

PSYCHOLOGICAL PREPAREDNESS FOR BREAST  
CANCER SURGERY  
by

Zuzana Cerna  
M.D., Charles University of Prague, 1983  
M.Sc(A.), University of McGill, 1994

A THESIS SUBMITTED IN PARTIAL FULFILLMENTS OF  
THE REQUIREMENTS FOR THE DEGREE  
DOCTOR OF PHILOSOPHY

in  
THE FACULTY OF GRADUATE STUDIES  
(Department of Counselling Psychology)

We accept this thesis as conforming  
to the required standard

THE UNIVERSITY OF BRITISH COLUMBIA  
© Zuzana Cerna, July 2000

In presenting this thesis in partial fulfilment of the requirements for an advanced degree at the University of British Columbia, I agree that the Library shall make it freely available for reference and study. I further agree that permission for extensive copying of this thesis for scholarly purposes may be granted by the head of my department or by his or her representatives. It is understood that copying or publication of this thesis for financial gain shall not be allowed without my written permission.

Department of

The University of British Columbia  
Vancouver, Canada

Date 27/07/2000

## ABSTRACT

This study explores the facilitation of preparation for breast cancer surgery. The aim of the study was to develop a reasonably comprehensive scheme of categories that would describe, from the perspective of women with breast cancer, what facilitates or hinders positive psychological preparation for breast cancer surgery and, therefore, identify and conceptually organize a broad array of these experiences.

The research method involved interviews with 30 women who underwent an operation for breast cancer 6-12 months prior to their interviews. The Critical Incident Technique was used to collect and analyze the data. The women were interviewed and asked to recall incidents that were helpful or hindering in their preparation for a breast cancer surgery.

A total of 362 incidents from 30 participants were collected, analyzed, and placed into categories. These incidents were organized into twenty-three categories: Receiving Educational Materials and/or Information; Obtaining an Explanation of Medical Procedures or Problems; Discussing Problems with Loved One; Getting Support and Encouragement from Others; Being Accompanied to a Medical Appointment; Helping Others; Engaging Oneself in Physical and Creative Activities; Developing Helpful Habits; Taking Action on Realizing Own Mortality; Experiencing Physical Closeness; Experiencing Deep Emotional Closeness; Realizing Shift in Relationship with Loved Ones; Healing Through Spiritual Experience and Visualization; Changing Perspective Through Comparison; Using Inspiring, Comforting Material; Getting Alternative Treatment; Establishing Professional Communication; Waiting for Medical Results; Sharing Experiences in Support Groups and

Counseling; Perceiving Professional Manners; Experiencing Positive Medical Settings; Getting a Recommendation/Approval of Medical Personnel, Questioning Competence of Medical Care or Personnel. The data also included information about participants' decision-making process regarding the type of operation for breast cancer and some observations on them were drawn.

Several procedures were used to examine validity, soundness and trustworthiness of the categories and subcategories. Three narrative accounts were analyzed in an effort to provide meaning and action to these categories.

The findings of this study may serve as a basis for better understanding of the process of preparation for breast cancer surgery. Through further examination of the categories and narratives some suggestions and recommendation for research and practice were made.

## TABLE OF CONTENTS

	<u>Page</u>
Abstract.....	ii
Table of Contents.....	vi
List of tables.....	viii
Acknowledgments.....	ix
CHAPTER I: INTRODUCTION.....	1
Statement of the Problem .....	1
Assumptions.....	3
Rationale for the Study.....	4
Approach to the Study.....	6
Objectives of the Proposed Study.....	7
CHAPTER II: REVIEW OF THE LITERATURE.....	9
Health Psychology and Breast Cancer.....	9
Factors Important for Preparation for Breast Cancer Surgery	11
Sociocultural Factors.....	12
Psychosocial and Psychological Factors.....	15
Medical Factors.....	21
Summary.....	22
CHAPTER III: METHODOLOGY.....	24
Instrumentation.....	24
Critical Incident Technique.....	25
Description of Participants.....	29
Protection of Participants.....	31
Specifications.....	32

