled them to receive feedback for caring tasks. Doing allowed physical expression of caring in the form of tasks as they were often unable to share emotive aspects of caring without crying or becoming emotional. Some learned that crying with wives was a "mistake," particularly if it had not been an acceptable or shared response between the couple before diagnosis. Informants felt guilty talking about their own feelings when they perceived their wives to be going through so much more than they were. Taking a submissive position was something informants believed was necessary, but it perpetuated the guilt they felt being healthy. It was perceived wives wanted husbands to be strong and in control of their feelings. As a result, informants were quiet and

supportive, while constantly trying not to show a lot of the intensity or depth of their underlying feelings.

V. RESULTS: ENDURING AND FINALIZING THE FIGHT

Enduring

I'm talking about the cancer experience. As far as the chemotherapy's concerned, I consider it all a part of the same ballgame.

Enduring was the encounter with the chemotherapy treatment for cancer. Figure 5 depicts how the quality of the marital relationship influenced the strategies utilized to fight and endure the side effects of chemotherapy.

Those who enjoyed a good marital relationship were active participants and shared the cancer experience with their wives. They accepted the disease as "their disease," were empathetic to their wives' suffering and emphasized "being positive" (cell a). Those who were in a poor marital relationship stayed to help their wives but were not hopeful of curing the cancer. They respected the decision-making of others and abided by the desires of their wives who were dependent upon them (cell b).

Those who had a good relationship, but indulged in self-pity, were convinced their wives could not endure the fight without their presence. They were skeptical toward the chemotherapy and not overly positive in their outlook. They made their wives dependent by taking over for them (cell c). Those with poor marriages felt no commitment or compassion toward their wives and took no responsibility for supporting them. These men eventually left because the situation became too difficult to endure, and often, they had found someone else for whom they cared (cell d).

| | | Quality of Marital Relationship | |
|-----------------------|---|---------------------------------|---------------|
| | | + | - |
| Strategy for Enduring | + | Participator a | Helper b |
| | - | Controller c | Deserter d |

Figure 5. Typology Illustrating the Relationship Between Quality of Marital Relationship and the Strategy for Enduring.

Struggling with Suffering

The purpose of "enduring" the fight was generally for the benefit of the wife who had cancer.

What is struggling? Struggling was described as:

When you're thrown into a pool and you can't swim, and you don't have a life preserver, that's the way I felt for a long time. In other words, struggling. It was hard to get up in the morning knowing that you were going to have another one of those days which was unpredictable.

The bottom line was that you're going to get chemotherapy, you're going to get sick, and hopefully it's going to help you extend your life. You suffer for two and a half days once a month, and you play the numbers game, whereby two and a half days in a month might give you a little longer to live.

The pain of watching somebody that you love going through pain, going through agony, that is the hardest part. That is the hardest part of the whole thing to deal with that. That was my hardest part — it wasn't the caring, or the cleaning up, or helping her to the washroom, or getting the pills.

It hits you when the person that's beside you gets sick, has never been sick, and goes through chemo, and comes home and vomits, and holds her teeth in her hand. You start seeing a person so differently. You know, you have to help them to the washroom because they're dizzy. Then you really get to love somebody beyond their physical being.

and during the later stage as the disease was progressing:

It was hell on wheels, watching her go downhill. Hardly being able to talk and eat. Just wasting away in front of your eyes, and in really terrible pain. There didn't seem to be much they could do about it.

Struggling involved apprehending, waiting and committing. The struggle permeated life and indulging in oneself was impossible because "the only trouble was she had it and I didn't." Some husbands became obsessed with the struggle.

Apprehending the Struggle

How is struggling assessed? The awareness of each other's needs was essential to the husband's confidence in perceiving his wife's responses. Informants assessed struggling by being vigilant of wives responses to chemotherapy. Evaluating the wife's response and one's own response to chemotherapy comprised apprehending.

Evaluating Wife's Response

Examining Beliefs

The following beliefs were expressed with openness and certainty. Husbands could not have endured the chemotherapy as well as their wives. Wives were stronger, tougher and more resilient, particularly in relation to pain and patience. Husbands would be more demanding and despairing in a similar situation. Wives had a more understanding nature and were more nurturing. One informant felt that he "would find it much harder to be that positive about myself than I am about her." Husbands would not make good patients as the "littlest thing that goes wrong with me is a major crisis." Many were uncertain whether they could endure chemotherapy. One informant, whose wife died after sixteen months of intermittent chemotherapy, was adamant: he would not take chemotherapy unless the disease was in the "very initial stage."

Grieving

Even though wives expressed fear of dying infrequently, by watching their wives grieve, informants were forced to realize that the situation was life-threatening. Informants reported wives began reading obituaries in newspapers, and some arranged their own funeral. One wife introduced the subject of dying by warning her husband that forty percent of spouses die within a year following their wives' death. He recalled, "This hit me like a ton of bricks. I just shut right up. She was telling me that she was going to die." Although he perceived her concern for him, the consideration of her death was too overwhelming for him to consider. Another wife slowly shifted household and family responsibilities onto her husband as she prepared for her death.

Second-Guessing

Second-guessing was putting yourself in the other person's position to understand their experience. Informants found the technique helped them to be:

... much more conscious of some of the things that I think I do, or I want to do, or that I do unconsciously. I try to be a little more conscious about what I'm doing, to be more supportive. I try to put myself in my wife's position and ask the question: What would I want me to be like if I were her?

Nurses or physicians were unavailable to answer questions, and informants found it difficult to refrain from asking wives for information. The dilemma was that one always wondered if he was right when *second-guessing*. It involved being empathetic and perceptive while recognizing he could not do everything to please his wife. One informant became aware of forcing his own joviality when his wife really wanted privacy. This strategy helped informants be less intrusive.

Changing in Response to Chemotherapy

The intensity of "being ill" was dependent on the drug type and dosage. As chemotherapy progressed, the struggle was more difficult for those whose wives were not improving. Changes in physical appearance became more obvious and included changes in weight, skin colour and texture, gums became tender in the mouth and "puncture marks" or bruises appeared on arms. Changes brought one back to reality, and wives were described as looking very sad and debilitated. One informant knew his wife suffered terrible "pain in her arms from being tortured so damn many times, her arms were just like a pin cushion." It was extremely sad for him to see that she "kept her arms covered because she did not want to be seen that way." Some developed a constant body odor. The changes most frequently mentioned as particularly unpleasant were those associated with temperament, hair loss, fatigue and nausea.

The "Chemo Crazy's"

Informants were amazed at the rapidity with which their wives' temperament would dramatically change. While watching this as well as recognizing the loss of their wives' sense of humor, the effects of the drugs became ingrained. One informant described his wife as a "Jeckyll and Hyde" and "an animal" as she screamed one minute and was compassionate the next. At one point, he had to hit her to "bring her out of her

hysteria."

During chemotherapy, depression was expected, but the magnitude of the actual response was not. Husbands were unprepared for the extreme changes as moods swung "up and down, like a yo-yo". Wives cried easily and were emotionally frail. A lack of understanding promoted anger as informants tried to find a logical reason for the behavior. One informant, who did not believe his wife was in a life-threatening position, could not justify her behavior and became angry, while another labelled the behavior the "chemo crazies." The physical effects would come and go, but the "mood swings were always there." When one was tired, they were "very hard to handle." Patience and understanding were needed as husbands tried not to "hate" wives or "hold a grudge." Some felt exploited, others said "she was just venting frustration at the one closest to her." One wife announced her intention to think only of herself, which was hurtful because the husband thought he was already putting his wife first. Assuming a passive role, informants did not argue or say anything in response to the temperament changes and would "back away" or "accept it" because mood swings "were not her fault."

Losing Hair

Informants did not perceive hair loss as the worst effect of chemotherapy, but "losing hair was a major trauma" for wives. Waiting for the event was more stressful than seeing wives without hair, although this was something to get used to. The wife's concern was to normalize, to wear a wig that was similar to her own hair style so that others would not notice. Often, the husband was the only one to see his wife bald. Some were frightened the hair loss was permanent. Others responded, "The fact that she lost her hair, well it's not very nice, but it's not the end of the world. It's going to grow back." This attitude was reinforced if they had talked to other women undergoing chemotherapy. Hair loss was a very personal matter and not to be discussed with

others. Informants resented the question, "Has she had any hair loss yet?" Hair loss meant "powerful" drugs were working, and this was consoling because not all drugs were powerful drugs causing hair loss.

Husbands reported wives were horrified with the hair loss and watched husbands responses closely. Many women lost hair all over their body and described themselves as "feeling neutered" or "like a eunuch." Sometimes humor was used to counteract the sadness of hair loss, but often, informants laughed with tongue in cheek.

While receiving chemotherapy, some husbands noted some wives wore an ice pack over their head to retard the drastic hair loss, while others did not. Hair loss was usually preceded by extreme headaches and occurred about three weeks after initial treatment with the "powerful" drug. Hair loss happened quickly, and hair fell out drastically in massive amounts. It bothered informants because it bothered their wives. Although conditioned to baldness as a common phenomenon for men, husbands were devastated because they knew how sensitive their wives were about their appearance. Wives cried to express their loss and relied on their husbands' comforting measures to re-establish their self-esteem as a woman and wife. Informants worried about being unworthy and letting their wives down. Husbands reported hair loss was something wives never accepted, but they "rebounded" as long as "nobody really noticed."

Fatigue

Weight loss due to nausea or lack of nutritional intake made wives appear drawn and fatigued. Informants who saw their wives with make-up on, hair done and dressed to go out forgot the stamina their wife had was limited. Social events became quite infrequent as wives did not feel like "doing anything."

Husbands perceived wives to be more dependent, and they responded with a desire to stay around the home, which, for some, was confining. Informants were often alone because wives were in bed. Some described it as "living alone," even though

they felt relieved their wives were sleeping: "If she's sleeping, she's obviously getting better." Quietness was mandatory because noise magnified and awakened wives. Some husbands endured "sleepless nights," while others slept soundly. Informants did not want wives taking more medication than required. One wife did not reveal her need for sleeping pills, and the husband was angry at being kept *in the dark*. Husbands worried that body defences would be compromised by taking too much medication.

Nausea

Watching and listening to nausea was difficult. One informant described it as "bloody hell" because there was often no respite between treatments. Nausea and lack of appetite persisted after cessation of vomiting. Wives were concerned about their appearance, and husbands were consistently trying to preserve their wife's self-esteem:

She didn't want me to see her without her false teeth. It used to break my heart. I wanted to scream. I just wanted to yell, because to see that—her worrying about me. That's the hardest part.

Most wives wanted privacy in the washroom when nauseated or vomiting, while others found the husband's presence comforting. Informants felt "impotent" in their helplessness as they were delegated to an "observer" role in the home. They worried about choking and were fearful of leaving the home:

It's a terrible thing, when you start getting out of the liquid vomit into the dry heaves. It's even worse, you just sit there and what can you do? It's just a helpless feeling — it's just a terrible helpless feeling.

Driving sometimes induced nausea. Frequently, vomiting began during the drive home after treatment, which necessitated a receptacle to use in the car. While one exceptional wife had learned to control her nausea through mind control, for most wives, the nausea quickly progressed to a state described as being "violently ill because there was no control of the throwing up, the gagging, and the nausea." For many, it was days before they were able to "operate on their own." Although marijuana was sometimes helpful, medication to counteract nausea was ineffective. Wives not "violently ill" were

considered "lucky" and "fortunate." One informant administered injections to control the vomiting which were minimally beneficial.

The inability to eat was also worrisome. Informants felt guilty preparing food for themselves when the odors associated with food preparation or the noise of a closing door would precipitate nausea. The nausea was depressing because "it brought reality right home, right now. It's not hidden. She's sick, there's no two ways about it." Many worried that wives were losing the "fighting spirit" and were "almost ready to give up." For increasingly longer periods after nausea subsided, informants "could tell she was not feeling good" even though wives "would not really say."

Fighting

Motivation and determination to fight was reinforced for those who were told by the physician, "She did not have too much time to live." Informants were proud of their wives' determination, fortitude and strength: "She seemed to have lots of fight in her. She was bound and determined it wasn't going to get the worst of her, and she carried on." Informants were also surprised by their wives: "She was resolved to the fact that she was going to be sick." When extra medication was required, one wondered how a person could possibly "take it" and consume so much. Increasing admiration for the acceptance of needles, the "poison" and its effects were evident: "I never figured that she would take as much abuse as she was able to. She always looked so sad." They believed their wives would never seriously consider not enduring treatment or ending their own lives.

Supporting

Informants assumed the "supporter" role and learned to accept the situation more easily because wives were "so good." Some were freed of their need to be in the home with wives when they perceived wives liked to "suffer in silence" and did not "want me to be around that much." Others were forced to recognize the enormity of the situation

when normally independent wives suddenly became dependent. Most husbands recognized wives were doing their best to endure the chemotherapy, often with no hope of not experiencing side effects. It was difficult to project hopefulness when sadness permeated their thoughts. For others, the suspicion of hopelessness reigned as they felt their wives were "giving up" the fight: "It was very hard to see my wife in that condition knowing that she was accepting anything. I believe she had, in a sense, accepted her fate."

The passive role allowed husbands to observe wives coping responses without interfering and to focus on "what she wants." This opened the door to planning and implementing their own strategies. It was believed that working wives were provided relief in that work was an effective "escape." Work interests provided distraction and a "reason" to endure and live with the cancer experience, while those who did not work, or were unable to work, tended to "worry or brood about it more."

Several informants saw their wives withdraw into a "sick world" which isolated them from the "healthy world" of the husband. Recognizing this response helped husbands appreciate the depth of fear and need for protection wives experienced. The lack of communication between the two "different worlds" kept husbands *in the dark*, wondering why this was happening, and if they were being punished.

Going to treatment was traumatic for all informants because wives "hated" chemotherapy: "She'd rather not go, and she would be silent during the trip to the treatment facility." Some were "fanatical" about getting to treatment on the exact day, which often became more flexible as time progressed and personal priorities changed. When treatments were postponed, fear often subsumed the philosophy of positive thinking adopted by husbands. The philosophy assumed the power of the mind to control the situation and was a most effective coping strategy for husbands. They were fearful that a setback caused by the postponed treatment would affect their fight to

maintain the positive attitude.

When wives talked about the cancer experience in detached and depersonalized clinical terms, informants were surprised. On rationalizing depersonalization, husbands suggested that talking about feelings could be emotionally upsetting and energy depleting while the fear of death made it "hard on a person." Talking about feelings could lead to a "poor me" attitude which most husbands found appalling. They noted wives stopped crying at one identifiable point during the chemotherapy and had no other outlet to express fear. Wives often wanted to do things about which informants were hesitant. For example, wives wanted to continue driving the car, and husbands were frightened that the residual effects of chemotherapy could potentially cause an accident.

Recognizing Own Response

Expressing Love

Husbands did not recognize the enormity of their wives need to feel loved. Husbands expressed their feelings of love and were surprised when wives declared they needed to hear it more. The most intimate time for expressing love was usually in the privacy of the bedroom. Some did not sleep together in the same room and lost this opportunity. Initially, spouses were awake during the night, but as treatments progressed, informants needed sleep to sustain their employment. Wives were up nightly, and many informants found this activity disturbed their sleep. Although they were together in the home more, spouses engaged in solitary tasks.

Expressing Suffering

The reluctance of husbands to legitimize their own suffering was evident: "I really don't like to see her suffer. I just have a difficult time handling that, but you handle it." One informant measured himself by his wife's response: "If she felt good, I felt good." He also responded as a mirror image:

When she was suffering with her cancer, in her bad times, I felt pretty bad too. When she rallied and was feeling good, cheerful, then it seemed as though I was too.

The submissive, one-down position husbands assumed served to hide their own suffering and placed less stress on their wives. For example:

When things bothered me, I suffered in silence. I accepted it and I dealt with it alone. But only in matters that affected my wife and I.

Creating Emotional Turmoil

When ongoing treatment showed no indication of improvement, helplessness became particularly despairing:

It was extremely difficult to see what was happening to my wife as a result of the chemistry. It was terrible. There was not a damn thing you could do about it. It was really horrendous, it's a horrible experience. I hate to think of what it was like for her.

I'd rather have suffered it myself. If I could have taken the drugs for her I would have done it.

An informant described his experience after a lengthy period of disease freedom:

Seeing [redacted] that condition really hurt me. It was bad enough to see her suffer with the disease, and then something else on top of that, it was just too much.

The uncertain outcome magnified helplessness: "Her life was constantly threatened, it wasn't as though she was out of the woods." When intense side effects did not occur, informants became pessimistic, wondering when they would start and if their wives would be able to endure them.

Informants could not witness pain, the sight of a needle or injections. Pain was assessed by facial expression, body movements, eyes and verbal response. The difficulty was often not with the present "real pain" but with thoughts of future pain they feared wives would experience. For many, crying represented weakness, pain, sorrow or lack of control. While crying was not inconsolable, husbands felt inadequate because they did not know how to comfort someone crying. Crying was like a pain "in their heart," but they were not free to express it because they had to be strong.

On experiencing their own drain of energy, informants were horrified to imagine the physical and emotional trauma their wives must be enduring: "I felt a lot of sorrow for her. It is extremely hard to explain, when you love somebody and watch them go through agony, or turmoil in their mind." After five consecutive days of treatment, one husband had to help his wife bathe and dress to prepare for treatment. He became extremely depleted as he also maintained employment. Husbands were frustrated with their lack of control and their inability to solve the problem of chemotherapy:

When you're right in the middle of those treatments you really can't see the light at the end of the tunnel it seems. And then it becomes a big problem.

For example, the unpredictability of missing a treatment due to low blood counts was discouraging. The imagined effect led husbands to ask, "Would the cancer proliferate?" or Would the body's defenses bounce back to enable the next treatment?

Living day-to-day was important. Taking full advantage of each day was the rule. If the wife felt well, then it was a good day; if the wife didn't feel well, then so be it. Realizing that one could not make "all things better" grew to acceptance as informants learned to live with the lack of choice: "You have no choice, you simply just do the best you can." One had to trust "they [medical personnel] are doing everything they can." It became easier to say "whatever is going to happen, I let happen, I don't try and fight it too much." this attitude allowed informants to move from fighting the inevitable to using energy constructively. Short term goals, such as, planning for holidays, were the only future plans made as long term goals became nonexistent.

Fear and sadness were always evident: "You're always scared, I was always afraid. Deep in your mind, you knew she wasn't going to get well and you were so afraid of that." For some, repressing anger conserved energy, while others realized anger was destructive when not expressed: "It could get me down." Often there was no one with whom one could express anger. For some, physical expression of anger was the only

outlet as they broke doors or put their fists through walls. Inanimate objects were always the subjects of abuse. Others were able to find a private place to yell or scream, but many felt they could not afford the time to do this. Trying to turn the anger into *making sense* was more palatable and conducive to helpful behavior. Most "never got rid of the anger" or accepted the disease and its treatment of chemotherapy because if one accepted this then hope was gone. When hope was gone, then one "gives up" the fight which was not acceptable to the informants.

For many, sadness could not be hidden. Confusion reigned because sadness was not directed toward any one particular loss. Sadness often produced tension, anxiety, frustration and physical illness because it was ongoing and unforgivingly relentless. Tears would often be a ramification of sadness. Informants were sad for wives, families and themselves. They took care not to let sadness overwhelm them and cause depression or the inability to fight.

Changing Lifestyle

Chemotherapy forced a change of lifestyle and became the focus of daily living:

It filled our lives. Chemo took a lot of your life. The pills after the being sick, then worrying about going back the next time. I guess that's all part of it.

Lifestyle changed to the point where it was described as "not normal":

It seemed like just the time that she got everything back to what you'd call normal, where she's got her appetite, then it's time for the chemo again.

For some, every treatment was "always so different, so new," while others felt they had about a "week of good health, relatively speaking" between treatments. Changing socialization patterns left some husbands feeling isolated, while others deliberately isolated themselves. Many wanted to socialize more but could not because wives were "quite often sick" or "didn't want to." Sometimes after socializing, wives got ill with nausea and vomiting, and the informants' reluctance to socialize after this was because

of the consequences to someone other than themselves. The principle of consequence also applied to holidays. Chemotherapy was scheduled to accommodate holidays, which gave an "extra week of holidays." However, on returning, "she had to pay for it" as treatments were scheduled closer together until the missed treatment was accounted for.

Husbands were not prepared for the sudden change in lifestyle:

You had to change your lifestyle a whole bunch. On those days you obviously couldn't plan on going out. You had to be around to take care of your wife.