Aim of the Activity.....	32
Participants' Demographics.....	33
Experiences Reported.....	33
Data Collection and Interview Procedures.....	34
Interview Guide.....	35
Data Analysis .....	39
Extraction of the Incidents.....	40
Forming Categories.....	41
Validation Procedures.....	43
CHAPTER IV: RESULTS.....	45
Description of the Categories.....	48
Receiving Educational Materials and/or Information..	48
Obtaining an Explanation of Medical Procedures or Problems.....	51
Discussing Problems with Loved One.....	53
Getting Support and Encouragement from Others....	54
Being Accompanied to Medical Appointments.....	57
Helping Others.....	58
Engaging Oneself in Physical and Creative Activities.....	60
Developing Helpful Habits.....	62
Taking Action upon Realizing Own Mortality.....	63
Experiencing Physical Closeness.....	64
Experiencing Deep Emotional Closeness.....	66
Realizing Shift in Relationship with Loved Ones....	67

Healing Through Spiritual Experience and Visualization.....	69
Changing Perspective Through Comparison.....	70
Using Inspiring, Comforting Material.....	72
Getting Alternative Treatment.....	73
Establishing Professional Communication.....	74
Waiting for Medical Results.....	76
Sharing Experiences in Support Groups and Counseling.....	77
Perceiving Professional Manners.....	78
Experiencing Positive Medical Settings.....	81
Getting a Recommendation/Approval of Medical Personnel.....	82
Questioning Competence of Medical Personnel.....	83
Decision-making Processes.....	88
Testing of Categories.....	97
Participants' Validation of Incidents.....	97
Reliability of Categorizing Incidents.....	97
Comprehensiveness of Categories.....	101
Participation Rate for Categories.....	101
Expert Validation.....	102
Comparison of Results with Related Literature.....	106
Examination of the Outcomes.....	117
Validating experience.....	118
Empowerment/Feeling in Control.....	120
Organizing Oneself/Active Approach.....	123

Belonging.....	125
Adaptation.....	126
Changes in Feeling: Relief/Anger.....	127
CHAPTER V: ORGANIZATION AND ANALYSIS OF CATEGORIES..129	
Narrative Account #1.....	129
Narrative Account #2.....	133
Narrative Account #3.....	137
Summary.....	142
CHAPTER VI: DISCUSSION.....	143
Limitation of the Study.....	145
Implication for Theory.....	147
Recommendation for Further Research.....	148
Recommendation for Practice.....	149
Personal Reflection.....	150
REFERENCES.....	152

**APPENDICES**

A. Letter from Participating Surgeon.....	162
B. Letter Describing the Study.....	163
C. Demographic Questionnaire.....	164
D. Consent Form.....	165
E. List of Suggested Questions.....	166

**LIST OF TABLES**

<u>Table</u>		<u>Page</u>
1	The Number of Helpful, Hindering, and Total Incidents per Category.....	46
2	The Percentage of Agreement Between the Evaluators' and Researcher's Category Scheme.....	100
3	Categories Ranked According to Participation Rate .....	104

## ACKNOWLEDGMENTS

I would like to acknowledge the generous financial assistance of the Canadian Breast Cancer Foundation -BC-Chapter. I am also deeply grateful to the many people who helped to launch, develop, and complete this research. Particularly, I wish to thank:

The 30 women who participated in the study and shared their experiences with me. This dissertation is a part of each of their stories and it is alive. It would not have been possible without you.

My supervisor, Dr. Larry Cochran, for his help and assistance in the research and writing of this thesis.

My committee members, Dr. Rod McCormick, Dr. Ivo Olivotto, and Dr. Marv Westwood, for their encouragement, support and valuable feedback.

Dr. Urve Kuusk, Dr Karol C. Dingee, and Dr.Peter Lim for sharing their experince and their patients with me.

My colleagues at my workplace for their understanding and support.

My life companion, Ludvik, for loving, nurturing, and being by my side.

And, my parents for fostering in me the belief that I could do anything I wanted.

## CHAPTER I

### INTRODUCTION

#### Statement of the Problem

According to National Cancer Institute of Canada (1999), breast cancer is the most common form of cancer diagnosed in Canadian women and the second leading cause of cancer death, surpassed only by lung cancer. One of every nine women in North America will develop breast cancer sometime during her lifetime, and for some women the risk is even greater (Berkow & Fletcher, 1987). The diagnosis and the treatment of breast cancer are both sources of considerable psychological stress for patients and their families. Although medical treatments of breast cancer have become increasingly effective for many women, the initial diagnosis still involves the threat that they may lose their life. Even in cases where the prognosis for survival is good, women may be threatened by the potential loss of significant aspects of personal functioning, or damage to their physical appearance, as a result of their treatment. Surgery remains the mainstay of initial breast cancer therapy, and is usually the first modality of treatment (which may also include chemotherapy, radiation therapy, hormonal and alternative therapies) involving either a mastectomy (surgical removal of a breast) or breast conservation surgery (removing just part of a breast with the tumor).

Relevant psychological literature reports a large range in the type and degree of psychological disturbance evident in breast cancer patients following diagnosis, surgery, and chemotherapy. Most women respond with temporary psychological distress, although others , according to Glanz

(1992), experience extreme stress reactions because of their inability to cope with the disease. Glanz (1992) demonstrated that as many as 25% of women with breast cancer suffer marked psychological morbidity associated with diagnosis and treatment, though this extreme psychological distress declines substantially within one year.

Maguire, Lee, and Bevington (1978) reported a significant degree of depression and anxiety in their study of women with breast cancer. Followfield (1989) also found that 20% of women in his study group possessed significant signs and symptoms of anxiety and depression 12 to 18 months after breast cancer surgery. Interestingly, the degree of psychological distress was not related to the type of surgery performed, but rather to whether or not the woman's doctor offered her a choice with regard to surgical operation.

Perhaps the most vital aspect of preparation for breast cancer surgery is the woman's decision-making process. According to British Columbia statistics, only 44% of women with pathologically node-negative breast cancer (a sign that the cancer is less likely to have spread through the body) in 1991 were treated with breast conserving surgery, compared with 68% of similar women treated in Ontario (Olivotto, 1995). Even within urban Vancouver the rate of BCS (breast conserving surgery) was only 50% compared to 69% in urban centers in Ontario (Olivotto, 1995).

Research conducted in British Columbia revealed that the woman's choice of operation (mastectomy versus breast-conserving surgery) was related to tumor stage, patient's age, and physical factors, as well as the patient's residence and socioeconomic status (Hislop, 1996). It is my belief

that one or more of the above factors probably serve as the *primary* factor, or set of factors, in the patient's decision-making process and it would be worthwhile to determine why 24 % fewer women in British Columbia have received breast-conserving surgery than in Ontario.

### Assumptions

Researchers agree that the psychological state of breast cancer patients influences operation outcome and consequent treatment. Others go on to suggest that it can influence the course of the disease. On this assumption Grossarth-Maticek and Eysenck (1989), investigated different psychotherapy techniques to help women with metastatic breast cancer, and found that survival time in their group improved by 50% across all types of psychotherapy.

Based on my experience as a medical doctor in the Czech Republic, I observed that women with breast cancer appeared to be affected by a wide array of interrelated psychosocial, medical, and biological factors. These factors are associated with the woman's culture, social support network, individual psychological coping strategies, self-concept, stage of cancer, and the specific types of treatment being used (Lippman, Lichter, & Danforth, 1988). I also noticed that only medical factors were typically addressed in the doctor's office, which suggested the need for medical professionals to better understand the process of preparing for breast cancer surgery, as well as the woman's decision-making process about the type of surgery. By better understanding these particular psychological

processes, medical professionals will be better equipped to help women prepare for a breast cancer operation.

Although previous research indicates that psychological preparation for breast cancer surgery can yield beneficial outcomes, there has been no attempt to comprehensively describe what affects this preparation from the woman's point of view. Most of the literature continues to approach the woman's experience from the outside.

### Rationale for the Study

There are several reasons for conducting a study investigating psychological preparation for breast cancer surgery.

Firstly, the diagnosis and treatment of breast cancer are sources of considerable psychological stress for patients and their families. By identifying experiences that facilitate and/or hinder positive psychological preparation for breast cancer surgery, educational programs to assist women in their preparation for surgery can be developed.

Secondly, physicians are very often the sole providers of patient information about both the disease and therapy. With limited time available to them even the most well-intentioned physician cannot provide all of the information that a patient may need. In fact, my personal observation of (rather) poor physician communication skills was often confirmed in the interviews. Physicians tended to utilize excessively specialized terminology and although it was of crucial importance for patients to understand their disease and the whole treatment process, they very often did not

understand every detail, and felt awkward asking questions within the limited amount of time they have with their physicians. Thus, this study may contribute to, and promote discussion of, more effective patient/physician communication, as well improve the communication skills of medical practitioners.