The unpredictability of response to treatment was disrupting. One newly married couple found the cancer experience interfered with establishing their identity as a unit, although it helped to establish their relationships with extended family. They were denied the control to make decisions about parenthood. Chemotherapy "took up so much of your life." Some wondered if the physician realized how much chemotherapy required of one's life because sickness lasted day and night, often with no period of reprieve for days. For others, a reprieve never occurred because it was constantly "on their mind." For those who worked, time was at a premium: "Your life is so full at the time; between my wife and work, there wasn't spare time to do anything else." Informants were always aware of the passage of time.

Many became "calendar watchers," admitting "it's terrible to live to a calendar." The calendar dominated daily living as it was something one could use to normalize life and "keep track of what was going on". Although the actual daily response to treatment was consistently unpredictable, one could determine how many days the sickness would last. The drastic change from being well before the treatment to the illness following treatment and back to being well again after the effects of the drugs had passed was unbelievable. The day of treatment was dreaded. It was important to plan ahead:

You just knew that you were going to be home all weekend. Your wife was going to be awfully sick. There's not a heck of a lot you can do about it. There's a reason for this, so just hang in there.

- "A reason" legitimized staying home. Husbands compared themselves with wives in terms of: who was most optimistic or pessimistic? more positive or negative? stronger? under most stress? happier or more sad?

When secretly wishing to stop chemotherapy, informants chastised themselves: "How could it bother me when she was the one going through it?" Suffering was often expressed as *feeling sorry*, which implies grieving for something that has been lost and regretting not having done more in the past. Thus, many husbands could not do enough for wives, while others mourned the loss of a mutually giving relationship. Husbands perceived themselves as the "givers" or "doers" and wives as the "takers."

When wives were stronger, the "giver" role was not possible. Husbands felt at fault because they were no longer stronger or more giving than their wives. When not helping "enough," informants became vulnerable to feelings of guilt.

Informants "settled into the chemotherapy itself," becoming resigned to the reality of chemotherapy: "I have to a certain extent gotten used to the fact that she's sick all the time—kind of try to cope with it." One husband coped by "taking care of myself and going out, doing things, more than I have before." Sexual relationships decreased, and many informants interpreted the decreased sexuality as a loss of interest in themselves. They had difficulty discussing this with anyone, especially wives, and their concerns were most often never resolved. Sometimes wives were not receptive to any form of touch. Informants felt rejected when the tactile response, often one of the most intimate ways of expressing caring, was rejected:

Informants learned to be prepared for wives refusing to go to treatment, which was considered a natural reaction to something so unpleasant. Some felt compelled to respond. One husband "had to be mean," "blunt" and "insulting" before his wife would agree to go. Most got anxious hearing "I want to die" because they felt this

meant their wives were "giving up". Informants described a protective role:

I've always been very protective of my family. If I could relieve them going through any problems I would. I would try to solve them, try to shield them.

Tolerating others in the family was difficult. Children were often described as demanding, self-centered, uncaring and inept at maintaining household chores. For younger informants, parents were supportive and helpful in managing the household; whereas for older informants, parental influence was not helpful because established methods of coping considered parents as outsiders. Grandchildren became important, and one couple moved their residence to be closer to grandchildren.

Personal coping strategies varied. Eating, smoking and/or drinking excessively were used, but if wives noted excessive habits, other ways of coping were devised because wives were not to worry. Some read the obituaries, in particular the age and cause of death, while others avoided this "like the plague." When the cause of death was not noted, husbands looked for the recipient of contributions to determine the cause of death. One husband ingested his wife's medication to try and understand her response. The ability to change was surprising: "You think you know yourself well, but you really don't until the actual thing happens to you." They learned to be flexible, which enhanced "becoming a better person." Informants felt something good had to come out of the experience, and they took better care of themselves and their wives.

Relating to Others

Few informants attended group meetings because, although helpful for sharing experiences with others in similar situations, they were not at ease discussing their personal concerns with strangers. Those who attended felt they did "not receive" as much as they gave to others. Sometimes the meetings had a self-consoling, "poor me" attitude which did not support the philosophy of positive thinking husbands had adopted as a coping strategy.

Relatives and friends gave too much support, making some wives feel like an "invalid" and subsuming the husband's *doer* role. Visiting increased and was stressful for those who wanted privacy. Although people did not always know what to say, most informants took strength from the caring and prayers offered on their behalf. For some, old friends were lost and new friends gained because wives were not always receptive or amiable. Informants felt acquaintances, those who were not considered friends, used avoidance because they did not know how to respond or were afraid of the emotional response they might receive. When acquaintances did say something, informants found "some will come and talk with me, sort of like a bereavement, as if your wife had died," and they felt like anyone feeling sorry for them. Many became frustrated with the first question that seemed to open most conversations, "How is your wife?", because continually answering "no change" never seemed to be enough. Rarely did anyone ask informants how *they* were doing.

Maintaining Health

On recognizing the stress they were experiencing, informants no longer took health for granted, and they worried that if they got sick, they would compromise their wives' health. Husbands compared their illness to that of wives and realized that to watch suffering was to hope you did not have to endure the same experience: "I used to feel guilty about saying to myself, thank God it isn't me. I surely wasn't glad that it was my wife. That guilt was really hard to shake or understand."

Being Informed

Informants often felt *in the dark* in terms of the information they received from either the physician or wives. For example, husbands did not understand the necessity for continuing chemotherapy when there was no indication of improvement. Those who accompanied their wives during the physician's examination perceived themselves as more knowledgeable than those who waited outside. Wives were often

uncommunicative after seeing the physician, and informants were reluctant to question. Asking rendered the standard neutral reply, "Oh nothing." Sometimes wives would not allow husbands to be present. These husbands wondered why. Was she deliberately keeping information from him? Was she punishing him for being the well one?

Husbands were told by wives not to ask too many questions, so they would often ask a nurse when wives were not present. Nurses were perceived to be noncommittal and noninformative. Most husbands had no contact with physicians and perceived physicians as being too busy. Some approached a nurse asking to see the physician, but they were not satisfied. Being *in the dark* made informants feel vulnerable. When wives were not sharing feelings, then how could husbands? Informants felt they had to withhold feelings, and silence was stressful because they really wanted to divulge their concerns. Sometimes they supported wives seeking counselling services, but they were not willing to seek help for themselves because the wife was the "ill" one. Over time informants learned to live with being *in the dark* and "sort of got use to it."

Initially, informants questioned the amount of knowledge they needed to have: "The more you read, the more frightening it becomes." "Finding a happy medium" was the ideal. Later, informants were grateful they knew and were familiar with the terminology as it helped them converse intelligently with others. Becoming knowledgeable helped them rationalize and accept behavioral changes in their wives. For some, the acquisition of knowledge was like a staircase; the more knowledge gained, the more aware they became of future eventualities. If cancer recurred, the stairs left to step on became fewer. Those whose wives were enduring recurrence of cancer were treated as "experts" because their experience of climbing this particular staircase was something others had not encountered.

Oriënting to the Future

Considering outcomes, an aspect of accepting, forced one to think of the future.

Informants preferred to live day-by-day, to stay positive and deal with reality. They planned secretly and alone, rarely discussing the future with anyone. The secrecy offered comfort and security. Some felt guilty, as if they were "giving up" when admitting wives were not going to "get well." Recurring disease often hastened *orienting to the future*. Unable to do this, some informants found death was as shocking as the diagnosis. They were unable to tolerate thoughts of dying, "shrugged them off" and never accepted the cancer experience.

Facing the fact involved considering the terminality of the cancer experience even though "hopefully, it won't be for a long time." "The day was coming" when chemotherapy would be ineffective and stopped. While informants dreaded this moment and experienced a "terrible sense of doom" as the recurring disease progressed, they acknowledged their lives would not end when wives died. They had to plan for the time following death because, when the time came, they might be overwrought and unable to act coherently. They desperately "hoped" wives would be there forever. Alternate methods of treatment, intentionally not pursued, were considered. Hope was waning, and they would have "tried anything" to prolong their wives' life.

Overwhelming sadness accompanied thoughts of missing wives. Husbands "felt bad" thinking of death when wives were alive and fighting, *but* they could not dismiss the thoughts that wives "might not make it." Many continued to think of a short term future only: "I know next year will be better" or "I think I can tolerate her [her behavior] for another four months." Others were unable to fathom anything beyond daily living. Those who witnessed wives receiving life support measures were more apt to talk about the future. The physician who prompted an informant "to think of his life too" freed him to think of the future without the accompanying guilt.

Preparing for the worst scenario included secretly considering questions such as:

Were wives going to become sicker and die? Informants refused to discuss issues of dying until the wife initiated the conversation. Maintaining the positive attitude to facilitate fighting was essential. Discussing the *worst scenario* while undergoing treatment was the same as speculating about death, which informants felt would neutralize hope for recovery. Some thought they "should" discuss it because others expected it, and they wondered if they were denying the possibility of death? Their answer was no. They acknowledged the existence of the cancer, *but*: "I know it's there. I know that it could be deadly. But, we'll deal with that when we have to." Therefore, not discussing dying with wives was both a buffer and a shared coping strategy. Talking openly about the future facilitated the acceptance of death. Some felt justified when wives completed wills or checked out existing insurance policies, while others became agitated by these actions which they perceived to be "giving up" the fight. Most did not want to consider losing their wives to cancer. Preparing for the worst scenario involved planning: "What will I do?" Many felt guilt-ridden considering the question and "blocked it out"; however, it kept reappearing and demanding consideration.

Planning for later illness included concerns about comfort and suffering pain. Informants began planning to accommodate their wives' wish to remain in the home by considering financial costs, nursing care services and home management. Unfamiliar with caring for someone in settings other than an acute care hospital, informants expressed fear of the unknown while trying to be practical. Major concerns involved the ability to carry on with their job, manage the home, help children respond to their mother and find caregivers to alleviate physical suffering. The greatest comfort was to look to others who had survived the fight. Informants feared their response to painful suffering. Concerns were compounded when earlier experiences with pain had been difficult. Some had witnessed others experiencing uncontrolled pain, and memories

lingered. One informant did not want his wife to be disoriented or in a morphine haze because he wanted her to be able to share her thoughts and feelings with him.

Planning for death was something no one felt comfortable talking about. What would happen when someone died? Who would they call? What would happen after someone died? Would his wife want him with her? If so, how would he know? Informants reported guilt thinking about such questions and experienced fear of the unknown at the same time. Thinking back to past experiences or seeking out those who were known to have experienced death helped some informants, while others had made decisions about death previous to the cancer experience:

Death was a subject that we sort of eased into. As time went on, we found that it was the topic that came up most often. It was also the topic that seemed to give the most comfort after it was discussed.

Many thought about how diaries kept by wives could benefit others, and they found solace in this.

Planning after death consisted of short term goals; although when young children were present, more long term planning was necessary. Loneliness invaded thoughts of the future, and husbands used coping mechanisms, such as, "working twice as hard to fill the void," to deter loneliness. Daydreaming, which offered fantasy, relaxation and enjoyment, was curtailed because of the guilt and this "almost morbid feelings of enjoying themselves." Daydreams included marrying again, where they would live, what work they would be doing and how their family would cope.

Waiting

The waiting game was timeless, fluctuating with the "ebb and flow of the disease"

The whole thing was a waiting game for me — waiting for results, waiting to see if there was any improvement, waiting to see if she was getting worse, waiting for the end of the chemotherapy. It went on and on and on.

Waiting was ongoing and endless unless one considered death an acceptable end. It was frustrating because *doers* felt comfortable problem solving and acting, whereas,

waiting was a passive activity. Informants waited for their wives to get ready, for a parking place at the treatment facility, for the physician to see their wives, for the results of the blood work, for the treatment to be over and for prescriptions to be filled. Waiting was incessant, prolonged, boring, extremely irritating, anxiety provoking and expected. Informants accompanying wives for admission to hospital had to wait for blood tests before they could be certain of admission. The conflicting pressure to return to work and the desire for the treatment to be completed made the hours of waiting seem longer.

Most informants waited in the hall during treatment, while some sat with their wives. Wives were more resigned to waiting. Informants often offered to get drinks or snacks for wives but rarely talked with anyone else unless the other person initiated a conversation. They rarely took a book to read but sat quietly watching nurses or physicians with the patients and families. Walking in the hall or questioning why they were being asked to wait so long were strategies to break the monotony.

Waiting was a time when "everything went through your mind, mostly about cancer. That was all you thought about." The lack of choice was frustrating: "You have to sit and wait your turn. What else can you do?" One wife missed her treatment because she was angry with waiting and left. Husbands wondered how women who came alone managed to wait without "someone to lean on." Several found waiting especially stressful because the physicians were uncommunicative. They waited, hoping to hear something positive, but they were never told anything.

The fight was measured by the results of diagnostic tests which were not routine but controlled by the physician. Uncertainty about when the tests would be done or "how the tests are going to work out" influenced waiting: "It was always the same everytime. It was always hoping and praying that things are still going to work out." One couple had to wait eleven months before the CAT scan: "Up until that point, we

did not know whether there was any hope or not. It is in that period of time that people find themselves in total distress."

Anger at the system, the lack of compassion of health care providers and the long wait for results of tests influenced coping. Informants perceived a lack of compassion in being forced to wait up to five days to get test results. It was demeaning when scans were not shown to them, particularly when wives, using creative visualization, needed to see the scans. Trying to obtain information, by phoning or personally requesting, was often unsuccessful. The anxiety of spouses increased as they mirrored each other.

Committing

While all informants decided to commit themselves to help wives endure the fight, factors influencing their decisions varied. The length of marriage implanted a sense of fairness in that they had been together through adversity before and it would be imprudent not to stay. Informants thought of themselves, knew they would not like to be alone and felt sorry for women who were alone. Other factors influencing the decision to commit were moral values, guilt, the determination of wives to fight and the length of the chemotherapy treatment. In most cases, the resolution to fight, made when the threat was imposed, was firm and not negotiable. Factors which influenced a re-evaluation included the promise of inheritance, previous successful chemotherapy and a genuine compassion or love for wives. Indecisiveness was influenced by frustration and anger with their wives' temperament, a belief the illness was not life-threatening, a new job, a lack of love for the wife and a liason with someone else.

Informants were aware of husbands who had separated from wives. Their consensus regarding the reason for leaving was the increasing stress in conjunction with an inability to respond positively to the wife's behavior. The uncertainty of the outcome of treatment along with the prolonged period of waiting associated with "not knowing what's going to happen" was indeterminable, "So I can see how easy it would

"be just to walk out and say, see you later, you know, it's your problem".

Implementing Strategies

Informants began to plan and implement ways of buffering. When the ability of husbands to implement strategies was compared with their resolution of anger, attitudes became evident (Figure 6).

| | | Ability to Implement Strategies | |
|--------------------------|---|---------------------------------|----------------|
| | | + | - |
| Ability to Resolve Anger | + | Acceptance a | Apathetic b |
| | - | Domineering c | Cynic d |

Figure 6. Typology Illustrating the Relationship Between the Husband's Ability to Resolve Anger and the Ability to Assist his Wife Endure Chemotherapy.

Those who dissipated their anger maintained a positive attitude (cell a). They were able to grow within the limitations imposed by the cancer experience and were accepting of the need to participate. Husbands who released their anger but were not able to implement strategies were lacking in self-control (cell b). These husbands were often lacking in emotion and physically ill. Their concern was often focused on themselves, and they projected a lack of concern for others. These husbands were minimally involved in helping their wives. Husbands who suppressed their anger were often stressed (cell c). If employed, they spent an increasing amount of time at work. They usually accompanied wives to treatment and never seemed able to do enough for their wives. These husbands were always rushed, had very high self-expectations and did not like to discuss the cancer experience. In the fourth cell, husbands who either repressed their anger or were unable to implement effective strategies were bitter and

negative (cell d). They felt like failures because they got very little positive feedback. They never spoke with anyone about the cancer experience, and they withdrew when others wanted to share experiences with them.

Husbands assisted wives by softening the blow, resisting disruption and preserving self. Softening the blow involved strategies which were supporting, endearing and designed to make day-to-day life easier. Resisting disruption involved denial of those behaviors known to disrupt. Preserving self involved strategies to help himself.

Softening the Blow

Informants provided supportive care: "You do whatever you have to for someone you love to make it as easy as possible." "Everything I did was strictly for my wife. I had to do everything to make it easier." The philosophy was that "anybody who had cancer must also have a fear of death that was second to none." They believed:

If you want to survive the situation, you really have to turn yourself into something that can be helpful to the person that's sick.

You just can't go through that kind of experience by yourself. There's just too many things happening emotionally and physically. You need someone that is close to you.

Even when resisted by wives, effective caring had to be continuous, constant, consistent and persistent. Being there, cherishing, normalizing, being positive, taking charge and adding on were perceived to be supportive.

Being There

Being there meant one had to be egotistical, believe in himself and the necessity of his role and become an "insider" who knew and understood chemotherapy. Husbands said: "She wants me with her. I want to be there. It's a mutual thing." The cancer experience often isolated the couple, and they had to support each other: "I go home with the anticipation of helping her cope. I know I have got to help." *Being there* was a self-expectation, and one perceived to be expected by wives. For example, one informant did not like hospitals, but he did accompany his wife for treatment.

Changing roles was involved, such as with one husband who had to be a friend because his wife talked with no one else. *Being there* meant knowing enough to leave wives alone and not hover over them suffocating their independence. Some took early retirement or denied themselves enjoyable leisure activities. *Being there* was often evaluated by the residual guilt they could experience if they did something else.

Being there and getting ready for chemotherapy became routine. Informants "stocked up" on liquids or food wives could tolerate. Sometimes conversation would dwell on the site for chemotherapy injection, but usually, distraction was used to "take the edge off the evening." A secret underlying sadness, which was never verbalized, always accompanied getting ready.

Experiences during chemotherapy differed according to the setting. Although they became exhausted from travelling and worried about what was going on in their absence, when their wives were hospitalized, husbands never felt "in the way." One informant, who had visited and found his wife on life support machines looking "ready to die," was always fearful of entering the hospital. Another witnessed an emergency in which the patient died, and after this, he wanted to be with his wife constantly.

Receiving treatment in a facility that offered small separate rooms had the advantage of privacy, the ability to stay with the wife comfortably during treatment, the ability to open a window for ventilation and the ability to feel free to "come and go" when a nurse was present. But these rooms were like "jail cells" after fourteen months of chemotherapy. In most cases, chemotherapy was given to everyone together in a small outpatient room. Informants felt inadequate in their attempts to allay their wives' nervousness. Rarely did couples touch, such as, holding hands, or talk a lot together. Most did not accompany wives to see the physician, and those who did had requested to do so. One informant accompanied his wife until she asked him not to.

During chemotherapy infusion, informants were present when wives requested

this. Several had prepared an audio tape of relaxing music for wives to listen to. Many felt "in the way" of nurses due to the size of the room, availability of chairs to sit on, and number of patients in the room. Some waited in the hall until needles were inserted for chemotherapy, and then they entered the treatment room. The clinic was always busy, and informants worried that the other women would be resentful of them when their own husbands were not present. One informant saw women alone and crying after treatment which reinforced his determination to be with his wife. Crying was rarely seen, but signs of nervousness and anxiety were observed. During treatment, informants hung around furtively finding excuses, such as, going to put money in the parking meter, to get outside. They wanted to be there but became claustrophobic, bored, restless and ached to leave. Those who had been accompanying their wives for some time recognized familiar faces. One informant, who felt he had hope to offer because he had been enduring treatment for a long time, would start conversations with others. Overall, many felt that it was not a place where they should be and felt ignored by the nurses until the nurses began to recognize them as familiar faces.

They believed it was "harder for the survivor to go there than it was for the patient" because "they felt among their own kind." The cancer institution was appreciated as "everybody was in the same boat" and not "moping." Watching children was difficult because they "didn't seem to appreciate what was happening or why they were there." Older people seemed very "strong and bold and accepted the fact they had cancer." "After seeing it over and over," informants were less fearful of "chatting with other women [patients] who were all very friendly." Realizing that time and experience had mellowed the experience for them, many found the familiarity comforting. One informant, whose wife died, never felt comfortable and said, "There was never anything good associated with the place. How could there be?" He felt every patient had an extremely "sad look." After treatment "one should not desert someone when

they're in trouble and or leave them alone." Some felt wives should not drive home alone "under the influence of chemotherapy" and made certain someone was with them.

Cherishing

Cherishing consisted of nurturing, listening, touching, humoring and doing. Informants changed, becoming more attentive, compassionate and considerate. They wanted "to be able to do more" and no longer took their wives "for granted." Emotions of affection, gratitude and love were similar to the "honeymoon stage" of newlyweds. Informants found solace in the marital relationship even though their sexual relationship had decreased. Although the "opportunities were always there to be unfaithful" and there was "no question about it, the thought sure enters your mind," most informants were loyal. Often, childhood experiences affected their faithfulness. For example, one informant's mother had been abandoned by her husband, leaving her with two small children, and he remembered what that abandonment had been like for his mother.