Thirdly, because medical professionals usually focus on the somatic and physiological aspects of cancer, psychological factors are often not addressed in their approach, or in their treatment of patients. I believe that the treatment of breast cancer patients must be holistic, and include a variety of physiological, behavioral, emotional, and cognitive aspects. Yet, such comprehensive programs are not commonly available in the hospital or clinical settings where women with breast cancer are primarily treated.

Fourthly, and more specifically, women need assistance throughout the extremely difficult time between their diagnosis and definitive operation for breast cancer. During this time when many women suffer marked psychological distress, they are confronted with various treatment options, and are expected to make many choices. Some women even exhibit extreme stress reactions at this time disabling their ability to make effective treatment decisions.

Lastly, the fast pace of medical progress, the multitude of options available for conventional medical therapy and advances in non-medical therapies often overwhelm professionals, as well as women with breast cancer. Some medical professionals are not familiar with alternative or non-medical therapies, nor do they approve of them-some may even feel offended when patients ask for advice about them. Therefore, it is hoped

that this study will establish whether there is a need for professional and organized assistance to help women with breast cancer properly explore all of their options.

### Approach to the Study

Recent research pertaining to the psychological treatment of breast cancer has sought to manipulate psychological factors during treatment in order to identify and enhance those interventions that lead to a positive outcome (e.g., increased survival time) (Holland & Mastrovito, 1980). Few attempts have been made to study the breast cancer experience from the patient's point of view (Frank, 1992). Even less research has focused on women's psychological preparation for breast cancer surgery.

Several articles have described different aspects of mastectomy and breast-conserving surgery. For example, researchers have compared the mental health effect of each surgery as it relates to the women, or group of women, undergoing treatment (Levy, Haynes, Herberman & Lee, 1992; Margolis, Goodman & Rubin, 1990; Van Heeringen, Van Moffaert & de Cuypere, 1990, Wellisch, DiMatteo, Silverstein & Landsverk, 1989), studied the emotional consequences of a breast operation (Zemore, Rinholm, Shepel & Richards, 1989), and investigated the psychosocial aspects of breast-conserving therapy of breast cancer (Blichert, 1992). However, there has been little research concerning the specific factors that influence psychological preparedness for surgery and capability for decision-making.

### Objectives of Proposed Study

The major research question was:

What factors facilitate or hinder psychological preparedness for breast cancer surgery?

Since patient decision-making has been emphasized in current approaches to treatment, a secondary question was:

What factors facilitate or hinder the decision to undergo a mastectomy or a lumpectomy?

Through interviews with women who had recently experienced breast cancer surgery, the main objective of this study was to identify and conceptually organize a reasonably broad array of experiences that facilitated or hindered positive psychological preparation. To this extent it was also important to assess the range of possible, or probable, psychological markers (such as hope or trust) that indicated progress in psychological preparation.

A second main objective of the proposed research was to describe factors influencing the decision-making process of women regarding their choice of elected surgery. Since decision-making at its best can be regarded as a form of empowerment, a potentially significant aspect of surgery preparation was to identify and organize the factors that influenced that decision-making. Combined, the information gathered allowed decision-making to be investigated within the specific context of psychological preparation for surgery. Based on this, a variety of questions

were considered, such as why women opt for one surgical treatment rather than another.

## CHAPTER II

### REVIEW OF THE LITERATURE

Breast cancer has been the most widely studied cancer with respect to its psychological impact. In part, this is because it is the most common cancer found in women, and also because this disease threatens an organ that is intimately associated with sexuality, self-esteem, and femininity, which are psychological issues of considerable concern to ill and healthy women alike. A comprehensive understanding of breast cancer also includes knowledge of the fact that cancer can return at any time after apparently successful treatment. Therefore a woman may never fully recover from the disease; she lives the whole of her life with the threat that one day the cancer may reappear. This chronicity has an inevitable impact on a woman's psychological adaptation to the disease.

The following is a review of research that has examined the psychosocial adaptation and psychological coping of women diagnosed with breast cancer, with emphasis directed toward their decision-making process. The scope of this review is limited to studies dealing with psychosocial factors rather than medical factors.

#### Health Psychology and Breast Cancer

Health psychology is a relatively young, but fast growing, area of the behavioral sciences. The field of health psychology brings together a multitude of contributors with diverse experience in research and practice, and with backgrounds and careers as both teaching psychologists and

health professionals ( Feuerstein, Labba & Kuczmierczyk 1986). Health psychology as defined by Matarazzo (1982, as cited in Feuerstein, Labba & Kuczmierczyk 1986), and as accepted and endorsed by the American Psychological Association, is an aggregate of specific educational, scientific, and professional contributions to the discipline of psychology and to the promotion and maintenance of health, prevention and treatment of illness, and the analysis and improvement of health policy and health care systems.

Growing scientific exploration in psychoneuroimmunology examines the connection between the mind and the body, and in particular, the effects of mental processes on hormone production, and on the individual's nervous and immune systems (McGinn & Haylock, 1993). Particular attention is given to the relationship between stress and neuroimmunology. There is a widespread consensus in the literature that stress influences, or impedes, the immunity response of the body, and therefore has a negative impact on body healing processes (Esterling, Kiecolt-Glaser & Bodnar, 1994).

The diagnosis of breast cancer is a significant stressor for any woman. More specifically, following diagnosis there is an extreme demand placed on women-not only to cope with the "death penalty" (how some perceive the diagnosis), but also to make correct decisions regarding their treatment. Previous research indicates that psychological preparation for surgery can reduce stress, and therefore yield beneficial outcomes for patients (Esterling, Kiecolt-Glaser & Bodnar, 1994), yet there has been no attempt in health psychology research to comprehensively describe what

affects this preparation. For this reason, the psychological preparedness of women for breast cancer surgery was selected for investigation in this study with an emphasis on women's decision-making processes.

### Factors Important for Preparation for Breast Cancer Surgery

Much of the literature has focused on specifying factors that substantially influence the psychosocial adaptation and psychological coping strategies of women with breast cancer. Holland and Mastrovito (1980) identified two primary groups of factors influencing psychological adaptation to breast cancer: medical and psychosocial. Medical factors, according to them, include symptoms, side-effects of adjuvant treatment, availability of prostheses and breast reconstruction, and psychological management by the health care team. Psychosocial factors consist of the cultural context, the patient's patterns of coping with stress, the point of the individual's lifecycle at which breast cancer occurs, and the woman's existing support system. Each factor can have a positive or negative influence by either increasing the amount of stress patients face, or adding to their resources for overcoming stress.

The most comprehensive review of factors contributing to the psychological response of women after diagnoses with breast cancer, and important to preparation for breast cancer surgery has been Holland and Rowland's 1989 study. They identified three main areas: a) the sociocultural context in which treatment options are offered; b) the psychological factors that the woman and her environment bring to the situation; and c) the medical factors, or physical facts, the woman must

confront in terms of disease stage, treatment, response, and clinical course. Holland and Rowland's (1989) outline has been utilized as a guideline to present the results of, and discuss more concisely, previous studies in this area of research.

### 1. Sociocultural Factors

#### a) Historical Background

In earlier times, women were told at the time of diagnostic work-up that they had something "suspicious" in their breast. They gave permission for a biopsy under anesthesia, and an immediate mastectomy, should the preoperative biopsy analysis demonstrate cancer. Early psychological studies demonstrate that, following radical mastectomy, women exhibited significant postoperative depression, anxiety, poor self-esteem and impaired physical and sexual functions (Schottenfeld & Robbins, 1974; Craig, Comstock, & Geiser, 1974; Maguire, Lee, & Bevington, 1978, Lee & Maguire, 1975). In addition to coping with a major surgical defect, these women received little social or psychological support outside of their own family. The societal taboos associated with cancer in general, and with the breast as a sexual organ, resulted in the diagnosis of breast cancer being kept a secret.

Over the past 15 years, there have been major shifts in breast cancer treatment which has yielded a number of varied treatment options, and medical treatment standard guidelines have been set by the medical community for treating breast cancer. The medical community has increasingly moved away from mastectomy as the uniform and standard

treatment for primary breast cancer (Veronesi, Saccozzi & Del Vecchio, 1995). Newer approaches have increasingly involved the use of breast-conserving procedures combined with radiation. However, there are still large gaps of information related to treatment of breast cancer. As the Canadian Cancer Statistic (National Cancer Institute of Canada, 1999) states, physicians and their breast cancer patients require greater access to the most current and scientifically advanced treatment options.