The basic needs of rest, sleep and nutrition were considered most frequently. For some, touch took on healing powers as back rubs, neck rubs and hugs became relaxing and comforting, but other wives resisted any form of touch. Partial and sometimes total abstinence from the sex act was initiated by the wife. Informants provided physical care, such as, bathing or taking care of homemaking tasks. Work behavior changed, and working overtime became nonexistent. When unable to be there, husbands asked friends or relatives to stay, or they hired someone to care for their wives in the home.

Nurturing included caring, loving and supporting to make wives "feel better." A self-awareness not to overdo cheerfulness or "cheapen themselves" was evident. Husbands knew too many compliments given unwisely would sound dishonest or "phoney." Wives were depressed and dissatisfied with themselves, causing them to

question their husbands' love. Therefore, how a compliment was given influenced the wife's self-image. Many believed they came to love their wives more deeply and wanted to convey this. They tried not to be patronizing and learned not to say "I understand how you feel." How can anyone really understand unless they have experienced it? Wives were pampered and some spent a great deal of money "spoiling" wives. The "spoiling" by spending money gave satisfaction and positive feedback because it was something to "give up" just as their wife was "giving up" a lot of her energy to undergo chemotherapy. Most expressed the notion that there was "nothing I won't do. If she wants something, I do it. Anything within my power, I'll do." One informant was told by his wife that he was doing too much, and upon reflection realized that, at the time, he was not listening nor could he have changed. Informants wanted "to make her well" and expressed "feeling lost." They "hoped" that what they were doing was enough, that it was "the right thing."

Husbands perceived wives needed to have someone nearby who loved them. Wives feared being alone or abandoned more than their spouse having an extramarital affair. Informants were present in the home for longer periods. They rushed home from work and *being there* became imperative to maintaining trust in the relationship. Many telephoned wives daily "to give her a chance to talk."

For some, caring meant accepting changes and assuming passivity, such as, following a new diet they did not like because it was important to wives or accepting anger by ignoring caustic remarks. The approach became one of "trial and error." Humor "lightened things up a little bit," reduced "tense situations" and was "something to take her mind off her problems." Some wives lost their sense of humor, making it difficult to judge how and when to try "to be funny." A smile offered immediate feedback: "The best time I have, really, is when she laughs."

Wives wanted to discuss their reading and wanted someone to listen: "I learned to

keep my mouth shut through sheer experience. I'd often just sit there and not say a word for two hours." Listening, a learned response, involved "sitting nearby and giving eye contact," but this was not comfortable for those used to action. Listening had two outcomes: it helped wives "vent some of their problems and get them out of the way," and informants learned what their wives were thinking about.

Normalizing

Normalizing was maintaining a lifestyle as closely as one could to the way it was before the cancer experience. Informants tried to "do the same thing every day that I normally do" around home because normalizing was supportive in its familiarity. Although some expressed frustration with doing everything, home maintenance was important: "You don't stop living because something has changed within the family unit." When children were living in the home, tasks were delegated. Informants believed "pitching in more" with tasks "made things easier" for wives. Weekly routines, such as, going to church, were maintained even when wives did not accompany the family. Sometimes a more devout belief in God became apparent.

Social interaction provided healthy distractions from the cancer experience. Getting out of the home made one feel less isolated and withdrawn and created "a little better outlook on life. Informants believed wives needed to "get out once in a while" because they were alone so much, and they "needed a chance to enjoy life." Usually, social activities decreased because wives were in bed earlier and the couple often isolated themselves intentionally. Most informants missed socializing with others.

Children needed to be informed of the illness. Older children were informed in greater detail than younger children. Informants, who usually told children, would not share their mother's suffering. Telling a daughter that her mother was facing the possibility of dying was devastating for one informant, and even when he knew his wife was dying, he never told his daughter "exactly". Daughters cried and were not

calm in their acceptance, while sons tended to be more stoic and calm. Because of the concentration on the marital dyad, older children were often ignored. Husbands with younger children assumed "mothering tasks." Normalizing was particularly important when small children were present because the couple felt bound to discuss what would happen after the wife's death. Informants found planning for the future comforting because it provided distraction, allowed the wife to voice concerns and be influential in her children's future and provided the informant with direction. This situation facilitated open discussion of the future and death between spouses, which, for others, are silent and taboo subjects. After chemotherapy, it was important to keep children from watching wives fight because wives did not want their children to see them suffering.

Some informants felt they "short-changed" their own parents. In many instances, in-laws were more involved and "put up a good front like everybody else, trying to keep things as normal as possible." One husband found the increasing intimacy with in-laws more comforting and supportive than his own family.

Acting in a way perceived to be expected by others was stressful because one had to act "normal" and not walk around depressed. Husbands had to "keep up a good front" because others would detect their unhappiness and avoid them. When they talked about the cancer experience, friends cried easily, so husbands had to be careful who they talked with. Appearing "positive" and confident about winning the fight as important because wives would sense anything less and become discouraged.

Taking Charge

Taking charge were isolated behaviors. *Taking charge* usurped the *doer* role in that husbands made a quick judgment about the value of something and became totally committed. Anger was often the impetus, such as when one informant called the Minister of Health and "had a fight with him" because his comments in the newspaper

reflected a lack of understanding of the cancer experience. Another controlled the television biographies his wife saw so that she only watched those which had a "happy ending." *Taking charge* was often legitimized by a wife's request. One wife requested her husband "get me out of this hospital," but the physician said she was dehydrated, needed fluid, and would not be discharged until the next day. He remembered "we checked out at midnight."

Informants worried about "pills" wives were expected to consume and assumed the task of making certain pills were taken at the right time, which was very difficult when husbands worked. One wife telephoned her husband crying because she had fallen asleep and missed a pill. *Taking charge* involved a series of actions to identify which pill was missed and what to do about it. Another described *taking charge* during the physician's appointment where his role was to remind his wife of instances of duress when she forgot to inform the physician. He knew the physician would then question his wife in more depth. When someone upset wives, they were no longer welcome in the home. For example, a relative used to talk about "all the people who did not make it" and was told not to visit or to talk with the wife again.

Being Positive

Being positive allowed one to be hopeful in the face of *guarded optimism* and allowed living "one day at a time." *Being positive* was confidence-building and helped temporarily repress the fear of the cancer experience. Informants thought both spouses must be positive to be effective:

Do not let whatever is happening get to you so that you start feeling negative. Once you start feeling negative then you have a problem. If it was both of you feeling negative, somebody else will have to come in and get you back on a positive note.

Being positive was a source of support because "if I was positive about things, and trying to make my wife positive, then she would feel better. In turn, I would feel better." Benefits were "you don't get so upset about little things anymore" or "you did

not think of it as such a bad disease anymore." *Being positive* was believed to affect length of survival and presumed "the getting well process was within oneself" not only within the realm of the medical model.

Being positive was difficult to generate when experiencing recurring disease or treatment cancellation. Often, *being positive* was the strategy used to "pull" wives out of moods. When one spouse was not as positive as the other, they "hoped that it was never on the same day." To prevent this, it was important to recognize what the other spouse was feeling and try not to be "down" at the same time. Therefore, this strategy meant the couple had to trust each other and not keep secrets. The assumption was that keeping secrets from someone who knew the other so well was impossible because they would "pick that up right away." When one did have a secret, it was very stressful and guilt-producing. For example, one informant had been informed of his wife's length of survival time by the physician. The secret of knowing made him nervous of his wife's potential resentment.

Being positive in the face of dismal statistics was difficult, so informants rationalized them as meaningless or denied them: "We will not be one of those statistics". The trepidation magnified when physicians did not offer any guarantee or positive encouragement. Informants looked to nurses for hope but perceived nurses "didn't want to be responsible for throwing out a ray of hope." They learned to follow "orders" and not ask questions because they really did not want to find out something that would make them "more negative, or more uncertain."

Being positive meant finding reasons to be hopeful, such as, seeking out information about successes with chemotherapy. Talking with someone who had finished chemotherapy and could "go back to their normal life" inspired hope. Hope was enriched when wives felt better, believed they were going to get better or went into remission. One informant believed hope was conditional, but *being positive* left no

room for doubt. Another did not like his wife "wondering" because "wondering was like looking hope in the face" and left room for doubt. Although one informant believed not making long-term goals implied being less hopeful, *being positive* was making reachable short-term goals. Praying or going to church helped some stay positive because it helped them accentuate the positive things about living. Comparing oneself to others often made one feel "lucky." Some "soaked up" all the "positive vibes" friends and relatives projected to enhance hopefulness.

Being positive was energy depleting. One informant described it as self-teaching or brainwashing which became an inherent part of his lifestyle. It involved "self-control and not letting the mind get out of control" or stray to negative thoughts. Self-control involved knowing the self well enough to control the negativism. For some, it took "double the effort" because they had to be positive for themselves as well as for their wives. They maintained they were always hopeful that something "might turn up" to help wives. Informants believed if they implemented strategies to help themselves remain positive, then they could influence their wives with *being positive*. The worst dilemma was when one was not hopeful and not able to perpetuate *being positive*.

Adding On

Adding on was being innovative, trying alternative means to augment conventional treatment. *Adding on* allowed the couple to experiment, within reason, and gave them some measure of choice and control. *Adding on* increased the chances of a better outcome of treatment. Often, the emphasis was on practicing those methods chosen continuously and, simultaneously, "putting them all together" so that they could act as catalysts for each other.

Reading "everything they could get their hands on" and discussing approaches with the nurse or physician encouraged innovative creativity. Methods included: creative visualization and imagery, dietary regimens, relaxation therapy, prayer and the belief

that one can heal oneself with God's help, cessation of smoking, increasing contributions to the cancer society, exercise (such as yoga or meditation), seeking counselling services, submitting to healing ceremonies and wearing a magnet or grounding stone.

Resisting Disruption

Wives experienced periods of ennui and were vulnerable. Informants were never aware of when these would occur and felt they must maintain self-control at all times to be helpful. They believed their wives attitude of determination and optimism helped make the cancer experience easier for themselves. In repayment, resisting disruption enhanced normalization. One informant related that he

... tried everything in his power not to cry, or show any emotion towards her disease or her condition, to go on with life as if nothing happened, but deep down you know you are doing it for a reason.

Informants wanted to be the closest person to their wives and did this by disguising their feelings and treading lightly. In retrospect, one husband said: "I did what I thought was best for her, what was right, at the time." Informants had to decide for themselves what this "right" thing was because talking to other husbands in similar situations was rare.

Talking about feelings threatened self-control, "I tried to do a good job of hiding my feelings from her. I never wanted to show weakness in front of her." Crying in front of wives was unforgivable because it exemplified a lack of self-control. One informant reported he "did break down once and she really worried," while another perceived his wife was "just barely hanging on to her sanity" and his crying would push her toward insanity. Crying was "feeling sorry for yourself." Losing control, becoming impatient and above all being patronizing, condescending or intrusive were behaviors not to emulate with wives.

Disguising One's Feelings

Showing anger or doubt would impede the ability to fight, and informants believed one had to be devious in disguising these emotions: "She would pick that up right away. That is one of the things that scares me." One informant said he "felt he was wearing a mask," and it was "very stressful being somebody that he was not."

It was difficult to "try and keep back the tears." Informants were not embarrassed to cry, but they believed wives needed someone who was "calm, sure and collected for solidity." Husbands needed the security of knowing wives could depend on them "not to crumble in front of her," so they focused on projecting the opposite of what they were feeling and tried to be cheerful. They cried by themselves, secretly, but they also had to recognize that no matter how much they tried to "hide it," sometimes "the real you was going to show, and you could not do anything about it." One informant said, "I learned not to cry, or show emotion, which has carried on in my life today."

Informants never considered sharing their feelings with wives: "I did not think I could ever unload that on her." It was easier for informants to talk about "after she was gone" than while she was alive, and some "cannot remember ever telling their wives how they felt about it." Many of the informants said, "The person who has cancer is carrying the biggest load in the world, and just barely hanging in there." Most wanted to talk: "I wanted to tell somebody. How does somebody get that feeling out of their stomach, of watching someone you love going through chemotherapy?" Several tried to talk but found wives did not want to listen. One wife told her husband to "shut up."

Guarded optimism was never discussed. When hearing of a test result, one was hesitant to become ecstatic, "because you were not sure if it was real or not." Informants were pleased and simultaneously doubtful. They hoped it was real but were afraid to be optimistic: "You can only put yourself in so many ups and downs."

Treading Lightly

Treading lightly involved strategies to avoid unpleasantness. Husbands took the passive, supporter role. *Treading lightly* was the ability to communicate in a way that one did not say "the wrong thing" or express something in "the wrong way." The wrong way was learned through past experience or through "trial and error." They had to be very careful because once something was said or done it could not be undone. One informant described a concern over finances when his wife had been attending a psychologist for counselling services. After six visits, he had asked his wife if she felt better after talking with the psychologist. She quickly asked why without commenting on his enquiry. He did not have time to formulate an answer and instinctively showed her the bill for services, which made him feel guilty for bringing it up instead of just paying the bill. After this incident, his wife would not consider going back to the psychologist or finding someone else who might not be as expensive to talk with. Any persuasion on his part met with a negative reply. The incident was devastating for him because he was afraid he had impeded his wife's ability to cope with the chemotherapy experience.

Many became so distrustful of their own ability to respond that they were afraid to talk. Solutions included becoming "listeners", waiting until wives talked to them, not "trying to start a conversation," avoiding the "wrongs" by doing more "rights" and hoping for the best. Although informants were trying to normalize their lifestyle, they were aware of things they should or should not do. They walked a tightrope, trying to create a lifestyle with "balance" so that neither spouse became upset or anxious and every emotional crisis was averted. One informant described it as "[feeling] like I was walking on eggshells a lot." *Treading softly* was described as, "It's got to feel safe, or I don't do anything at all." Anger presented a dilemma. Some would leave rather than argue, others acted normally and "snapped back," although in a "slightly milder" way.

The dilemma was that they wanted to normalize life and certainly did not want to make their wives feel like invalids. They wanted to "let her know that there wasn't any cause to speak to me that way" but not to argue. The diplomatic approach was spurious.

Treading lightly allowed for the *doer* role, and husbands received the feedback needed for their own self-esteem. They could not allow the role reversal of wives comforting or pleasing them: "I did not want her comforting me, that would be bad." Above all, they did not want wives feeling helpless. They wanted wives to be free to be selfish.

Discussing sexual response was difficult due to an unsureness of how sexual intimacy should be shared. Some couples resumed sexual intimacy but not to the degree they had enjoyed before the cancer experience. Those who did not resume sexual relations believed their wives felt sexually inadequate due to the changes brought about by the surgery or chemotherapy. Some wives experienced pain on intercourse, while others felt neutered and unattractive. The dilemma was that informants did not want wives to interpret the lack of sexual intimacy as a reflection of their love for them. Some informants had to be careful not to communicate any romanticism because wives might interpret this as a sexual innuendo and find it threatening or frightening. While some couples talked about their abstinence openly, most found talking difficult. It was a painful discussion for husbands because the sexual response was integrated with how they identified as part of a marital couple, and it became more difficult if the couple did not usually share personal feelings with each other. Taking the path that offered the least emotional upset for his wife was perceived to relieve her of any undue stress, that is, not discussing the sexual response at all.

Omitting the Truth

Omitting the truth was used when informants could not say something positive or complimentary. Everything was evaluated with an awareness of being controversial.

For example, they could not tell their wives they were looking great when she looked ill, so they would not say anything. Other strategies included distracting discussions to other topics or refocusing by telling wives of the love they felt for them rather than dwell on appearance. Omitting the truth was defensive, for example, when husbands did not inform wives of increased drinking or smoking habits or when having a relationship with another woman. The strategy was justified by protecting wives from more suffering and allowed husbands to continue even though expressing guilt.

Preserving Self

Informants became "self-supporters" to maintain control. A self-supporter conserves energy, maintains motivation and sharpens his helping skills.

Conserving Energy

Self-control was an important ingredient influencing the behavior of husbands. For many, the need for self-control was uppermost in their minds: "You police your own thinking. You have to be your own policeman. When you don't want to think about something, that's when you have to turn it off." Through conserving energy and releasing tension, informants were able to maintain self-control. For some, self-control culminated in thinking positively and affected how they projected themselves. A strategy for maintaining self-control was finding a way to release the cumulative tension. One informant had a "switch" he was able to turn off and on that helped him concentrate on his work during work hours and on helping his wife while at home. The "switch" helped "block everything else out." Many released tension by finding a private place to yell, scream or cry: "It is amazing at how the energy and tension flows out of you. You heal yourself." For another, self-control meant controlling his own mind, and he used meditation, hypnosis or yoga to change the conscious state of his mind to what he wanted it to be.

Keeping Busy

Keeping busy was one way to focus thoughts on something else. Wives, who stated or inferred their desire to be alone, gave husbands permission to think of themselves, and some felt "happy to get out" on their own. Going to and from work was their only private time for introspection and the secret expression of sadness.

Work, the most common way of *keeping busy*, was an "escape" from the helplessness they were experiencing. Work offered total immersion, and they "didn't have much time to think about their own problems." For one informant, who communicated very little with his wife, work represented "peace or companionship" not available at home. When a job offered travelling opportunities for those who excelled, the expectation to excel introduced pressure to succeed at work because "trips" became goals the couple planned and looked forward to. Work provided a different milieu with different things to do and think about. Work was like "stepping into another world"; but as soon as they left work and got in their car to go home, the "real world" of the cancer experience was back. Retirement was not an alternative for most husbands, and work was a legitimate part of their time away from home. Although working was a necessity, many expressed guilt at being away from their wives. One informant, even though he needed the money gained by working, felt that he was "pushing his wife away when he went to work."

Several employers did not accommodate the needs of husbands, and work became an intense stressor, producing a lot of anger. Two husbands changed employment, two took an early retirement and another was ready to quit during this study. Many remained because of seniority, age and the need for income or because they felt they had no choice. Others had flexibility in their work hours and colleagues who helped them when needed.

Healthiness

Exercise, in the form of group sports, such as, hockey, or individual sports, such as, running, swimming or tai chi, was relaxing as it "helped to get rid of frustrations." Active sports kept the energy level "up" during the day and helped them sleep throughout the night. Exercise was self-indulgent and allowed time to think. For some, the enjoyment from exercising was undermined by guilt as informants realized they were enjoying something that their wives could not enjoy. Most resolved this dilemma by rationalizing their ability to support depended on energizing themselves. Most wanted to be feeling "the best I can if I am going to be of any use. I can not afford to get sick." They took care of themselves with proper diet, sleep and exercise. Although many had periods of indulging, all informants became more aware of the need to look after themselves so that they could be "useful" to wives.

Sleep was an escape during crises; however, most intentionally stayed awake during nights when wives were ill after chemotherapy. One informant found "power naps" taken before going home from work essential to his survival. Sleep was important because, when tired, it was easier to feel negative or sorry for yourself and more difficult to maintain a positive attitude.

Seeking Out

Seeking out people to talk with led to a sense of personal satisfaction. Talking was doing something to find a sense of meaning in the cancer experience and was described as "sharing your burden." Through sharing, one came to understand more about the cancer experience and was able to formulate questions. Asking questions was one way of coming to understand. Most sought a male rather than a female to talk "at." Talking "at" required a good listener, whereas, talking "with" required a listener and a talker. Talking "at" let informants "lay out their emotions, their feelings." Talking was particularly useful when feeling "angry" or "down." The attributes of someone chosen

to talk "at" were that he was caring, loving, compassionate and knowledgeable about what the informants were going through. A good listener did not interrupt or question what was being said.

It often took the wife's prodding to make the husband realize that he should seek help. The prodding freed him to talk with someone else since he was not betraying her by doing so. Often, *seeking out* involved talking with someone they had not known before, and this allowed them to express feelings that they could not verbalize to someone they knew. They were free to let "the stream of consciousness to go" without feeling they were "laying a trip" on a friend. However, most informants did not want or were not ready to talk, and they admitted that even if someone had approached them, they may not have talked about such private thoughts. Others stated that it would have been better for them if they had found someone to talk to, such as, "an outsider" who was not sharing the experience with them personally, and would have appreciated "a little bit of prompting." They reiterated the need to trust and like the person.

One institution offered a meeting for husbands held one morning a week, with the leader being a clergyman. In order for husbands to avail themselves of this opportunity, treatment had to fall on the specific day. One husband found the group to be like a drop-in centre. Although he was welcomed and talked with another husband, he did not feel this was helpful for himself. He had not known what he expected to find helpful, but he knew that he did not find it there.

Talking was considered acceptable when the focus remained on the wife. One informant, who described himself as "tense" and paralyzed with fear during the whole illness, never talked openly with anyone. Bitterness and anger endured, and he wanted everyone "to stay away from him" because the last thing he wanted was "sympathy" or "anybody feeling sorry for me." Talking meant being the recipient of sympathy, which might, in turn, make him feel sorry for himself. In the past, he had "always

talked with his wife" and "was not used to talking with a stranger." He admitted to feeling "not right" about going to talk with someone and felt that he would be divulging secrets or being weak. His statement "Who was I going to talk to?" implied that he really did not know where to turn at that time: "My mind was so screwed up anyway but, to try and straighten it out, it would have been definitely too much." He did have one good experience when a nurse approached and talked with him. However, following their talk, he felt he had said too much, felt weak for having talked to someone about his difficulties and felt like apologizing to the nurse whom he never saw again. In contrast, another informant felt the need to talk about the cancer experience right from the beginning. He felt he "could not pretend that nothing was happening," and talking about it meant he was not denying his wife's illness. He told his boss, which relieved him of trying to "hide" the knowledge from others. Telling his boss also enabled some flexibility and security at work, that is, if his wife needed him and he had to leave work urgently, his boss would be more understanding.

Most adhered to a code of secrecy established to curtail their own self-interest, and only one informant found that talking helped him deal with his wife's rejection. He felt lonely and stated that "bringing everything out in the open" was "mentally healthy," which implied that not talking about it could cause mental illness. He was going "stir crazy" staying in the home as his wife withdrew from any interaction. The intention to seek professional counselling, expressed with "if somebody mentions to me that I am changing or seem to be getting weird" indicated the need to remain normal and sane. Perceptions of others were important. Informants thought they were coping, and when others told them what they were doing, they were surprised. Receiving feedback from others was important to gaining insight into ways of conserving and channeling energy.

Maintaining Motivation

Compassionate and supportive friends were gratifying. They knew "you were

hurting" and "did little things" to show caring. Caring nurtured informants who could then reciprocate with their wives. Reminding oneself of how it felt to be the recipient of such warmth was catalytic and stimulated further exchange. Husbands needed to be acknowledged in order to maintain their own self-esteem, and they rarely said "no" to any request from family members. The best motivator was to say "I am doing the best that I can." When one could say this, then he need not feel guilty about anything and could protect his self-esteem. Looking for feedback from physicians was ongoing because informants perceived little was given. When physicians "looked pleased" without verbalizing anything or said "She'll be alright," informants were ecstatic.

One informant described himself in a "social worker role" when talking with other husbands. By giving them hope, he reinforced his own determination to be hopeful. Helping others did not help his own positive attitude because they were always discussing someone else's problems. Why did he not share his own problems? He wanted to motivate others, but he found it difficult to ask for help because he was the "expert" who had been experiencing chemotherapy for years. He felt he should know how to help himself. These high self-expectations were reflected in what he expected of physicians and nurses, and one of his constant frustrations was that they were constantly failing him.

Knowing "that more people are surviving" and seeing people who "have conquered this problem" helped supply legitimate and inspiring proof of success. One informant felt knowing he was moving physically closer to his nuclear family after chemotherapy made a difference. For some, knowing statistics helped, but for others, statistics were dismal and not helpful. Knowing those who administered treatments, becoming familiar "with the place and the people" and normalizing the routine of chemotherapy maintained motivation. Keeping notes helped keep things in perspective. Nurses, perceived to ignore informants, were not particularly helpful. Rationalizing that nurses

were there to spend time with their wives did not make it any easier to accept.

Sharpening Helping Skills

Controlling anger sharpened helping skills. Once anger was identified, it could be controlled, but many were unwilling to acknowledge and express their anger. They were angry at "the torture" imposed by the chemotherapy and lifestyle changes forced upon them: "I was mad, I was damn mad! I was mad at life. I was mad at everything. I had to give up my job. I had to do all these things I didn't want to do." As one man said, "Anger is something you don't want to repress. You can become really disgusted with yourself." When unable to express anger, husbands had to "try very hard not to get angry at their wives," which induced more stress. Anger was described as "bad," "negative thinking," "stressful" and a "killer" that one must be careful of because it has "a sort of bitterness about it." Anger was associated with helplessness "you can't do anything about." Conversely, release of anger was relaxing and rewarding. Most informants felt they never got rid of their anger but learned to deal with it through self-control. One of the most effective means was to "allow" the time to cry, to "fall apart" and then "suck it up, and take it full again."

Husbands tried to determine the effectiveness of a helping strategy. They "watched" for signs of satisfaction, such as when their wives smiled or were more "cheery" in their demeanor, and for tenseness, such as by body posture and facial expressions. Sometimes informants received feedback from a third party, such as when a mother-in-law said that her daughter told her she was "very lucky" to have such an attentive husband. A smile was worth everything because it reinforced the worthiness of their role and made them feel "that it was worth it". Being appreciated was "one of the benefits." When a wife said "did I ever tell you I love you" or "I feel so safe when you are around me," the informant knew he was doing the right thing.

Helping inappropriately, such as when informants became too protective, made

wives dependent. A sign of overprotectiveness was when informants had difficulty leaving wives alone and invented ways of leaving which made sure they were still involved. One man used to write down the times when his wife's pills were due and then phone her from work to make certain she took them. Another used to do all the cooking and cleaning so that nothing was left for his wife when she was alone. This was problematic for some because they set themselves up for feeling guilty when they recognized wives had become dependent.

Finalizing

There were two specific emotive responses during the finalizing phase: relief and despair. Husbands were relieved their wives "made it" or finished, and there was also "luck" associated with being alive and together as a couple. Many did not talk about their relief, but "after a while, you learn how to talk about it" because "time has healed the wound." Husbands did not have to identify with being the healthy one any longer because they perceived their wives to be better. Time allowed informants to "calm down," and they were relieved at no longer having to live by a calendar.

Needing to find something good in the experience, many felt the family unit and marital dyad were strengthened. Others saw the experience "as a bit of an omen" which made them realize "life was a gift." Many felt they were being given the chance to change their lifestyle and were going to take the opportunity. Some began to put their wives "on a pedestal" as "you did not really appreciate her till you almost lose her."

For several informants, the end of treatment meant despair because chemotherapy was no longer effective in fighting the cancer. In most cases, it was stopped by the physician, leaving the spouse no choice or control. One informant questioned the value of the chemotherapy and was told it *might* prolong his wife's life for a few days. He did not want her suffering more unnecessarily and considered her quality of life before death. He discussed the efficacy of the treatment with his wife and left the decision to

her. She chose to deny treatment and return home, which was a relief for both spouses. In another case, the wife denied treatment saying, "[I] would rather die than go through this, that this [is] absolutely no way to live. Living [is] good, but this [is] horrible." She had been enduring intermittent chemotherapy for six years, with a cancer that progressed insidiously. Her husband said, "I was as relieved as she was when she decided no. We had discussed it, and she was prepared to die." Another wife had shut herself away "in her own little world," and the spouses "were apart" even though the husband was with her.

Several considered "did life ever go back to normal?" as waiting for tests continued. One informant described being optimistic but not eager for more chemotherapy. He felt it would be "as bad as the first time all over again." *Guarded optimism* surfaced as husbands hoped to "maintain this holding pattern." Part of the problem was that "an end was not in sight." They saw themselves waiting forever for tests results, and it was "always going to be a little traumatic." Trying to be realistic, one informant saw his wife returning for future "shots of chemo" until "they find a better way of dealing with it." Many felt "chemotherapy was better than death," and as long as it was given, the cancer was being treated and death was being denied.

VI. RESULTS: THE VETERAN

Husbands emerged from their wives' last administration of chemotherapy with a sense of fulfillment regarding the fight and the finality of making it through. They recognized changes wrought by the chemotherapy and gained a new perspective on the nature of waiting or marking time. Figure 7 depicts this process.

Making it Through

Being a veteran of the chemotherapy experience had lasting effects because of the unforgettable memory of such a devastating experience. One can never forget that cancer can be deadly, and husbands reverted back to "the waiting game again. Is it going to develop in another part of her body?" and hoping, "we hope we do not have to repeat it again." Some celebrated reaching "the top of the mountain" by doing something pleasurable, such as, taking a holiday with their wives.

Informants all expressed pride and admiration for their wives. For example, "I think that is just incredible, to go through that horrendous experience and still come out with a sense of humor." They were in awe of their wives and wondered if they could endure as well. Waiting to find out if the fight had been successful was stressful. The first check-up and set of diagnostic tests would be the best positive indicator, and the couple waited anxiously. Although some continued to talk of "cure," many considered the words "control" and "remission" to be more applicable to their fight. As one husband explained, "A lot of people think that a cancer, once cured, cannot return, but a cancer can return as it is within the system." His wife had not experienced recurrence and had been treated with one course of chemotherapy treatment lasting fourteen months. These thoughts reflect *guarded optimism*, which is forever prevalent.

"It was no longer the immediate stress of having to worry about getting through the chemotherapy and my wife getting better," or as one informant explained, "I am not as

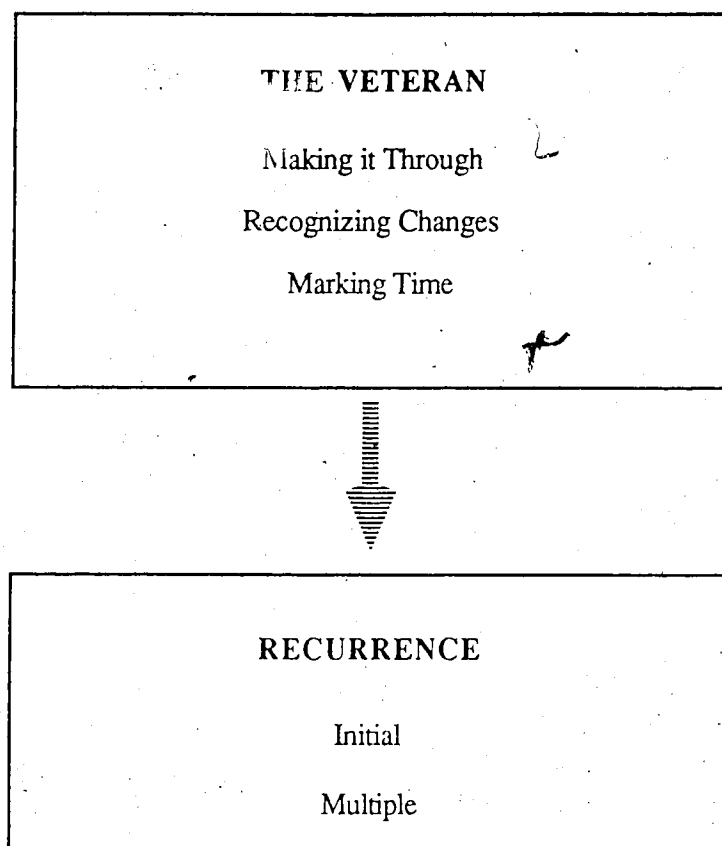


Figure 7. The Process of Emerging as the Veteran and Potential Recurrence Experienced by Husbands Whose Wives Receive Chemotherapy Treatment for Cancer.

tense anymore because I feel pretty confident about the situation." Informants had learned to accept "the thing" and wanted to "have fun" because they had made it through, too. It was time to get on with living "some sort of normal way of life." Satisfied they had done the "best that we could so far" indicated that it was not over yet but they were "trying to be optimistic." Some wanted to "repay the favor" with others not as fortunate. One couple had endured "heavy" chemotherapy for three months and considered themselves "lucky" they were able to "get it over with quickly." They began to think of "getting involved" with helping others almost immediately.

Informants debriefed as they evaluated and assessed things they would change. Changes included not interfering with wives lifestyle to such an extent and not letting their own day-to-day life revolve around the "doer" role to the exclusion of everything else. They were left with more time and energy. One informant became so subsumed in his role that afterward he stated, "Maybe I'm lost, maybe I got lost as a result of this devastation. I don't know what the heck to do with myself now."

Stress increased as check-up times came near. It was hard to relax until after the first check-up. The worry about recurrence was something which some adapted to, while others could not "relax until about five years from now. If you can make it to five years, you have probably had the problems cured." The belief of the "magic five-year point" predominated, and calendar watching continued. Although chemotherapy was "a means to an end," the uncertainty of "how it is all going to turn out" or the "not knowing" was the "hardest part, without a doubt."

Recognizing Changes

Guarded optimism reappeared as informants wondered if wives would ever return to their "old selves", the way they were before the chemotherapy began. Informants believed thoughts of "normalcy" were idealistic, and they wondered if they were "just fooling themselves." Wives were not as self-centered: "we are not I anymore, we are

we and we are together." At this time, husbands decided "things were going to be okay." The biggest physical change was the growth of fine hair, which some had believed might never grow back. One husband described this event as the "real turning point" for his wife. Skin color improved daily with better sleep patterns. Strength and stamina improved as wives began to do more.

The most significant changes for informants were the emotional ones: "She is more like she used to be." The regrowth of hair was considered to be the greatest factor contributing to the stabilization of the wives' mood. Several described their wives as "a different woman," being more outgoing, participating in different activities and starting to "come out of that shell she was in." Physicians warned social, emotional or physical changes would be unexplainable, and informants were constantly vigilant for these. Some changes happened quickly, such as, the hair growth, while others, such as, emotional changes, happened slowly. Changes were noted up to two years after the chemotherapy treatment was finished. A change in memory and slowed mental process was most noted by informants.

Husbands experienced residual anger. They were angry at "things" or "others" rather than at themselves, their wives or the nurses. Anger was directed toward the physician or situations, such as, having to move their residence closer to the family or the treatment facility. Of those whose wives died, many were angry "at what happened" and missed their wives. One informant left the Roman Catholic church because he could not understand how a loving God could do such a thing to his wife. Reliving the experience, through talking about it, was emotionally depleting.

Informants described changes in themselves. Changes were attributed to their determination that their wives were "getting well." Changes included a greater freedom to enjoy life, using a physician for personal health faster and more often and a change in patience and tolerance of others. Many described "things do not seem to bother me

as much anymore," while resentment of employers for causing personal stress during the cancer experience escalated. Emotional changes occurred, particularly in the way they looked at the world around them. Comments ranged from "it made a new man out of me" to "everything was totally different." One informant described seeing other husbands change as he watched them during his wife's illness. He noted changes in the way they talked with people, and he saw everyone go through a stage of feeling sorry for themselves. He believed that everyone went through the recurring stage of "feeling sorry for himself" and that some times were worse than others. He stated that the experience either made husbands more sensitive, "more in tune with other people's feelings, more open-minded," or it made them "extremely hard, bitter and insensitive to other's feelings." He contended that the husband who went through chemotherapy with his wife had so much going on around him, "so much emotion, so much action, so much happening" that one had to change in response.

Many strategies informants learned became entrenched within their personal coping repertoire. For example, bitterness continued for one informant. He explained that he could probably change his attitude, but it would take more effort than he was willing to expend. Others described aging and changing career goals as a result of the cancer experience. Nightmares experienced during the chemotherapy began to subside.

Most continued with the positive philosophy of living day-to-day and adhered to the philosophy that something good came from going through adversity. They believed the experience made them better men and better persons to live with. As one informant said, "It was an interesting experience. You would like everybody to go through it and gain the experience but not have the emotional upset." Many stated their lifestyle had been one in which they had taken too much for granted and vowed to change. Others recognized they had learned "not to say the wrong thing"; whereas, before the experience, they would have said whatever was on their minds. Others improved in

their ability to "sit and listen to people, and feel their feelings" with more insight and sensitivity. Many experienced the freedom to dream and make long-term plans: "We are making plans for the new year, and it is nice to look ahead again."

Marking Time

Waiting was looking for the unexpected and never knowing if the cancer was going to recur. Husbands were thankful chemotherapy was over and hopeful of a cure, but they were afraid to be too optimistic, believing they might be denying reality. As time passed, good check-ups were tallied, and this fear decreased.

With no more chemotherapy to plan your days around, life got back to "normal." Wives were often back at work and able to manage homemaking. The couple could now spend their money on things they enjoyed doing, and holidays or trips became frequent. The ability to go out for an evening was something to look forward to. The couple socialized more and did not feel the need to isolate themselves from friends. It was easier to "talk freely and openly about the situation, without fear of breaking down." Thoughts were naturally optimistic and positive. Informants were more confident as check-ups passed with no evidence of cancer. Memories of the horror faded and orientation was to today and tomorrow. Informants began setting goals for the future so that wives would look forward to more pleasant things rather than look back at the unpleasant effects of chemotherapy.

Waiting was stressful because without treatments there was nothing to fight the cancer if it was growing. The first few check-ups gave a sense of security in that something was being done, and the couple experienced indicators of successful treatment. The periods between check-ups were silent and uneventful unless symptoms developed. Diagnostic tests, such as, scans, were done with check-ups, usually in three-month intervals after cessation of chemotherapy. The time seemed lengthy, and it was very difficult to keep hoping when wondering "Is it getting better?"

Sometimes informants were unable to protect their wives. One wife went for a job interview and had to identify her health status and health history. The employer asked about her probability for survival. Another practical application was realized when applying for a loan. The loan was denied because of the possible loss of the wife's earning power if the cancer recurred. Life insurance was denied.

The fear of recurrence "crept into their thoughts every so often," but when this was weighed against having come through the chemotherapy and the fact that their wives looked well, these thoughts were repressed with less and less effort as time progressed. Thoughts such as "the feeling that I might have to go through that again someday scared the hell out of me" were kept secret. One informant said, "If I had my druthers, I'd certainly prefer to live out of this situation. I could live without this stress." It was more difficult to repress these thoughts when you knew someone who has just had cancer recur or who has died from cancer: "There are always those fears in the back of your mind, that things are not going to be the way you really want." When wives worried, the same response was triggered in husbands.

Husbands did not want to "dredge it up and go through the pain they had already gone through." However, when with "an insider," they were empathetic and caring. "An insider" was someone who was a survivor or who lived with someone who had cancer. An outsider was someone who had no idea what the disease was or the experiences that people go through. One informant said,

I really care for the insider who had to live with someone who has the disease. I really feel for them. I know exactly what they are going through. I try to give them help and encouragement.

Informants felt they had done everything they could do and "thanked God their wife had not had anything show up." Many believed this was their "acceptance stage." That is, once the fight was over, they could look back and accept it, but they could not accept it while going through the fight. Informants were euphoric, while wives often

commented on death and dying, such as "I might not be here next year," and husbands "were not sure how to react" to such a comment.

When considering "what if" cancer recurred, the unanimous response was that it would be worth it to go through chemotherapy again because it would mean prolonging life. They really did not want to consider "what if" because they were concentrating on being optimistic and positive, but it was "easy for me to say, I am not the one who suffers." All informants believed wives would choose to undergo chemotherapy again:

I know that my wife would not want to go through it again. She did not like going through it the first time, but if it's a necessary evil, then I suppose that she would go through it.

Planning for recurrence did not occur: "We will have to deal with that particular conflict at that time." Informants were more concerned with the test results than with observing wives for visible body changes.

Some became political advocates for cancer patients. Strategies included writing letters to Members of Parliament, campaigning for funds, campaigning for a better facility and writing letters to the institution offering ways to improve the care. One informant, who cannot go near the clinic without feeling physically ill, campaigned for funds for the Cancer Society. Interest in anything to do with cancer grew as they continued to read current news and media releases about cancer. Parents considered the risk to children and practiced prevention, such as, making sure children went to a reliable physician for check-ups and by teaching self examination, because "you just hope you do not get it. I would be devastated if my children got cancer."

For those whose wives had rejected chemotherapy or who had the treatment stopped by a physician, there was "no wonderment anymore" because they knew why chemotherapy was stopped. One husband felt happier to be the one looking after his wife in the home: "You are there and you can do everything that has to be done right now." He wanted to be with his wife without hospital personnel around interrupting

their closeness. It was easier for friends to visit in the comfortable atmosphere of their home. At this point in treatment, husbands believed their wives had accepted the fact that their disease was leading to death and that the point of dying was "not far off."

RECURRENCE

The indication of a diagnosis of cancer in some other part of the body recycles informants back into the process of the threat, the fight and the veteran.

Initial Recurrence

After chemotherapy, waiting for the three month check-up with the physician and for an indication of success or failure of the treatment was stressful. Informants wondered whether the cancer was spreading and often imagined it was. They looked for signs of disease progression and considered the difference between curing and controlling the cancer. Controlling the disease meant stopping the progression of cancer without curing or eradicating it completely. Metastases, or the spreading of cancer within the body, was always feared, particularly to the bone, liver and pancreas. Metastases to the brain was not considered. Recurrence meant the disease was winning, death was inevitable and "the days were numbered."