#### b) Decision Making Patterns

Today, women diagnosed with breast cancer tend to be aware of the plurality of existing views concerning primary breast treatment. Most recognize that often there is not a single "best" treatment, but rather various options, and their preference with respect to these options will be considered (Fallowfield, 1992). Fallowfield (1992) also emphasized the importance of health professionals understanding the emotional response of women to the diagnosis of breast cancer, as well as factors that contribute to this multifaceted response, and how to best assist women with their coping. Fallowfield (1992) indicated that women should have access to precise survival statistics for each mode of treatment. However, consulting physicians may offer different interpretations of data available from studies that compare mastectomy and breast-preserving surgeries.

Valanis and Rumpler (1985), in their study, provided a thoughtful review of the many issues faced by women in choosing among breast cancer treatment alternatives. Factors such as a woman's previous life experiences, her personal and demographic characteristics, as well as

those of her social support network (family and friends), and her physician were identified as influencing treatment selection. Two factors-anxiety and the physician/patient relationship, were specifically influential on the decision-making process.

Their findings corroborated with Carey (1999), who studied factors related to the coping response in 40 women, aged 30 to 86, prior to, and following, breast biopsy. The factors evaluated were state of anxiety, critical thinking ability, and information-processing capacity (concentration). The results suggested anxiety and information overload could compromise decision-making at a critical period, making an informed decision difficult.

As Valanis and Rumpler (1985) stated, another factor that must be considered when evaluating the decision-making process is the physician-patient relationship. A study of patients' perceptions about giving informed consent for chemotherapy (Penman, Holland, & Bahna, 1984) found that information conveyed verbally by the physician played a principal role in patients' efforts to arrive at a decision about treatment, and the written form of information contributed to a far lesser extent.

Bartlett (1991) forwarded some suggestions about the woman-physician relationship. Her complex and extensive study of six women coping with metastatic breast cancer suggested that women found it helpful when their doctors communicated openly about the disease and its treatment, and demonstrated good clinical skills such as empathy, reflection, flexibility, consistency and validation. The women also appreciated doctors who refrained from giving information that would worry

them unnecessarily, and let them know what to expect of treatments and medicines.

## 2) Psychosocial and Psychological Factors

Taylor's (1983) cognitive theory of recovery from breast cancer involves searching for positive instrumental meaning as an important aspect of recovery, and interprets this process as "cognitive adaptation", or the "readjustment", of a patient's thinking. This personal meaning was hypothesized as based on "illusions," which were defined as positive beliefs or positive interpretations of facts. Taylor (1983) assumed successful recovery from suffering involved illusion. This study indicates the importance of the researcher's stance while studying the meaning of a human experience, as well as the confusion that can result when this stance is not made explicit.

In an excellent review of published studies on the psychosocial correlates of breast cancer and its treatment, Meyerowitz (1980) identified the psychosocial impact of breast cancer as falling into three areas: psychological discomfort (anxiety, depression, and anger), changes in life patterns (consequent to physical discomfort, marital/sexual disruption, or an altered activity level), and fears and concerns ( mastectomy and death).

Psychological impact is modulated by variables within the woman, as well as her illness experience, and her environment, all of which have been widely studied, and which account for the extraordinarily wide range of responses to breast cancer. Using an outline of these variables to organize

her review, Meyerowitz (1980) summarized the nature and direction of impact of these variables on women with breast cancer.

According to research sources, psychosocial adaptation to breast cancer can be examined from four different perspectives: (a) the life stage at which breast cancer occurs; (b) the woman's personality and coping strategies; (c) her social support network; and (d) cultural factors.

#### a) Life Stage

Throughout the literature, there remains a general consensus that the point in the life cycle at which the breast cancer occurs, and the social tasks that are interrupted, or endangered, are of significant importance. A breast cancer operation poses a threat to the sense of femininity and self-esteem in all women, however this threat's particular impact may be more prominent in young women when attractiveness and fertility are typically more important. Holland and Rowland (1989) pointed out that breast cancer occurs more frequently in older women who may be experiencing other losses (e.g., spousal death, physical deterioration or deterioration of memory). Therefore women at different ages may all experience a difficult period of adaptation, having to adjust not only to losses in their social environment, but also to their potential loss of life. This supposition was further verified by Fotopoulos and Cook (1980), who found a high level of distress in older women diagnosed with breast cancer.