Any amount of waiting became even more difficult once the cancer started spreading:

It seemed as if you were getting back on that old treadmill again. Now you know what it is. Your hopes were not is it or isn't it spreading but rather, is it or isn't it getting better or worse? You were always hoping that there was some sign of remission or some sign that something was working.

When waiting for test results, couples sat quietly and did not talk about remission. Test results were awaited impatiently because they were a measure of disease progression, and something upon which husbands based their hope. Several compared it to the

inevitable demise of the AIDS victim. During this period, the time spent waiting was worse than any other time because now there was nothing concrete, such as, surgery or chemotherapy, to adapt to. One informant reported that the "big five-year obstacle" was almost insurmountable, and he was "very uptight all the time" because it was something he had to think about and plan for constantly. For another informant, *finding out* meant waiting because he had been informed by the physician that his wife's death was imminent. She lived longer than expected, and all he could do was wait patiently while trying to be supportive. In this case, he had trusted the physician's prognosis and as a result he had to deal with the guilt associated with presumptuously preparing for his wife's death.

Even though the three month check-up had passed, *suspecting* behaviors continued. Some wives found abnormalities, and husbands began to worry in earnest. One informant, whose wife found a breast lump, "prepared for the worst" only to have "it turn out well." Others reassured their wives, telling them to go back to physicians they trusted. One informant, whose wife found "lumps on her neck," examined these, became worried and acted. The couple went to the physician who offered medication for stress headaches, implying the symptoms were the wife's fault and not due to any disease progression. Although the physician did not positively diagnose their suspicions, he did suggest more chemotherapy. In this case, *finding out* was very subtle, and *facing the fact* was made more difficult. The physician was not perceived as being truthful. Some experienced existential concerns about death. These concerns were often due to the increased knowledge acquired going through the chemotherapy process, such as, learning that metastases always occurs prior to death.

Acting out in response to hearing something unexpected from the physician caused anxiety for one husband. His wife isolated herself more than before and withdrew into her own "world." He tried to *second-guess* her responses in order to understand

them. *Worry* was evident in concerns about a missed treatment, its effect on the cancer, his responses to his wife's moods and how he could implement strategies to cope with recurrence. Strategies included *preserving self* and considering the future, his changing lifestyle and relationships with others and his own emotional turmoil. One wife became angry, and the husband let her decide about further chemotherapy, although he had no doubt she would return for chemotherapy. He rationalized her anger toward the cancer was being displaced on the physician and tried to implement strategies to facilitate her decision for further chemotherapy.

Sometimes the first exposure to chemotherapy was as a treatment for recurrence. One informant described the "process of emotional letdown" he experienced during chemotherapy. He felt that the worst part of the experience, which lasted six years, was during the *struggle with suffering* stage even though chemotherapy prolonged life for another year.

Remission, or cessation of the cancer progression, was a great relief. One informant said, "It felt as if a great burden had been lifted off of our shoulders." Another informant described remission being as good as a cure. Living with uncertainty and waiting became integrated into day-to-day living. Looking to others for inspiration took on new meaning as informants were hopeful of controlling the disease.

Multiple Recurrence

Being informed by the telephone was helpful for those finding out about recurring cancer. The underlying assumption was that the informant would tell his wife about the extent of her disease. For one informant, this approach allowed him to express disappointment privately before telling his wife, and he felt better prepared "to handle it." He felt he could tell his wife in a more humane manner than the physician because he could tell her when, where and how he wanted, and this allowed him to maintain control of the situation.

Even though the "ring of familiarity sounded [on being informed]," the response was still one of devastation and despair. Although informants felt "better equipped" knowing what to expect and what to do, the response of shock and fear never lessened. Some stated that they were better equipped because they had not gone directly from surgery into chemotherapy. Others described being able to accept the disease more readily because they had been through the fight before and lived with it longer. One was never prepared because the experience was never the same. The fear of death was just as acute. Acquired coping skills, learned during the period of reprieve since initial chemotherapy, included the need to be more assertive when asking questions about the disease.

Witnessing a couple whose cancer had returned was difficult and made one realize that "it could end at any time, without warning" and "nothing was guaranteed about remission." Husbands wondered why some cancers retreat while others advance: "Was their cancer going to retreat?" Previous success with recurrence was motivating. Informants expressed a "hardening," which increased with each recurrence: "I am hardening myself to accept the fact that she might not be here. I can not say that I am giving up because we keep fighting every day." The hardening was preparing to "get ready" for the day when cancer recurred.

Often, chemotherapy became "magic medicine" and was no longer feared because "it gave my wife years longer than we expected her to have." Another informant thought his wife was coming out of remission and was told by a nurse "it's a lot harder to get into remission the second time, and even if you do, it does not usually last very long." He could not bring himself to tell his wife, and he carried this burden of information alone. Informants expected that "someday" the cancer would not be controlled. Although each recurrence was "different," they went through the same process again:

I don't see how you could learn anything about how to control your emotions or how you are feeling. You are going to feel what I feel, absolutely devastated, no matter how many times you go through it. It's not something you ever get used to, that is, in the sense that it would be easier the second time around. I'm human, I'm not a machine. I'm not dealing with mechanical duplication, I'm also dealing with emotions.

If you felt a certain way the first time around, it's not going to be easier just because you have been there once. You can't say I've been through it once, so the second time is easier. Could even be the second time is harder because now you are a person who has a tendency to preconceive the facts as they were.

Once a success had been achieved, one became more committed to *being positive*, hopeful and living day-to-day: "As her treatments worked, we would recognize it working. We would say let's not get morbid. Let's stay alive. Let's stay alert. We'll keep going. We'll keep making plans." The philosophy remained "we will deal with that when we come to it" because they did not want to ruin "today."

There was a different emphasis placed on the phases of enduring: "We're just over the shock again, and getting back into the fighting mode. We are trying to talk about it a lot, and face the facts." Diagnostic tests were not as important. One husband was not as aggressive about getting test results because he dreaded them and avoided *facing the fact*. Another, whose wife refused to attend the physician's interpretation of diagnostic tests, went to get the test results alone. Taking them home to his wife was hard because they had always received the results together.

Informants emphasized *orienting to the future* and *being positive* more than before. They considered "what it was going to be like without her," especially when children were present in the family. One informant became less committed, decreased his help and withdrew into himself; whereas, other informants remained committed. Thus, recurrence was a time for re-evaluation of their commitment to endure the chemotherapy.

Emotions were close to the surface, and informants recognized their need to let

them "overflow, when by themselves." Stress was incredible while informants waited for test results and for physicians to determine "how to fight" or to initiate the treatment. Trust in the physician's judgment was crucial to emotional adjustment. Informants needed to feel confident and secure in what the physician said about the control of the disease progression with chemotherapy. One of the most anxiety-provoking situations was when the blood count was not high enough to allow chemotherapy, while without chemotherapy, the cancer continued to grow.

Talking about dying was taboo: "I never wanted to admit it, but deep down I did. We never talked about it." One informant, whose wife became progressively sicker, remembered questioning the efficacy of treatment. His wife had given him her chemotherapy schedule, and he replied, "I don't think we are going to go." She told him "you have nothing to say about this." He felt rebuked and guilty saying to himself, "She is right." He learned to disguise his responses after that. Another, whose wife endured repetitive chemotherapy, related, "I worried, at home or whenever we were together. We did not talk about it, but it was constantly on our minds."

Several factors influenced the husband's ability to implement strategies. These included the number of recurrences, the length of time between recurrences and the length of time the disease had been progressing. As the length of the cancer experience and the frequency of recurrences increased, informants found it more difficult to remain "positive." They became more introspective when the physician or the wife implied a lack of "positiveness" about controlling the disease. Husbands were grieving while trying to maintain the outer facade of *being positive*.

Informants began "conserving energy" because they were fearful their wives were dying. They wanted to be ready to deal with the crisis of death. They began to surmise what it would be like and thought of plans they might have to initiate. They were ambivalent about secretly *getting ready*, but they knew they had to *resist disruption* if

they were going to be helpful. Husbands were fearful of their wives dying and felt guilty as they tried to make concrete plans to prepare: "Maybe I shouldn't be thinking about these things". Negative thoughts prevailed, and they worried about "becoming more positive." One informant said, "I don't know how I would be able to handle it if I was all by myself, that is, if my wife was not able to keep fighting." They really did not want to think about this until they had to, but that was almost impossible to do: "I was worried about my wife dying. I thought about how I would cope." Many coped by *keeping busy* and by helping others endure the battle. Others said that their feelings changed for the better due to the personal strength they had developed to overcome this "horrible experience." They never resolved "why" their wives had to go through this "punishment," and many remained angry, believing chemotherapy to be worse than the disease.

Concrete strategies included gathering more information. When acquiring knowledge, spouses depersonalized the illness, which helped control emotional response in the presence of each other. The initiation of treatment and establishment of treatment routine offered security. Hope, inherent in either initiating or continuing treatment, offered longevity and enhanced *being positive*. *Being positive* was related to how one lived life and what they did to resist giving up, while *being hopeful* was related to the attitude one had toward controlling the disease and longevity. Thus, one could be positive without being hopeful.

What did husbands fear?

Informants feared *giving up* the fight because they did not want to lose their wives and believed the loss of their wives would be "absolutely and completely devastating." They feared watching their wives die or suffer with pain. They feared the "emptiness" that would be left when their wives succumbed to cancer. They feared for their families and how they would manage. The greatest fears for husbands were the loss of hope

and of *being positive* because they were afraid their wives would notice and be adversely affected.

SUMMARY OF FINDINGS

The experience of husbands whose wives undergo chemotherapy is best understood as a three stage process: the threat, the fight and the emergence as a veteran. Throughout this process, husbands engage in buffering behaviors designed to be protective and supportive. Buffering is a process with which husbands deliberately assess actual or potential harm to their wives and then cognitively plan and implement strategies designed to buffer and maintain the well-being of their wives.

The Threat

The "total" shock, fear and loss of control associated with the diagnosis of cancer is devastating. The "wait and watch" approach by some physicians illustrates the helplessness the informants of this study were forced to accept. Gaining control began as a paramount strategy to deal with the cancer experience. As well, the paradox of playing it safe and entertaining thoughts of *guarded optimism* began. Informants did not want to oppose the wishes of their wives or the physician, but they experienced doubt about their wives' ability to live with cancer. The buffering process began as husbands worried that their wives would sense the depth of their sadness and the doubt and uncertainty they had about the outcome of the cancer experience. Informants described "mirroring" their wives anxiety, and the stress informants experienced in this life-threatening situation is clearly evident.

Informants began waiting, but the emphasis in this stage of the process was on responding to the confirmed diagnosis of cancer. They desperately tried to gain control by acquiring knowledge and making sense of or rationalizing the situation. The

helplessness the informants felt due to the situation was expressed as anger.

The Fight

Admitting to the diagnosis and deciding to fight provided informants with a sense of control. They believed they could help, but *guarded optimism* was always present. They were afraid to be too hopeful and compensated by becoming obsessed with the struggle to endure their wives' chemotherapy. During the fight, the desire of husbands to exhibit self-control and some measure of situational control was an underlying theme. As husbands struggled to buffer the effects of chemotherapy for their wives, they also struggled to maintain control of their own feelings of helplessness. Being kept *in the dark* and the informants' perception of the lack of communication with their wives and with health care providers exemplified their feelings of helplessness and powerlessness. In most cases, informants had to learn to accept the lack of control and devise strategies to accommodate the situation.

To some degree, sadness and fear were always present. With their ability to defer their own expression of emotion and focus on buffering, informants displayed tremendous self-control. They assumed a passive role, especially when the effects of chemotherapy were most dramatic. While this role had a buffering function, it also allowed them to hide their own suffering. Although the informants only discussed issues related to dying when their wives introduced such topics, they certainly thought about them. A conspiracy of silence surrounded dying as neither spouse initiated or discussed the "worst scenario" related to cancer. The *doer* role helped informants focus on the wife and reduced the stress caused by high self-expectations and guilt.

Several factors were potentially debilitating for informants. They were overwhelmed by compassion and empathy for their wives, and in most cases, the marital relationship became closer and stronger. Along with this, the informants' sense of responsibility increased self-expectations, and this stressed informants to the point

where they were fearful of disappointing their wives or not being equal to their wives' admirable response to chemotherapy treatment. Informants were constantly fighting feelings of guilt created by being the healthy bystander watching the effects of chemotherapy. Their wives' mood swings and nausea were the most disturbing emotional and physical effects for husbands to endure, and the lack of socializing and loneliness were frequently mentioned lifestyle effects. Part of the loneliness was self-inflicted as informants rarely shared their concerns, feelings or emotional responses with anyone. They spent the majority of their time working or at home. Informants were left to engage in solitary events when wives were ill or sleeping. Some found this aspect of the experience lonely and socially isolating.

In order to acquire control, for example, to make appropriate decisions based on adequate knowledge, informants felt they must be knowledgeable about the kind of cancer their wives had and the progress of cancer growth. Their ability to cope was dependent on the information they were able to acquire. Often, due to the attitude of health care providers and their wives, access to information was blocked and sometimes completely inaccessible.

Many coping strategies were planned and implemented. Strategies functioned as buffers, such as, those designed to *soften the blow* or *resist disruption*. Without the maintenance strategies included in *preserving self*, the buffering process would have been ineffective. That informants recognized the importance of these behaviors was a strength, but their inability to talk with others about their anger, fears and concerns appears to have been detrimental to their ability to adapt to such a stressful situation. Informants may have overcompensated with keeping busy and focusing on their wives in order to deny these feelings, but the feelings always came back to haunt them during quiet moments. Some wished they had been able to talk to someone else, an outsider, and recognized that remaining silent was impeding their ability to cope with the cancer

experience. Denial and the philosophy of live for today and not tomorrow seemed to be the essential ingredients in *being positive*. *Being positive* was the philosophical basis of day-to-day lifestyle and revealed an effort to overcome the paradox of *guarded optimism*. *Being positive* incorporated trust and hope in the efficacy of chemotherapy. Unfortunately, *being positive* was often enacted with considerable effort because of the constant awareness that chemotherapy might not be successful in eradicating their wives' cancer.

The Veteran

Although informants described relief and happiness when the chemotherapy was over, they were also doubtful and fearful about the progress of the disease. The perceived lack of positive feedback from health care providers was detrimental. They had to continue to generate *being positive* for both their wives and themselves, and they experienced a serious lack of energy. Without the *doer* role to keep them physically active, many felt lost for something to do. They had focused all their energy toward buffering and this changed as wives became more independent. The change was disturbing and puzzling as informants re-evaluated their role. Anger began to be expressed. As had been too occupied before to actually think about what the cancer experience meant to them, some felt this was the time of accepting the reality of their wives' cancer. Thus, in order to accept the illness, it had to have a personal meaning for them, and this could not be determined without time, thought and a less stressful environment. They needed to find something positive that evolved out of the experience. Often this was reflected as a growth in themselves and in the way the world around them was perceived. As they considered themselves experts, many wanted to become involved in helping others experiencing chemotherapy treatment for cancer.

Recurrence

Recurrence restarted the process of the threat, the fight and the emergence of the veteran. Although "better equipped" about what to expect, the total devastation and loss of control recurred. Metastases was feared because it was synonymous with death. Death was a topic which was never discussed between spouses and this was a very stressful time for informants as they desperately tried to think positively and *second-guess* their wives responses. Worry was evident but not discussed. Waiting began again. Test results became pivotal milestones upon which decisions were made for further chemotherapy. It was a relief to begin chemotherapy again because it meant the cancer was being treated, thus, hope was still alive. Informants became "hardened" to thinking about the future without their wives, but they never liked the idea. They did not feel as guilty thinking of the future because it was becoming a short-term reality. Perhaps because they had become so energy depleted and could not deny their own feelings anymore, informants were more aware of their need to conserve energy. They were forced to step out of their long-standing plan of strategy of living day-to-day and *being positive* and became vulnerable.

Hypotheses Generated for Further Research

From the preceeding data and interpretation, the following hypotheses were identified:

1. Husbands who assume the passive, submissive, one-down position during chemotherapy are more likely to feel isolated, lonely, confined and depressed.
2. Husbands who express *guarded optimism* are less hopeful.
3. Husbands who exemplify buffering behaviors will express more perceived control of the situation and appear less powerless.
4. Husbands who are adequately informed will be less anxious.
5. Husbands who verbalize their fear will perceive more situational control and express more guilt.

VII. DISCUSSION

The findings in this study represent the first time the experience of husbands whose wives have undergone chemotherapy for cancer has been documented and specific stages of development identified. These findings have then been juxtaposed to the progressive stages of cancer and the treatment modality of chemotherapy (see Figure 1).

In this chapter, the method of grounded theory is discussed as well as the strengths and limitations of the two interview methods. Implications for nursing practice and nursing research are suggested.

Evaluation of Method

Grounded Theory

The method of grounded theory facilitated the generation of a three stage theory depicting the process through which husbands experienced chemotherapy as a treatment for their wives' cancer. The method allowed the interviewer the flexibility to fully explore and understand the husband's experience because interviews continued until one was satisfied with the richness of the data and the saturation of categories. The exciting challenge of constantly comparing findings across informants was enhanced by the freedom to use creativity along with inductive and deductive reasoning to elicit more information and to ask the "right" questions.

The questioning techniques were important because data were self-reported. The validity of the research was dependent on the intensity and accuracy of the self-report. The use of repetitive interviews and effective questioning techniques enhanced the creative and reasoning skills of the interviewer. While saturating categories, opposing views were considered as well as constantly looking for the rationale to explain behaviors. Hence, the evolving theoretical framework fit the descriptions provided by

informants. The strength of the grounded theory method was in the goodness of fit between the process depicted in the theory and the data obtained through interviews.

The use of constant comparison, an adequate sample size and repetitive questioning over several interviews with informants increased the validity of the findings. The use of informants who had previously experienced chemotherapy served to enrich the data because the interviewer had the opportunity to verify findings between those describing chemotherapy from the retrospective perspective and those describing chemotherapy from a current perspective.

The findings were exploratory and lent themselves to further research. This method made no attempt to quantify data, and the findings obtained with this particular sample will not be replicated exactly by another investigator. However, the grounded theory method lent itself to the generation of hypotheses which can be tested in future studies. Depending on the research questions, further qualitative or quantitative methods may be used to gather more data to extend the existing theory. For example, if one wanted to question the incidence of *guarded optimism* with husbands whose wives are receiving chemotherapy, a survey method may be appropriate.

Interview Method

The assumption that the use of two interviewing methods, those of face-to-face and telephone, would expand the richness of the data obtained by the interview was not as expected. The information shared by informants in this study was highly emotional. The telephone interview method offered a means of sharing the experience while maintaining control through anonymity.

Face-to-Face

Contrary to expectation, face-to-face interviews were more difficult to arrange, shorter in length and less productive in terms of the depth of discussion and variety of topics. Although informants were friendly and eager to tell their story, it took longer to

gain their trust. They were nervous and intimidated, particularly when they became emotional during the interview. When this occurred, the informant changed the topic of discussion and valuable data was lost, while dross (information not relevant to the topic being studied) increased. The method of grounded theory assumes constant comparison of data across informants. This was difficult as some informants became emotional and changed the topic or refrained from talking about certain emotional issues. In view of the results of this study concerning the need for informants to control their emotive responses with wives, this finding was not surprising. The consistency of information obtained varied within the individual interview but was validated during future interviews.

The investigator had to keep one eye on the tape recorder to make sure it was running properly and that the tape did not need to be turned or changed. This necessitated breaking eye contact with an informant who was already nervous and watching the interviewer for nonverbal cues. A nervous informant and interviewer made note taking difficult. Jotting down notes was a useful strategy during long discursive passages of dialogue. Note taking facilitated the skills of this interviewer in that one could listen more intently and formulate more meaningful questions based on pertinent information shared by the informant. For example, an informant may mention five different topics of conversation within one single dialogue, and the interviewer did not want to interrupt his train of thought by questioning during the dialogue. Therefore, questioning skills and resultant data obtained through interviewing was not as rich during face-to-face interviews as it was during telephone interviews.

A preparatory strategy was to prepare potential questions for each individual interview. These questions were formulated to probe areas of inconsistency, negative cases or data obtained from another informant. However, the use of prepared questions was difficult during face-to-face interviews. The questions could not be kept

in view of the interviewer because the paper on which the questions were written made the informant nervous. Informants acted as if it was a hidden agenda for the interview, and they waited for the interviewer's questions rather than telling their story.

Telephone

Telephone interviews provided the anonymity which gave informants permission to become emotional if they so desired. Informants had control of the setting in which the interviews took place. They did not have to feel self-conscious about losing control because they could disguise emotive responses. The issue of choice was important because the findings of this research have indicated that informants are really given very little option for controlling personal choice during the chemotherapy experience. The telephone interview gave informants the control to be emotional or not, and this option seemed to enrich the data as it widened the scope of information they were willing to share with the interviewer. The advantage of anonymity for the interviewer was that nonverbal cues, such as with the nervousness associated with the first interview, were not being picked up and possibly misinterpreted by the informant.

Telephone interviews minimized the time spent in travelling and allowed for more subjects to be interviewed in one day. In keeping with the findings, husbands did not want to spend time away from their work or their wives. The informants were willing to volunteer their experiences but were not willing to travel to the interviewer. The worry and logistics of finding a quiet private place to meet with informants was not necessary with the telephone method. Informants decided when the interview would be most private and advantageous for them. Thus, there were rarely interruptions during telephone interviews; whereas, during face-to-face interviews, interruptions were usual.

While both methods allowed self-disclosure, all of the informants using the telephone method of interview volunteered comments regarding their belief that

participation in the study was of personal benefit. These informants expressed their feeling of finally being given the opportunity to discuss all their concerns and feelings with someone who was listening in a nonjudgmental manner. Telephone informants stated that they had discussed topics during the interviews which they had not disclosed to anyone else. This was not indicated with the face-to-face informants. The telephone format seemed to ensure a therapeutic interaction with negligible risk for informants.

Although the face-to-face format was more threatening due to the informants' opportunity to observe both verbal and nonverbal cues, regardless of the method, the interviewer was nervous when interviewing a new informant. While nervousness abated after the initial interview, the face-to-face method continued to be more difficult when trying to project a nonjudgmental response to statements shared by informants. It was the contention of this investigator that the best format for data collection, using this sample of informants and with this interviewer, was the telephone interview format.

Critique of Findings

The discussion of the findings will focus on three major results: the husband's response of buffering, the changes that occurred within the marital dyad and the husband's response of fighting.

Buffering and the Changing Marital Dyad

When the family is viewed as a dynamic system, the emphasis is on the interrelatedness of family members and the mutual affect they project toward one another. The prime purpose of the family is to support its members (Northouse, 1986), which, along with the traditional protector role of the husband, supports the finding that informants want to buffer and protect their wives. When a change, such as an illness, occurs in the system, the family must make a compensatory response to adapt (Leahey & Wright, 1985). A family is able to create a balance

between change and stability through its ability to adapt (Wright & Leahey, 1984). For example, informants' roles were redefined to include tasks such as making meals or cleaning the home.

Normalcy is representative of the tendency families have to balance change and stability. When an illness disturbs the system, normalcy is altered, and after the temporary disturbance has passed, normalcy is restored. When an illness is prolonged, such as with chemotherapy, the disturbance to family stability becomes greater and more sustained, causing the family to shift to a new and different level of balance (Wright & Leahey, 1984). The family reorganizes and finds new strategies to create a balance between change and stability. Husbands in this study were in a state of constant change with very little stability because they never knew what reactions to expect from their wives. Developing and evaluating effective strategies to recreate normalcy was difficult. From the husband's perspective, another aspect of normalcy was that family members try to project themselves as "normal" and want others to perceive them as "normal." The findings of this study not only allude to normalcy being a "within family" phenomenon but it is also indicative of how the behavior of family members is interpreted by others outside the family system. Normalizing refers to behaviors an individual uses to continue what is perceived to be a normal life (Miller, 1983). The findings of this study indicate the process of normalizing to be a strategy used to maintain the facade of normalcy while hiding the husband's feelings of disruption.

The marital dyad is referred to as the spouse subsystem when considering family systems theory. According to Minuchin (1974), the spouse subsystem plays a role in supporting spouses and provides a resource for coping with stressors constantly affecting the family. The spouse subsystem has boundaries which protect it from other subsystem demands within the family which could disrupt its functioning. Although

husbands in this study were part of families in various developmental stages, the function of the spousal subsystem became very important. Husbands strengthened the spouse subsystem boundary in order to enhance buffering their wives to the point of excluding others. The spouse subsystem boundary became rigid and impermeable, which was confining and isolating for the husbands.

A dyadic relationship, such as the spousal subsystem, needs to experience balance with degrees of symmetry and complementarity based on equality of status for each partner (Wright and Leahey, 1984). Husbands in this study tended to take a one-down position to their wives and relinquished a relationship of equal status. Husbands let wives take the position of providing instructions and husbands took the role of *doer*. This relationship was not satisfying because of the lack of reciprocity. As chemotherapy progressed, couples became more attuned to coping with the effects of chemotherapy and varying degrees of complementarity and symmetry were established. However, the lack of reciprocity continued to be present during the time wives experienced the most disruptive side effects. This investigator hypothesizes that the *taking charge* behavior of husbands was a response inherent in re-establishing symmetry after the effects of chemotherapy had subsided. Husbands also felt that they mirrored or reflected the responses of their wives, and this is supported by the concept of circular causality (see also Minuchin, 1974). This reciprocal pattern between spouse and patient was also noted by other researchers (Klein, Dean, & Bogdonoff, 1967; Neuhring & Barr, 1980).

The Fight

Neither the fight nor the imperative strategy of *being positive* have been noted in the cancer literature reviewed by this investigator. Although spouses have been interviewed, their responses have been grouped and quantified according to the existing theoretical frameworks, such as, grief theory. The fight will be considered in terms of

powerlessness, hope, advocacy and victimization.

Powerlessness

Helplessness has been described as "the perception that one's own actions will not significantly affect an outcome" (Miller, 1983, p. 38). This powerlessness is situationally determined and different from the stable personality trait of locus of control. Coping strategies may vary depending on the locus of control of the individual and the perceived degree of personal control one has to affect the outcome of the situation. Therefore, determining the personal meaning of control for individuals, that is, whether the individual sees the control of the situation dependent on the situation itself or why the situation occurred, is important. Although husbands considered why cancer afflicted their wives, they were not preoccupied with this and chose to concentrate on the situation of their wives' chemotherapy treatment for cancer and how to buffer her from the effects of the chemotherapy.

While personal control has been a focus in the literature on patient response (Lewis, Haberman, & Wallhagen, 1986; Lewis, 1982; Slaby & Glicksman, 1985; Werner-Beland, 1980), the consideration of control for the well spouse has not been considered. Werner-Beland (1980) illustrates the need to control as a response to the helplessness felt by someone with chronic illness. A similar struggle seems to be apparent for the husbands in this study.

Informants who had a sense, or an illusion, of control were less anxious. An illusion of control was created through the use of behavioral, cognitive and decisional strategies similar to those specified by Averill (1973). In some cases, such as, when the threat was perceived to be less harmful, these strategies were beneficial in creating control of the situation. However, many husbands experienced learned helplessness as they endured the repetitive unpredictability of their wives' response to chemotherapy.

Helplessness has been described as a syndrome which mimics depression and

represents a failure of mental coping mechanisms (Miller, 1983). This description supports the finding that husbands reported signs of clinical depression and loneliness during those times when the chemotherapy side effects were the most debilitating for their wives. The results of this study also indicate situations within which husbands expressed feeling both powerless and in control simultaneously. Although contrary to the literature, the occurrence of perceived personal control of the situation along with powerlessness to control the disease outcome seemed to motivate informants to fight harder.

Hope

"Hope" is the Thing with Feathers
That perches in the soul
And sings the tune without the words
And never stops
At all.

Emily Dickinson, Life 32 from Part 1, Life XXXIII

Hope is an intrinsic component of life and a valued, private and powerful resource for decreasing powerlessness (Miller, 1983). Hope is anticipating the future and having something to look forward to (Hickey, 1986; Hinds, 1984). Hope restores power and is a potent aspect affecting how one maintains a positive attitude (Miller, 1983). Conversely, hopelessness is a barrier to optimal quality of life and growth (Brandt, 1987). Hope has been referred to as an emotion, an expectation, an illusion and a disposition (Miller, 1985). Hope nurtures and is the salient quality of a "survivor" attitude (McGee, 1984). Hope is the ingredient that enables an individual to move from a state of weakness and vulnerability to a state of growth, with the ability to live as fully as possible (McGee, 1984; Miller, 1985). Hope is highly subjective (Breznitz, 1986; Bruss, 1988), multidimensional and process oriented (Dufault & Martocchio, 1985). Dufault & Martocchio (1985) present six dimensions of hope:

affective, cognitive, behavioral, affiliative, temporal and contextual to demonstrate the dimensions and scope of hope. Hope is metaphorical and has been referred to as a protection, a bridge leading one from darkness to light, an intention without fear, a rewarding end in itself (in that, hoping reduces fear and worry, Breznitz, 1986). Thus hope becomes a means of coping with ongoing stress. The findings of this study indicate that hope is a significant feature of the fighting attitude of husbands.

Brandt (1987) found that women receiving chemotherapy exhibited low levels of hopelessness. The finding of this research indicates that hopelessness fluctuated with husbands and was always present to some degree in their feelings of *guarded optimism*. The paradoxical feelings associated with *guarded optimism* were certainly more frequent during those periods when wives were suffering visibly and for longer periods of time. Breznitz (1986) suggests that hoping can thrive concurrently with total helplessness in stressful situations. A degree of hopelessness was also evident in husbands' coping behaviors. Those who were more doubtful and least hopeful were those who were often unable to set future goals and represented the "giving-up-given-up" complex described by Engel (1968). The findings of this study indicate that the uncertainty, worry, doubt and anticipatory grief informants expressed were all affective behaviors indicative of hopelessness, and they reflect the feelings expressed in *guarded optimism*.

Husbands thought of hope in terms of cure or control of the cancer and of returning to their previous lifestyle. Vailliot (1970) believes that hope inspires someone "to be" through utilizing internal resources and the strength of others. Although strategies which the informants implemented to instill hope were similar to those described by Vailliot (1970), this view of hope is very different from that expressed by informants. The finding that what husbands were saying was not congruent with what they were doing warrants further investigation.

Hopelessness reflects a feeling of giving up (Miller, 1983). What is one giving up? Because husbands believed that hope was necessary for cure or control of the cancer, they believed that any indication of hopelessness would be admitting a loss of control for cure and admitting to impending death. Informants were aware that their wives were sensitive to their feelings and were fearful of reflecting any indication of hopelessness. Bruss (1988) supports this notion and states hopelessness can be more detrimental to the patient than the disease process itself. Husbands had to fight their own feelings of hopelessness and project hope constantly to their wives, and this became stressful and guilt provoking. Guilt was introduced with the initial awareness of *guarded optimism* because they were faced with their feelings of hopelessness and felt the need to hide these from their wives. It is this investigator's contention that informants had to constantly reinforce the need to fight, or be hopeful, as a motivation strategy for themselves as they continued buffering.

Advocacy

The buffering process involved the perception of an advocacy role. The findings indicate husbands wanted to be advocates for their wives, but they were incapable of fulfilling the role as defined by Kohnke (1982). That is, they never had the knowledge to inform their wives, to their own satisfaction, of what was involved with chemotherapy and cancer. The supportive aspect of advocacy represents what informants spent their energy and time trying to fulfill. In order to be supportive, husbands felt they had to be loyal and present in the home. In order to defend the decision to undergo chemotherapy, husbands had to fight to find efficacy in the treatment as they were constantly faced with the "horrible" undesirable side effects. Often husbands fell into the defending and rescuing position described by Kohnke (1982). The husbands believed their wives expected them to fight for them, such as, seeking out knowledge for them.

The traditional male role in the family is one of accepting responsibility for other family members. This self-responsibility was compounded for those who were feeling guilty. Guilt was most frequently a product of either hiding their feelings of helplessness and *guarded optimism* or for being "healthy" while their wives were "ill" and enduring the effects of chemotherapy. The increase in self-responsibility was evident in their determination to fight and endure alongside their wives.

Victimization

The literature on victim blaming can be used to support the fighting attitude of husbands (Allison, 1982; Labonte & Penfold, 1981; Wikler, 1987; Wortman, 1983). Husbands believed that by helping their wives decide to undergo chemotherapy they assumed responsibility for the horrible side effects. The literature clearly implies the negative connotations that victim blaming can have for the decision-maker (Allison, 1982; Wikler, 1987). The husband, through his involvement in the decision-making process, internalized an awareness of the self-imposed risks in accepting the chemotherapy. The husbands also recognized that there was an aspect of individual choice for which he had to accept responsibility, regardless of the advice of the physician. Those husbands who assumed self-responsibility felt obligated to be loyal, protective and supportive, that is, to stay and help their wives. They felt responsible for taking on the fight with their wives, and this action is consistent with the literature. Some husbands shared ownership of the disease and the chemotherapy with their wives, which further illustrates their commitment to self-responsibility. Husbands had very little or no control over the situation of chemotherapy, but they perceived themselves to be partially liable for the effects of the treatment. In addition, the findings indicate husbands deviate from any aspect of self-interest and focus all their energy on helping their wives. This single-mindedness left no option but to persist in their determination to help their wives overcome the effects of the chemotherapy.

Implications for Nursing Practice

The findings of this research have several implications for clinical practice. The overall implication is that husbands whose wives are receiving chemotherapy for cancer need some assistance to cope more effectively with the cancer experience. This is not to say that these informants are coping ineffectively because the data indicates they do continue to function in socially acceptable ways at work and within the home.

However, husbands do experience a great deal of stress and anxiety, which makes them vulnerable to ineffective coping. Nurses can implement interventions to help husbands develop more effective coping strategies during their wives chemotherapy treatment for cancer.

The Threat

During the threat, consideration must be given to find means whereby husbands can assume more control in the prediagnostic and diagnostic periods. An effective strategy may be to find means of imparting the knowledge which the client feels in need of rather than what the health care provider thinks is appropriate. The findings indicate informants are overwhelmed with knowledge, but they still felt dissatisfied with what they were able to understand and retain. Perhaps husbands need to have the choice of seeking out a designated person with whom they can talk, either personally or by telephone, and discuss the questions to which they may be seeking answers. These findings indicate husbands may have an individual preference for one format and should have the option to choose.

While the current trend in nursing practice supports the holistic approach toward the patient and family, the findings of this research indicate that very few measures are taken to assess ~~serve~~ ^{serve} with husbands of patients receiving chemotherapy. These findings clearly indicate that the husband is influenced by his wife's chemotherapy treatment for cancer and is in need of support. Sources of individual and group support

may be helpful to impart knowledge and to get feedback concerning the successes of others who have had chemotherapy. However, one must keep in mind two factors.

The first is that husbands are concerned primarily about their wives and want to be with their wives. Husbands are not going to have the time or the motivation to be away from their wives for lengthy periods of time. Secondly, their knowledge of cancer is minimal. They need to know the basic terminology and the information concerning their wife's kind of cancer. Therefore, counselling must be individualized.

The Fight

Informants were tired and depleted of energy. They need positive feedback from health care providers, both physicians and nurses, and faster feedback from the diagnostic tests, which they perceived to be the most important indicators of disease progression and success with chemotherapy.

Spouses were not equal in their status or in their ability to support each other. Health care providers need to recognize these discrepancies in order to help those who are in need. During the fight, husbands experience a great deal of stress, which appears to relate to dealing with change. Everything in their environment is changing, and their only stability seems to be in the workplace. The findings indicate changes in marital sexuality and communication patterns along with unpredictable changes in wives' temperament and personality as they response to the chemotherapy treatment. Husbands are frightened to say anything, and as a result, they usually talk to no one. They do not know what to expect and are constantly vigilant, trying to assess the "right" way to respond. Nurses and physicians need to spend more time with husbands. Husbands will not initiate contact because they feel their wives should have priority. Therefore, nurses will need to initiate an assessment, perhaps on an ongoing basis during the times wives are receiving chemotherapy. The findings indicate that husbands tend to stay in the hallway rather than accompany their wives during

chemotherapy infusion. They feel out of place and do not usually talk to anyone else. They have indicated group sessions would not be helpful during the fight because the way in which they project themselves to others outside the family must be "normal." There is no doubt that husbands experience many stressors during the fight and that they deny their responses while focusing on those of their wives. There is a necessity for more planned attempts at offering support to husbands in the hospital setting during their wives chemotherapy treatments for cancer.

The findings indicate that the spousal conspiracy of silence, which limits communication concerning the future and issues of dying during the fight, had definite functions to buffer the stresses placed on both the wife receiving chemotherapy and her husband. Therefore, this should be respected and not tampered with. Instead, other outlets for husbands must be found because they indicated the need for discussion outside the marital dyad which could be labelled as legitimate by both spouses. Data indicates that men were more likely to talk with other men rather than with women. Keeping this in mind, nurses may use planned rather than chance opportunities to introduce husbands whose wives are in similar stages of chemotherapy. Given the option, husbands would then be able to decide how to use the peer as mentor or whether to become involved at all.

The Veteran

During the emergence as a veteran, informants were more relaxed because the chemotherapy was completed and they felt free to talk with others about their experience. This was a period of renewal when husbands reviewed their experience with chemotherapy and began to set new goals. Their fears and doubts were still present, but knowing the treatment was over and seeing their wives improving rapidly served as positive indicators of successful treatment. Informants described this as a time for accepting what had happened, which may be why they are able to talk about

the experience more easily. Some felt let-down, with a lack of energy and a feeling of being lost because they no longer had the *doer* role dominating their day-to-day lifestyle. This change was stressful and indicated the vulnerability of informants during this period of renewal. They are more ready to take advantage of group support during this stage as they are eager to help others and talk about their experiences. Those husbands who had taken early retirement to help their wives endure chemotherapy were particularly vulnerable, and nurses must become more attuned to assessing their need.

The findings indicate that the couple facing multiple recurrence should be offered assistance to help them discuss issues related to death and dying. They need help attempting to break down the wall of silence they have conspired to erect between them concerning these contentious issues. At this time, the possibility of dying becomes a reality that is painful to discuss because the future is growing shorter and they have no other choice but to try to talk about it. Having denied themselves the luxury of talking about issues surrounding dying for so long, the couple needs help to begin. For the husband, his worst nightmare was that of his wife succumbing to the disease, and he is very resistant to discussing this openly for fear it will happen. Waiting takes on a new dimension of anxiety and fear. Health care providers need to learn more about this aspect of the husband's experience because the findings of this study indicate these fears grow in magnitude while remaining just as difficult to talk about. Some informants described a "hardening," which is a defense husbands use to help them cope with the anticipation of losing their wives. The findings also indicate that staying hopeful and living day-to-day continue to be important for husbands. Perhaps at this time, more than any other, health care providers need to be aware of how these positive coping strategies can be enhanced.

Primary nursing should offer the patient and the husband planned and continuous guidance provided by one nurse from admission through discharge. The essential

elements of the primary nursing model are accountability, autonomy, coordination and comprehensiveness, and it assumes a more collaborative role with the physician (Hegyvary, 1982). If desired, the husband should be able to establish an ongoing, consistent and trusting relationship with the primary nurse. The primary nurse, present during the chemotherapy treatment, could talk privately with the husband at this time which would be more timely for the husband's needs. The primary nurse has the opportunity to tailor her/his skills of observation and communication to the needs of the husband. The husband would have the opportunity to ask questions and share his concerns. For example, the primary nurse would be able to identify the husband's need for more immediate feedback from diagnostic tests. In response to this, the primary nurse would collaborate more directly with the physician and assume responsibility for ensuring the communication of test results to the husband. Above all, she/he would get to know the patient and her husband, be able to interact with the husband as a person and be more sensitive to his vulnerability and his concerns. The primary nurse must be more attuned to the skills of active listening. The husband striving to maintain self-control will need a nonjudgmental listener who is not aggressively encouraging self-disclosure. He will need a primary nurse who is empathetic, willing to answer his questions and interested in his experience of his wife's chemotherapy treatment for cancer.

Waiting alone in the hallway during chemotherapy was found to be distressing. A specific room, such as a drop-in centre, should be available for husbands to meet and collaborate during the time their wives are receiving chemotherapy. This would allow those who find comfort in peer group support to become more self-directive. Husbands would have a specific place they could go to for quiet conversation, and they would not be left in the hallway feeling "in the way" while their wives receive chemotherapy. Instead of becoming more anxious watching others, husbands would

be given the opportunity to do something to reduce their own anxiety while continuing to accompany their wives to chemotherapy. While the peer group may not be the most effective way in which to help husbands during the fight, it has potential during the threat and the veteran stages. The comradery of the peer group may offer comfort to husbands throughout the chemotherapy experience in that it offers the opportunity to discuss issues with other husbands which they have been unable to share with their wives. It is also important that information for counselling services be more visible and available for husbands. A drop-in centre would be the ideal location for this type of information.