#### b) Personality and Coping Strategies

Each woman has her own style of adaptation to stress, and many studies have shown that this style has a remarkably constant quality. Gorzynski, Holland and Katz (1980) assessed different coping styles and their effectiveness in controlling emotional distress, before biopsy for breast cancer, and ten years later. Patients' coping styles, or patterns, were found to be unchanged over time.

Reardon and Aydin (1993) studied 96 breast cancer patients and found that coping strategies were significant predictors of changes in a woman's stress level and mental outlook. The positive attitudes of patients about their own responsibility for recovery contributed to positive changes in their lives.

In another study, Royak-Shaler (1991) reviewed the psychological effects of treatment for breast cancer patients. His findings demonstrated psychological coping styles and levels of distress as prognostic indicators for the survival of breast cancer patients. He suggested that better outcomes for the quality of life of breast cancer patients were noted among women who took an active role in monitoring their own health while undergoing diagnosis, treatment, and recovery. Active involvement included problem solving, expressing emotions, and restructuring one's lifestyle.

In addition to the above factors, "fighting spirit" was found to be positively correlated with better psychosocial adjustment to treatment in a study of 49 women with breast cancer (Friedman, Nelson, Baer, & Lane, 1990). It was further demonstrated that coping by avoidance was reliably

connected to poorer psychological adjustment to treatment for breast cancer.

After interviewing 300 women treated for the early stages of gynecological and breast cancer, Cobliner (1977) detailed a profile of characteristics and coping strategies observed in women who were considered to have adjusted successfully to their conditions. He delineated their psychosocial characteristics and coping strategies as follows:

1. A positive general self-image, and an absence of irrational ideas about cancer.
2. A positive image of femininity, which suffers little alteration, if any, as a result of the disease or its treatments.
3. Strong faith in their doctors, and a high degree of trust in the clinic or hospital where they are treated.
4. A belief in the efficacy of the particular treatment they receive.
5. A desire and opportunity to confide their worries and intimate concerns to another person, usually another woman.
6. Involvement in an activity or occupation that gives them satisfaction.
7. A good relationship with a husband, sexual partner, or close friend.
8. Concordance between their life expectation and its degree of attainment.
9. The nature and success of any attempted resolution of a life crisis in the past.

When a mastectomy is performed as a part of a woman's cancer treatment several mental health researchers have pointed out the need to better understand women's coping strategies, in order to help them better adapt to their situation, and to integrate their mastectomy experience with a gratifying life style ( Lippman, Licher & Danforth, 1988; Cobliner, 1977).

### c) Social Support Network

Spiegel's (1992) study was one of the most significant recent research studies in the field of psychosocial studies related to breast cancer survival. He worked with metastatic breast cancer patients--one group of whom participated in weekly group psychotherapy, and learned different coping strategies, and another group that received only routine oncological care. Eight months after the initial intervention, the two groups began to diverge in outcome, with the weekly psychotherapy group eventually surviving twice as long as the control group. In fact, several of the psychotherapy patients were still alive at the end of the ten-year study. This study supported the idea that psychosocial support may influence the progression of cancer, as indicated by differences in length of survival. Possible mechanisms for these psychosocial effects on progression of the disease include changes in diet and exercise, better use of health care, and positive effects on the sensitivity of the endocrine and immune systems to stress.

Glanz (1992) indicated that social support, cognitive therapy and supportive information have positive effects on breast cancer patients. Waxler-Morrison, Hislop, Mears, and Kan (1991) examined the social

support systems of 133 women, and found that social contacts were statistically associated with better survival rates. The results of another study (Hannum, 1991) of 22 women with breast cancer also suggested that interpersonal (social) variables were equal to, or more important than, intrapersonal (individual) variables in the effectiveness of coping with breast cancer.

#### d) Cultural factors

Most published reports about women's reactions to breast cancer have been heavily influenced by cultural factors, with the emphasis placed on women's sexual and maternal roles. Many women may face difficulties retaining, or adjusting, their self-concept relating to these roles and particularly to the stigma attached to the breast cancer and loss of the breast. For centuries, artists and poets have celebrated the female form, and have emphasized its aesthetic and symbolic meaning. In our modern context, enormous amounts of psychic energy and capital resources go into glamorizing, idealizing, and sensationalizing the female breasts. While female breasts may be anatomically described as mammary glands, this part of the female body presently elicits a variety of dependent, nurturing, and sexual reactions (Schain, 1985).