Since telephone interviews were proven to be an effective communication mode for husbands in this study, a telephone hot-line should be introduced for husbands whose wives were receiving chemotherapy. Volunteers should include those husbands who were retired and in the veteran stage, or whose wives had not survived. These husbands would be knowledgeable and experienced in the process of living with a wife who experienced chemotherapy treatment for cancer and their ability to empathize with those going through the process could be invaluable in meeting the needs of husbands such as those who volunteered for this study.

Implications for Nursing Research

The findings of this research provide new insights into the husband's fear throughout the chemotherapy experience. While some studies have focused on the meaning of the illness (Chekryn, 1984; Gotay, 1984; Howell, 1986; Parsons, 1977) for these informants, the meaning of fear must be delineated as it is clearly different and demarcated for each of the three stages of their non-patient experience of cancer chemotherapy. Once the meaning of fear has been described, additional study is needed to identify those factors which constitute adequate coping with their fear during

their wives' chemotherapy and to explore whether or not methods of coping can be predicted. This study should be replicated to include men with cancer who are receiving chemotherapy in order to determine if the response of their wives is similar to or different from husbands. It is possible that this type of study will show that fear influences the lack of control informants feel during this experience and that strategies for enhancing personal control should be designated for the individual rather than the situation.

The findings of this current study indicate spousal communication, particularly with setting long-term goals or issues related to dying, is minimal. Spouses do not share their feelings; instead, the well husband listens to his wife. When the wife is receiving chemotherapy, the communication between couples needs to be studied. Longitudinal follow-up is needed to clarify interaction during the three stages of the process. This would identify if any one stage is more stressful or obstructive to communication and what changes occur between stages as the cancer and the chemotherapy progress. This would also establish whether or not spouses are aware of the horror and devastation each is experiencing or if there are ways the nurse can help the husband or wife deal more readily with these responses. An untapped area of research concerns that of the family. For example, how do other family members interact with and respond to the husband whose wife is experiencing chemotherapy for cancer?

Valuable information can also be obtained from research using an experimental design. One variable which seems to influence the husband's response is his ability to express anger. An experimental design to evaluate husband response to counselling designed to explore feelings of anger would pave the way for the development of effective strategies to help husbands experience their wives' chemotherapy treatment for cancer. An experimental group would attend counselling, while a control group would experience chemotherapy without counselling. Also, the importance of studying

husband responses during the three separate stages delineated in this study should not be overlooked.

Generally the nurse was found to be insensitive to the needs of husbands experiencing their wives chemotherapy treatment for cancer. Future research needs to look at how nurses can interact with husbands in a more humanistic manner.

Summary

The findings of this study represent the first time the experience of husbands whose wives undergo chemotherapy treatment for cancer has been delineated into three stages (i.e., the threat, the fight and the veteran), and juxtaposed to the stages of the medical model of treatment for cancer. Grounded theory was used to analyze transcriptions of data obtained through the use of open-ended, unstructured interviews. The method allowed the interviewee to continue concurrent data collection and data analysis until categories were saturated and the evolving theoretical framework fit the descriptions provided by informants. When comparing the use of telephone and face-to-face interview formats, the telephone format was found to be the better format for data collection with this particular investigator and with this sample of informants.

The findings of this study contribute to the literature by exploring the experience of non-patient husbands as their wives responded to chemotherapy treatment for cancer. While experiencing ongoing unpredictability and constant change, varying degrees of helplessness were expressed by husbands during the three stages of their wives' chemotherapy experience. Helplessness was associated with fear and the lack of situational control. Husbands engaged in a process of buffering which acted to simplify and reduce the stress of day-to-day life for their wives and gave them a sense of situational control. They focused all their energy toward buffering strategies designed to protect their wives from the "horrible" effects of chemotherapy. Husbands

became very protective of their buffering role, and many resented any intrusion even from relatives or friends.

One of the most effective buffering strategies was *being there* because it was something both the husband and wife wanted. Husbands wanted to cherish and nurture. They recognized the danger of overdoing it with too many compliments or of hovering when wives were nauseous and ill after chemotherapy. Many believed they came to love their wives more and were surprised to learn wives needed to be told of their love more frequently. The buffering strategies of *normalizing* and *being positive* were stressful for husbands. They perceived they had to act "normal" with others and not walk around looking depressed. They had to "keep up a good front" because others would detect their sadness and avoid them. They had to appear positive and confident about winning the fight at all times because wives would sense anything less and become discouraged, with the potential of "giving up" the fight. Also, *being positive* was one of the only ways, along with the use of humor, that husbands were able to "pull" wives out of their unpredictable moods. These strategies were always juxtaposed with the fear that they were "fooling themselves" or setting themselves up for a bigger shock because they were not preparing themselves for the worst scenario, the death of their wives.

Husbands found themselves caught in the paradoxical situation of *guarded optimism*, in which they projected a positive attitude to their wives while wondering about the efficacy of being so positive. The paradox of playing it safe and having *guarded optimism* created stress. They did not want to oppose the wishes of their wives or speak of their doubt concerning the efficacy of the chemotherapy. They feared this would be detrimental and, in a sense, unfaithful to their wives. *Guarded optimism* has not been documented as such a powerful influence on the husband's behavior in previous research findings. This paradoxical phenomenon reappears in varying

degrees as he witnesses the effects of his wife's chemotherapy. In turn, husbands initiated the buffering process and worried that their wives could sense the depth of their doubt, sadness and uncertainty. Buffering was often the only action they could take to help their wives and, at the same time, gain situational control so that their own sense of helplessness abated. Husbands assumed a passive role and focused all thoughts and actions on their wives rather than expressing their own suffering, compassion and sadness.

The marital couple was bound in a conspiracy of silence, within which neither discussed issues surrounding dying or the future. Husbands wanted and needed to plan for the future, and so they planned secretly and alone. For most, the secrecy offered comfort and security, while others felt guilty, as if they were "giving up" on the thought of their wives getting well. Surprisingly, this conspiracy of silence also appears to inhibit any sharing of emotion. Many husbands rationalized that sharing emotion would be too upsetting or energy depleting and could adversely affect the fight. It was necessary to hide their own suffering in light of the suffering experienced by their wives. Therefore, the expression of their deepest emotions was kept private.

Husbands had high self-expectations as they admired their wives' response to the "horrible" effects of chemotherapy and they wanted to respond equally well. They experienced guilt at being the "healthy" bystander. Coping strategies were always evaluated in terms of their ability to buffer, and they willingly took a submissive one-down position in relation to their wives. Short-term planning was the norm because thinking of the future was taboo. The logical extension of this was to live day-to-day and develop a positive philosophy. Even though thinking of the future was taboo, this positive philosophy helped husbands stay hopeful. The findings suggest the most vulnerable period of time for husbands occurs when the chemotherapy is finally over. *Emerging as a veteran* created vulnerability because their *doer* role and the

buffering process were changing.

The most disturbing effect of chemotherapy for the husband was the unpredictable temperment and mood swings of his wife, a finding previously undocumented. Husbands were constantly amazed at how quick and drastic the mood changes could be, and they were never able to discern any predictable pattern. Nausea was an uncomfortable effect due to the sense of helplessness husbands experienced when listening to and watching the retching and vomiting experienced by their wives. Wives were always ill for some period of time after chemotherapy administration, and husbands felt responsible for staying home and close to their wives. The cancer experience often isolated the couple, and for some, the lifestyle changes associated with being isolated and lonely were particularly difficult. Surprisingly, husbands did not perceive hair loss as the worst effect of chemotherapy. Rather, they were more concerned with finding the "right" way to act in order to buffer their wives experience. All informants were proud of the determination, fortitude and strength shown by wives enduring the effects of the chemotherapy and concluded they did not think they could endure the suffering as well.

Maintaining self-control was mandatory to buffering. Talking about emotional responses threatened self-control and was believed to be a sign of weakness. Husbands believed wives expected and needed them to be strong, and they had to "try and keep back the tears" because crying was a sign of weakness. Several tried to share their feelings but found wives did not want to listen. Husbands described trying to avoid any emotional crisis was like walking a tightrope. Self-control was thought to be a precursor of the philosophy of positive thinking they adopted, and above all, husbands had to project themselves as *being positive*. Husbands rarely sought out someone to talk with, but when they did, they preferred someone they did not know, someone who was a good listener and a male rather than female. They did not talk to

others because talking meant divulging secrets and being unfaithful to their wives. Talking could potentially make one feel sorry for himself, lead to weakness and undermine self-control.

Husbands frequently lacked the knowledge they expected of themselves concerning the kind of cancer their wives had and the chemotherapy. Some felt they were kept vulnerable, deliberately *in the dark* and were placed in a situation of learned helplessness. They learned not to be too assertive and not to ask too much or they would be told even less by both wives and health care providers. Some reported feeling guilty asking questions or seeking support because they were the healthy ones, and health care providers should be spending their time with their sick wives. One of the most disturbing situations was when friends and acquaintances asked about their wives and they did not feel knowledgeable enough to answer properly. Afterward, the self-imposed pressure of "having to know" everything was recognized, but during the threat and early fight with their wives' chemotherapy, this was a major stressor for husbands. Sometimes husbands were ambivalent about "knowing." On the one hand, the more they knew the more frightened they were, while on the other hand, the more they knew the more they could anticipate and buffer for their wives.

Informants unanimously reported that marital bonds were strengthened through the chemotherapy experience even though some wives withdrew from their husbands into their own "sick world." All reported varying degrees of pain and sadness along with compassion for the suffering their wives were enduring. They did not like to see their wives suffer or cry. Thus, most informants would do anything to buffer the experience, even to the point of retiring from employment.

Husbands were problem solvers and felt comfortable in this role. They took care of their own health in order to be able to continue buffering the experience for their wives. This was the only way husbands could rationalize thinking of themselves during the

chemotherapy. When they did something enjoyable, something their wives could not do, they suffered guilt feelings. Many situations did not lend themselves to problem solving and, throughout the chemotherapy experience, waiting was one situation which most informants found intolerable.

The findings indicate husbands experience a great deal of stress, anxiety and fear, and they described being changed by their wives' chemotherapy experience. It was important that something good was rationalized out of such a terrible experience. Acceptance did not begin for husbands until the final stage of the process. Their reported readiness to accept was influenced by the experience of watching their wives suffer the horrible side effects of chemotherapy treatment for cancer. Husbands needed support in coping with the unpredictable responses of their wives and with their own lack of situational control. The implications for nursing practice and nursing research suggest the need to explore why nurses were unable to assist the husband in these endeavours. The primary nursing role is suggested to enhance effective nursing intervention helpful for husbands experiencing their wives' chemotherapy treatment for cancer. The findings indicate that the reality of the husband's experience cannot be ignored by nurses and that different nursing interventions are appropriate to assist husbands during each of the three stages of the process of living with chemotherapy. This qualitative study contributes to the paucity of research explicating the experience of the husband whose wife is living with and receiving chemotherapy. The findings exemplify a three stage theory depicting the husband's experience which should be utilized in further testing.

REFERENCES

- Abrams, R. D. (1966). The patient with cancer - his changing patterns of communication. *The New England Journal of Medicine*, 274, 317-322.
- Allison, K. (1982). Health education: Self-responsibility vs. blaming the victim. *Health Education*, 20(3), 11-13, 24.
- Asken, M. J. (1975). Psychoemotional aspects of mastectomy: A review of recent literature. *American Journal of Psychiatry*, 132, 56-59.
- Averill, J. R. (1973). Personal control over aversive stimuli and its relationship to stress. *Psychological Bulletin*, 80, 286-303.
- Averill, J. R. (1968). Grief: Its nature and significance. *Psychological Bulletin*, 70, 721-743.
- Baider, L., & De-Nour, A. K. (1984). Couples' reactions and adjustment to mastectomy: A preliminary report. *International Journal of Psychiatry in Medicine*, 14, 265-276.
- Baider, L., Rizel, S., & De-Nour, A. K. (1986). Comparison of couples' adjustment to lumpectomy and mastectomy. *General Hospital Psychiatry*, 8, 251-257.
- Baxley, K. O., Erdman, L. K., Henry, E. B., & Roof, B. J. (1984). Alopecia: Effect on cancer patients' body image. *Cancer Nursing*, 7, 499-503.
- Bell, J. (1987). *Psychosocial impact of breast cancer on the marital couple*. Paper presented at the 1987 International Nursing Research Conference, Washington, D.C., Oct 16, 1987.
- Bell, J. (1986). *The psychosocial impact of breast disease (benign and malignant) on the marital couple*. Unpublished doctoral dissertation, University of Calgary, Calgary.
- Bloom, J. R. (1982). Social support, accommodation to stress and adjustment to breast cancer. *Social Science and Medicine*, 16, 1329-1338.
- Bloom, J. R., Ross, R. D., & Burnell, G. (1978). The effect of social support on patient adjustment after breast surgery. *Patient Counselling and Health Education*, 1, 50-59.
- Brandt, B.T. (1987). The relationship between hopelessness and selected variables in women receiving chemotherapy for breast cancer. *Oncology Nursing Forum*, 14(2), 35-39.
- Breznitz, S. (1986). The effect of hope on coping with stress. In M. H. Appley & R. Trumbell, *Dynamics of Stress*, (pp. 295-306). New York: Plenum Press.

- Bruss, C. R. (1988). Nursing diagnosis of hopelessness. *Journal of Psychosocial Nursing*, 26(3), 28-31.
- Canadian Cancer Society. (1987). *Canadian Cancer Statistics 1987*. Toronto: Canadian Cancer Society.
- Chekryn, J. (1984). Cancer recurrence: Personal meaning, communication, and marital adjustment. *Cancer Nursing*, 7, 491-498.
- Christman, N. J. (1987, October). *Uncertainty, hope and psychosocial adjustment during radiotherapy*. Paper presented at the American Nurses' Association Council of Nurse Researchers International Nursing Research Conference, Washington, D.C.
- Cline, B. W. (1984). Prevention of chemotherapy-induced alopecia: A review of the literature. *Cancer Nursing*, 7, 221-228.
- Colombotos, J. (1969). Personal versus telephone interviews: Effect on responses. *Public Health Reports*, 84, 773-782.
- Coons, H. L., Leventhal, H., Nerenz, D. R., Love, R. R., & Larson, S. (1987). Anticipatory nausea and emotional distress in patients receiving cisplatin-based chemotherapy. *Oncology Nursing Forum*, 14(3), 31-35.
- Cooper, E. T. (1984). A pilot study on the effects of the diagnosis of lung cancer on family relationships. *Cancer Nursing*, 7, 301-308.
- Corbin, J. M., & Strauss, A. L. (1984). Collaboration: Couples working together to manage chronic illness. *Image*, 16(4), 109-115.
- Cotanch, P. H., & Strum, S. (1987). Progressive muscle relaxation as antiemetic therapy for cancer patients. *Oncology Nursing Forum*, 14(1), 33-37.
- Dodd, M. J. (1988). Patterns of self-care in patients with breast cancer. *Western Journal of Nursing Research*, 10(1), 7-24.
- Dodd, M. J. (1984a). Patterns of self care in patients receiving radiation therapy. *Oncology Nursing Forum*, 11(3), 23-27.
- Dodd, M. J. (1984b). Measuring informational interventions for chemotherapy knowledge and self-care behavior. *Research in Nursing and Health*, 7, 43-50.
- Dodd, M. J. (1983). Self-care for side effects in cancer chemotherapy: An assessment of nursing interventions - Part II. *Cancer Nursing*, 6(6), 63-67.
- Dodd, M. J. (1982a). Assessing patient self-care for side effects of cancer chemotherapy - Part I. *Cancer Nursing*, 5, 447-451.
- Dodd, M. J. (1982b). Cancer patients' knowledge of chemotherapy: Assessment and informational interventions. *Oncology Nursing Forum*, 9(3), 39-44.

- Dodd, M. J., & Mood, D. W. (1981). Chemotherapy: Helping patients to know the drugs they are receiving and their possible side effects. *Cancer Nursing*, 4, 311-318.
- Dracup, K. A., & Breu, C. S. (1978). Using nursing research findings to meet the needs of grieving spouses. *Nursing Research*, 27, 212-216.
- Dufault, K., & Martocchio, B. C. (1985). Hope: Its spheres and dimensions. *Nursing Clinics of North America*, 20, 379-391.
- Duigon, A. (1986). Anticipatory nausea and vomiting associated with cancer chemotherapy. *Oncology Nursing Forum*, 13(1), 35-40.
- Dyk, R., & Sutherland, A. M. (1956). Adaptation of the spouse and other family members to the colostomy patient. *Cancer*, 9(1), 123-138.
- Eardley, A. (1985a). Patients and radiotherapy: 1. Expectations of treatment. *Radiography*, 51, 324.
- Eardley, A. (1985b). Patients and radiotherapy 2. Patients' experiences of radiotherapy. *Radiography*, 51, 325-326.
- Eardley, A. (1985c). Patients and radiotherapy: 3. Patients' experiences after discharge. *Radiography*, 52, 17-19.
- Eardley, A. (1985d). Patients and radiotherapy: 4. How can patients be helped. *Radiography*, 52, 19-22.
- Edstrom, S., & Miller, M. W. (1981). Preparing the family to care for the cancer patient at home: A home care course. *Cancer Nursing*, 4(2), 49-52.
- Ekberg, J., Griffith, N., & Foxall, M. J. (1986). Spouse burnout syndrome. *Journal of Advanced Nursing*, 11, 161-165.
- Engel, G. L. (1968). A life setting conducive to illness: The giving up—given up complex. *Annals of Internal Medicine*, 69, 293-300.
- Epp, J. (1986). *Achieving health for all: A framework for health promotion*. Ottawa: Ministry of Supply and Services Canada.
- Fernsler, J. (1986). A comparison of patient and nurse perceptions of patients' self-care deficits associated with cancer chemotherapy. *Cancer Nursing*, 9, 50-57.
- Field, P. A., & Morse, J. M. (1985). *Nursing research*. Rockville, Maryland: Aspen.
- Flor, H., Turk, D. C., & Scholz, O. B. (1987). Impact of chronic pain on the spouse: Marital, emotional and physical consequences. *Journal of Psychosomatic Research*, 31(1), 63-71.
- Folkman, S., & Lazarus, R. S. (1980). An analysis of coping in a middle-aged community sample. *Journal of Health and Social Behavior*, 21(9), 219-239.

- Forester, B. M., Kornfield, D. S., & Fleiss, J. (1978). Psychiatric aspects of radiotherapy. *American Journal of Psychiatry*, 135, 960-963.
- Foxall, M. J., Ekberg, J. Y., & Griffith, N. (1985). Adjustment patterns of chronically ill middle-aged persons and spouses. *Western Journal of Nursing Research*, 7, 425-444.
- Frey, J. H. (1983). *Survey research by telephone*. Beverly Hills: Sage.
- Gates, C. C. (1980). Husbands of mastectomy patients. *Patient Counseling and Health Education*, 1, 38-41.
- Germino, B. B. (1984). *Family members' concerns after cancer diagnosis*. Unpublished doctoral dissertation, University of Washington, Seattle.
- Giacquinta, B. (1977). Helping families face the crisis of cancer. *American Journal of Nursing*, 77, 1585-1588.
- Glaser, B. G. (1978). *Theoretical sensitivity: Advances in the methodology of grounded theory*. Mill Valley: The Sociology Press.
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory, strategies for qualitative research*. Chicago: Aldine.
- Gloeckner, M. R. (1983). Partner reaction following ostomy surgery. *Journal of Sex and Marital Therapy*, 9(3), 182-190.
- Goldberg, R. J., Wool, M. S., Glicksman, A., & Tull, R. (1984). Relationship of the social environment and patients' physical status to depression in lung cancer patients and their spouses. *Journal of Psychosocial Oncology*, 2(3/4), 73-80.
- Goldberg, R. J., Wool, M., Tull, R., & Boor, M. (1984). Teaching brief psychotherapy for spouses of cancer patients: Use of a codable supervision format. *Psychotherapy and Psychosomatics*, 41, 12-19.
- Goldstein, V., Regnery, G., & Wellin, E. (1981). Caretaker role fatigue. *Nursing Outlook*, 29(1), 24-30.
- Gorden, R. L. (1980). *Interviewing: Strategy, techniques and tactics*. (3rd Ed.). Homewood, Illinois: Dorsey.
- Gotay, C. C. (1985). Why me? Attributions and adjustment by cancer patients and their mates at two stages in the disease process. *Social Science and Medicine*, 20, 825-831.
- Gotay, C. C. (1984). The experience of cancer during early and advanced stages: The views of patients and their mates. *Social Science and Medicine*, 18, 605-613.
- Grandstaff, N. W. (1976). The impact of breast cancer on the family. *Frontiers of Radiation Therapy in Oncology*, 11, 146-156.

- Grobe, M. E., Ahmann, D. L., & Ilstrup, D. M. (1982). Needs assessment for advanced cancer patients and their families. *Oncology Nursing Forum*, 9(4), 26-30.
- Hampe, S. O. (1975). Needs of the grieving spouse in a hospital setting. *Nursing Research*, 24(2), 113-120.
- Hart, K. (1987). Stress encountered by significant others of cancer patients receiving chemotherapy. *Omega*, 17(2), 151-167.
- Hegyvary, S. T. (1982). *The change to primary nursing*. St. Louis: C. V. Mosby Company.
- Hickey, S. S. (1986). Enabling hope. *Cancer Nursing*, 9(3), 133-137.
- 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.
- Hinds, P. S. (1984). Inducing a definition of "hope" through the use of grounded theory methodology. *Journal of Advanced Nursing*, 9, 357-362.
- Hinton, J. (1981). Sharing or withholding awareness of dying between husband and wife. *Journal of Psychosomatic Research*, 25, 337-343.
- Hinton, J. (1980). Whom do patients tell? *British Medical Journal*, 281, 1329-1331.
- House, J. S. (1981). *Work, stress and social support*. Reading, MA: Addison-Wesley.
- Howell, D. (1986). The impact of terminal illness on the spouse. *Journal of Palliative Care*, 2(1), 22-30.
- Hutchinson, S. (1986). Grounded theory: The method. In P. L. Munhall & C. J. Oiler, *Nursing Research, a Qualitative Perspective*, (pp. 111-129). Norwalk, Connecticut: Appleton-Century-Crofts.
- Jamison, K. R., Wellisch, D. K., & Pasnau, R. O. (1978). Psychosocial aspects of mastectomy. I. The woman's perspective. *American Journal of Psychiatry*, 135, 432-436.
- Janofsky, A. I. (1971). Affective self-disclosure in telephone versus face to face interviews. *Journal of Humanistic Psychology*, 11, 93-103.
- Karlsson, J. A., & Andersen, B. L. (1986). Radiation therapy and psychological distress in gynecologic oncology patients: Outcomes and recommendations for enhancing adjustment. *Journal of Psychosomatic Obstetrics and Gynaecology*, 5, 283-294.
- Kennedy, M., Packard, R., Grant, M. M., & Padilla, G. V. (1981). Chemotherapy related nausea and vomiting: A survey to identify problems and interventions. *Oncology Nursing Forum*, 8(1), 19-22.

- Kegeles, S. S., Fink, C. F., & Kirscht, J. P. (1969). Interviewing a national sample by long-distance telephone. *Public Opinion Quarterly*, 33, 412-419.
- King, K. B., Nail, L. M., Kreamer, K., Strohl, R. A., & Johnson, J. E. (1985). Patients' descriptions of the experience of receiving radiation therapy. *Oncology Nursing Forum*, 12(4), 55-61.
- King, T., & Taylor, C. (1987). The outpatient way. *Canadian Nurse*, 83(9), 23-25.
- Klagsbrum, S. (1983). The making of a cancer psychotherapist. *Journal of Psychosocial Oncology*, 1(4), 55-60.
- Klein, R. (1971). A crisis to grow on. *Cancer*, 28, 1660-1665.
- Klein, R. F., Dean, A., & Bogdonoff, M. D. (1967). The impact of illness upon the spouse. *Journal of Chronic Diseases*, 20, 241-248.
- Knafl, K. A., & Deatrick, J. A. (1986). How families manage chronic conditions: An analysis of the concept of normalization. *Research in Nursing and Health*, 9, 215-222.
- Kohnke, M. F. (1982). *Advocacy, risk and reality*. St. Louis: C.V. Mosby.
- Krant, M., & Johnston, L. (1978). Family members' perceptions of communications in late stage cancer. *International Journal of Psychiatry in Medicine*, 8, 203-217.
- Kristjanson, L. J. (1986). Indicators of quality of palliative care from a family perspective. *Journal of Palliative Care*, 1(2), 8-17.
- Kubricht, D. W. (1984). Therapeutic self-care demands expressed by outpatients receiving external radiation therapy. *Cancer Nursing*, 7(1), 43-52.
- Labonte, R., & Penfold, S. (1981). Canadian perspectives in health promotion: a critique. *Health Education*, 19(3-4), 4-9.
- Lauer, P., Murphy, S., & Powers, M. J. (1982). Learning needs of cancer patients: A comparison of nurse and patient perceptions. *Nursing Research*, 31(1), 11-16.
- Lazarus, R. S., & Folkman, S. (1986). Cognitive theories of stress and the issue of circularity. In M. H. Appley & R. Trumbull, *Dynamics of Stress*, (pp. 63-80). New York: Plenum Press.
- Lazarus, R. S. (1966). *Psychological stress and the coping process*. New York: McGraw-Hill.
- Leahey, M., & Wright, L. M. (1985). Intervening with families with chronic illness. *Family Systems Medicine*, 3(1), 60-69.

- Leiber, L., Plumb, M. M., Gerstenzang, M. L., & Holland, J. (1976). The communication of affection between cancer patients and their spouses. *Psychosomatic Medicine*, 38, 379-389.
- 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. (1982). Experienced personal control and quality of life in late-stage cancer patients. *Nursing Research*, 31, 113-119.
- Lewis, F. M., & Bloom, J. R. (1979). Psychosocial adjustment to breast cancer: A review of selected literature. *International Journal of Psychiatry in Medicine*, 9(1), 1-17.
- Lewis, F. M., Haberman, M. R., & Wallhagen, M. I. (1986). How adults with late-stage cancer experience personal control. *Journal of Psychosocial Oncology*, 4(4), 27-42.
- Lichtman, L. R., Taylor, S. E., & Wood, J. V. (1988). Social support and marital adjustment after breast cancer. *Journal of Psychosocial Oncology*, 5(3), 47-74.
- Lichtman, R. (1982). *Close relationships after breast cancer*. Unpublished doctoral dissertation, University of California, Los Angeles.
- Lindemann, E. (1944). Symptomatology and management of acute grief. *American Journal of Psychiatry*, 101, 141-148.
- Lovejoy, N. C. (1986). Family responses to cancer hospitalization. *Oncology Nursing Forum*, 13(2), 33-37.
- Maguire, P. (1981). The repercussions of mastectomy on the family. *International Journal of Family Psychiatry*, 1, 485-503.
- McCorkle, R., & Benoliel, J. Q. (1983). Symptom distress, concerns and mood disturbance after diagnosis of life-threatening illness. *Social Science and Medicine*, 17, 431-438.
- McCorkle, R., & Donaldson, G. (1986). Anticipatory grief in persons newly diagnosed with life-threatening disease. In G. Hongladarom & R. McCorkle (Eds.), *Issues and topics in cancer nursing*, (pp. 207-223). Norwalk, Connecticut: Appleton-Century-Crofts.
- McGee, R. F. (1984). Hope: A factor influencing crisis resolution. *Advances in Nursing Science*, 6(4), 34-44.
- Miller, J. F. (1985). Hopefulness. *American Journal of Nursing*, 85, 23-25.
- Miller, J. F. (1983). *Coping with chronic illness*. Philadelphia: F. A. Davis.
- Miller, M. W., & Nygren, C. (1978). Living with cancer - coping behaviors. *Cancer Nursing*, 2, 297-302.

- Minuchin, S. (1974). *Families and family therapy*. Cambridge, MA: Harvard University Press.
- Morris, J., & Royle, G. T. (1988). Offering patients a choice of surgery for early breast cancer: A reduction in anxiety and depression in patients and their husbands. *Social Science and Medicine*, 26, 583-585.
- Morse, J. (1988). The ethics and purpose of qualitative nursing research. *Western Journal of Nursing Research*, 10, 213-216.
- Morse, J. (1986). Quantitative and qualitative research: Issues in sampling. In P. Chinn (Ed.), *Nursing Research Methodology: Issues in Nursing*, (pp. 181-191). Maryland: Aspen.
- Neuhring, E. M., & Barr, W. E. (1980). Mastectomy: Impact on patients and families. *Health and Social Work*, 5, 51-58.
- Norris, J. R. (1986). *The experience of mothers consenting for daughters' abortions*. Unpublished master's thesis, University of Alberta, Edmonton, Canada.
- Northouse, L. L. (1988). Social support in patients' and husbands' adjustment to breast cancer. *Nursing Research*, 37, 91-95.
- Northouse, L. L. (1986). *A study of the psychosocial adjustment of patients and spouses to breast cancer*. Unpublished doctoral dissertation, University of Michigan, Ann Arbor.
- Northouse, L. (1981). Mastectomy patients and the fear of cancer recurrence. *Cancer Nursing*, 4, 213-220.
- Northouse, P. G., & Northouse, L. L. (1987). Communication and cancer: Issues confronting patients, health professionals, and family members. *Journal of Psychosocial Oncology*, 5(3), 17-46.
- Northouse, L. L., & Swain, M. A. (1987). Adjustment of patients and husbands to the initial impact of breast cancer. *Nursing Research*, 36, 221-225.
- Oberst, M. T., & James, R. H. (1985). Going home: Patient and spouse adjustment following cancer surgery. *Topics in Clinical Nursing*, 7(4), 46-57.
- Panzarine, S. (1985). Coping: Conceptual and methodological issues. *Advances in Nursing Science*, 7(4), 49-57.
- Parkes, C. M. (1975). The emotional impact of cancer on patients and their families. *Journal of Laryngology & Otology*, 89, 1271-1279.
- Parsons, J. P. (1977). A descriptive study of intermediate stage terminally ill cancer patients at home. *Nursing Digest*, 5(2), 1-26.
- Peck, A., & Boland, J. (1977). Emotional reactions to radiation treatment. *Cancer*, 30, 180-184.



- Peters-Gordon, H. (1982). Breast cancer: Varied perceptions of social support in the illness experience. *Social Science and Medicine*, 16, 483-491.
- Pfefferbaum, B., Pasnau, R. O., Jamison, K., & Wellisch, D. K. (1977). A comprehensive program of psychosocial care for mastectomy patients. *International Journal of Psychiatry in Medicine*, 8(1), 63-72.
- Quinn, M. E., Fontana, A. F., & Reznikoff, M. (1986). Psychological distress in reaction to lung cancer as a function of spousal support and coping strategy. *Journal of Psychosocial Oncology*, 4(4), 79-90.
- Quint, J. C. (1963). The impact of mastectomy. *American Journal of Nursing*, 63, 88-92.
- Revenson, T. A., Wollman, C. A., & Felton, B. J. (1983). Social supports as stress buffers for adult cancer patients. *Psychosomatic Medicine*, 45, 321-331.
- Rhodes, V. A., Watson, P. M., Johnson, M. H., Madsen, R. W., & Beck, N. C. (1987). Patterns of nausea, vomiting, and distress in patients receiving antineoplastic drug protocols. *Oncology Nursing Forum*, 14(4), 35-44.
- Rhodes, V. A., Watson, P. M., & Johnson, M. H. (1986). Association of chemotherapy related nausea and vomiting with pretreatment and posttreatment anxiety. *Oncology Nursing Forum*, 13(1), 41-47.
- Rhodes, V. A., Watson, P. M., & Johnson, M. H. (1985). Patterns of nausea and vomiting in chemotherapy patients: A preliminary study. *Oncology Nursing Forum*, 12(3), 42-48.
- Rogers, T. F. (1976-1977). Interviews by telephone and in person: Quality of responses and field performance. *Public Opinion Quarterly*, 40, 51-65.
- Rowat, K. M., & Knafl, K. A. (1985). Living with chronic pain: The spouse's perspective. *Pain*, 23, 259-271.
- Sabo, D., Brown, J., & Smith, C. (1986). The male role and mastectomy: Support groups and men's adjustment. *Journal of Psychosocial Oncology*, 4(1/2), 19-31.
- Schmidt, D. (1978). The family as the unit of medical care. *The Journal of Family Practice*, 7, 303-313.
- Seligman, M. E. P. (1975). *Helplessness*. San Francisco: W. H. Freeman and Company.
- Siegel, K., & Weinstein, L. (1983). Anticipatory grief reconsidered. *Journal of Psychosocial Oncology*, 1(2), 61-73.

- Silberfarb, P. M., Maurer, L. H., & Crouthamel, C. S. (1980). Psychosocial aspects of neoplastic disease. I. Functional status of breast cancer patients during different treatment regimens. *American Journal of Psychiatry*, 137, 450-455.
- Slaby, A. E., & Glicksman, A. S. (1985). *Adapting to Life-Threatening Illness*. New York: Praeger.
- Smith, E. M., Redman, R., Burns, T. L., & Sagert, K. M. (1985). Perceptions of social support among patients with recently diagnosed breast, endometrial, and ovarian cancer: An exploratory study. *Journal of Psychosocial Oncology*, 3(3), 65-81.
- Spiegel, D., Bloom, J. R., & Gottheil, E. (1983). Family environment as a predictor of adjustment to metastatic breast carcinoma. *Journal of Psychosocial Oncology*, 1(1), 33-44.
- Stern, P. N. (1980). Grounded theory methodology: Its uses and processes. *Image*, 12, 20-23.
- Stern, M. J., & Pascale, L. (1979). Psychosocial adaptation post-myocardial infarction: The spouse's dilemma. *Journal of Psychosomatic Research*, 23, 83-87.
- Stetz, K. M. (1987). Caregiving demands during advanced cancer. *Cancer Nursing*, 10, 260-268.
- Stoner, C. (1985). Learned helplessness: Analysis and Application. *Oncology Nursing Forum*, 12(1), 31-35.
- Strauss, A. L. (1984). *Chronic illness and the quality of life*. (2nd Ed.). St. Louis: C. V. Mosby.
- Sudman, S., & Bradburn, N. M. (1983). *Asking questions*. San Francisco: Jossey-Bass.
- Thomas, S. G. (1978). Breast cancer: The psychosocial issues. *Cancer Nursing*, 1(2), 53-60.
- Thorne, S. (1985). The family cancer experience. *Cancer Nursing*, 8, 285-291.
- Thorne, S. (1983). *The family cancer experience: A qualitative study of families in which an adult member is living with cancer*. Unpublished master's thesis, University of British Columbia, Vancouver.
- Tringali, C. A. (1986). The needs of family members of cancer patients. *Oncology Nursing Forum*, 13(4), 65-70.
- Vachon, M. L., Freedman, K., Formo, A., Rogers, J., Lyall, W., & Freeman, S. (1977). The final illness in cancer: The widow's perspective. *Canadian Medical Association Journal*, 117, 1151-1153.

- Vaillot, Sister M. C. (1970). Hope, the restoration of being. *American Journal of Nursing*, 70, 268, 270-273.
- Vess, J. D., Moreland, J. R., & Schwebel, A. I. (1985a). An empirical assessment of the effects of cancer on family role functioning. *Journal of Psychosocial Oncology*, 3(1), 1-16.
- Vess, J. D., Moreland, J. R., & Schwebel, A. I. (1985b). A follow-up study of role functioning and the psychological environment of families of cancer patients. *Journal of Psychosocial Oncology*, 3(2), 1-14.
- Warwick, D. P., & Lininger, C. A. (1975). *The sample surgery: Theory and practice*. New York: McGraw Hill.
- Weisman, A. D. (1979). *Coping with cancer*. New York: McGraw Hill.
- Weisman, A. (1972). *On dying and denying*. New York: Behavioral Publications.
- Weisman, A. D., & Worden, J. W. (1985). The emotional impact of recurrent cancer. *Journal of Psychosocial Oncology*, 3(4), 5-16.
- Weisman, A. D., & Worden, J. W. (1977). *Coping and vulnerability in cancer patients: Research report on project omega*. Boston: Harvard Medical School.
- 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.
- Weisman, A. D., & Worden, J. W. (1975). Psychosocial analysis of cancer deaths. *Omega*, 6(1), 61-74..
- Welch, D. (1982). Anticipatory grief reactions in family members of adult patients. *Issues in Mental Health Nursing*, 4, 149-158.
- Welch, D. (1981a). Planning nursing interventions for family members of adult cancer patients. *Cancer Nursing*, 4, 365-370.
- Welch, D. A. (1981b). Waiting, worry and the cancer experience. *Oncology Nursing Forum*, 8(2), 14-18.
- Welch-McCaffrey, D. (1985). Cancer, anxiety, and quality of life. *Cancer Nursing*, 8(3), 151-158.
- Wellisch, D. K. (1985). The psychologic impact of breast cancer on relationships. *Seminars in Oncology Nursing*, 1(3), 195-199.
- Wellisch, D. K. (1981). Family relationships of the mastectomy patient: Interactions with the spouse and children. *Israel Journal of Medicine and Science*, 17, 993-996.

- Wellisch, D. K., Jamison, K. R., & Pasnau, R. O. (1978). Psychosocial aspects of mastectomy: II. The man's perspective. *American Journal of Psychiatry*, 135, 543-546.
- Werner-Beland, J. A. (Ed.). (1980). *Grief responses to long-term illness and disability*. Reston, Virginia: Reston.
- Wikler, D. (1987). Who should be blame for being sick? *Health Education Quarterly*, 14(1), 11-25.
- Woods, N. F., & Earp, J. A. (1978). Women with cured breast cancer. *Nursing Research*, 27, 279-285.
- Wortman, C. B. (1983). Coping with victimization: Conclusions and implications for future research. *Journal of Social Issues*, 39, 195-221.
- Wright, K., & Dyck, S. (1984). Expressed concerns of adult cancer patients' family members. *Cancer Nursing*, 7, 371-374.
- Wright, L. M., & Leahey, M. (1984). *Nurses and Families*. Philadelphia: F.A. Davis.

APPENDIX A

UNIVERSITY OF ALBERTA FACULTY OF NURSING

Informed Consent for Face-to-Face Interview

Project Title: Living with Chemotherapy: Perceptions of Husbands
Investigator: Sharon Wilson, R.N., Candidate for Master's in Nursing
Telephone: 432-8233
Faculty Supervisors: Dr. J. M. Morse and Dr. I. D. Forrest
Telephone: 432-6250

The purpose of this research project is to increase nurses' understanding of the experiences of men whose wives are currently undergoing chemotherapy or who have just finished chemotherapy. Two to four interviews will be required, each lasting approximately one hour. Interviews will be tape recorded. During the interviews questions will be asked regarding your experiences and feelings about what it is like for you when your wife is receiving chemotherapy. Your name will not appear in any written account of the study. Written information provided by the participant will be kept by the researcher in an anonymous form.

There may be no direct benefits to the participant of this study, but the information that you give us may be helpful in the future for nurses when supporting husbands in similar situations.

This is to certify that, I _____
hereby agree to participate as a volunteer in the above named project. I understand that there will be no health risks to me resulting from my participation in this research project. I give permission to be interviewed and for the interviews to be tape recorded. I understand the tapes will be erased when no longer needed for ongoing research or educational purposes. I understand that I am free to deny any answer to specific questions and that I may stop the interview at any time and withdraw from the project. I have been given the opportunity to ask whatever questions I desire, and all such questions have been answered to my satisfaction.

I give permission for the use of any written information which I may choose to give to the researcher and understand that my name will not be associated with that information.

Participant _____

Researcher _____

Date _____

APPENDIX B

UNIVERSITY OF ALBERTA FACULTY OF NURSING

Informed Consent for Telephone Interview

Project Title: Living with Chemotherapy: Perceptions of Husbands
Investigator: Sharon Wilson, R.N., Candidate for Master's in Nursing
Telephone: 432-8233
Faculty Supervisors: Dr. J.M. Morse and Dr. I.D. Forrest
Telephone: 432-6250

I want to thank you again for your interest in this nursing research project. The purpose of the project is to increase nurses' understanding of the experiences of men whose wives are currently undergoing chemotherapy or who have just finished chemotherapy.

Consent

I will be asking you many questions about yourself, your family and your experience with chemotherapy. I will be doing two to four telephone interviews depending on my need to clarify topics we have discussed together during previous conversations. The interviews will last approximately an hour or longer. I plan to tape record the interviews.

During the interview, if you do not wish to answer any questions you may refuse, and you may stop the interview at any time and withdraw from the study. Your name will not be used in any written account of the study and the tapes will be erased when no longer needed for my ongoing research or educational purposes.

Do you have any questions? _____

Are you willing to be interviewed? _____

Participant Name: _____

Interviewer Signature: _____

Date: _____

Is this a convenient time to talk with you? If not, can you suggest another time for me to phone back.