As well, women's breasts are often a source of feminine identification, and their appearance has a critical impact on self-esteem. What happens to a woman when she is diagnosed with breast cancer, and is faced with radical or conservative surgery on such precious organs? It is

obvious that a woman facing the alteration of such socially valued organs in nearly all instances feels anguish, fear, and/or depression.

Another cultural factor affecting psychosocial adaptation is Western society valuing family and children. All these factors negatively influence the breast cancer patient's coping ability, adaptation to the disease, and her overall level of psychological functioning (Lippman et al., 1988).

### 3) Medical Factors

While the type of medical therapy depends on the extent of the disease and the patient's age, treatment very often requires total or partial surgical removal of a breast, and subsequent radiotherapy with side effects like breast swelling, redness or darkening, pain, blistering and fatigue, or chemotherapy with side effects like loss of hair, chronic nausea, loss of weight, pain, fatigue, chills and fever. Disfigurement from the surgery, combined with the secondary effects from chemotherapy and radiotherapy, and the risk of death create tremendous stress in these women.

There are also some unique features of breast cancer which should be taken into consideration. The therapist is called upon to help a patient deal with a disease over which neither the patient nor the therapist has control. Breast cancer varies widely in its prognosis at diagnosis. From the beginning, one must be able to accept that there may be no cure medically or emotionally, and that psychotherapy may be purely supportive (Haber, 1993). On the other hand, breast cancer may be medically treatable, and the experience may free the patient to work very actively and productively

on her major life issues, and to experience enormous emotional change and growth.

### Summary

As indicated in the introduction, recent research on the psychological treatment of breast cancer has attempted to manipulate psychological factors during treatment, in order to identify and enhance those interventions which lead to positive outcomes (e.g., increased survival time). Although there have been many studies completed in the area of breast cancer research from many different perspectives, few attempts have been made to study the breast cancer experience from the patient's point of view. Most of the literature continues to approach the patient's experience from the outside. The patient is seen either as someone whose emotional distress needs to be reduced or overcome so that she can return to normal (Holland & Mastrovito, 1980), or alternatively, as someone with a number of psychological and social problems that require solutions, with the help of a counselor (Schain, 1985).

Underlying most psychological approaches to women suffering from breast cancer is the assumption that recovery means an adjustment or readjustment towards normality. However, the experience of breast cancer and mastectomy involves facing one's own mortality. Thus, the meaning of one's illness, and of one's life as a whole, become very important issues for the patient, and the sense of meaning in life may change. Taylor (1983), for example, hypothesized that this personal meaning based on positive beliefs, or positive interpretation of facts, may be essential for adequate coping with breast cancer.

Rosser (1981) pointed out the need for research into the meaning of the breast cancer experience for patients. She emphasized the need for a narrative component in such research, which should be done through careful listening to the patient, and should include a detailed recording of statements to better understand the experience. She also suggested that such research must deal with the dichotomy between personal meaning and objective reality, though she did not specify how. Her view was consistent with results of Taylor's (1983) study.

Frank (1992) concluded that the women's, or patients', experience was missing in present breast cancer research. He suggested first person narratives to fill the gap in research, therapeutic and medical practice. I agree with him that there is a need to take a hermeneutic stance in both research and therapy, over scientific objectivism.

While previous research indicates that psychological preparation for breast cancer surgery can yield beneficial outcomes, there has been no attempt to comprehensively describe what affects their preparation.

## CHAPTER III

### METHODOLOGY

#### Instrumentation

Qualitative research methods were selected because the information gathered from these processes is particularly appropriate for uncovering the meanings that people assign to their experiences (Hoshmand, 1989; Polkinghorne, 1991). In trying to identify a specific research method that was congruent with my assumptions and theory, the Critical Incident Technique appeared to be a particularly suitable way of exploring the difficult and stressful time of women's recent diagnoses with breast cancer. At this time women face a great physical and emotional challenge, an operation and the possible loss of a breast. The Critical Incident Technique is an established and reliable interview method designed to elicit what elements facilitate, or hinder, a designated aim (Flanagan, 1954). With this technique as a framework, the study required participants to look inside themselves and identify and describe their experiences (White, 1989).

In this chapter, the history and general nature of the Critical Incident Technique is presented, followed by a description of participants, specifications of the study, interview procedures, data analysis and validation of categories.

### Critical Incident Technique

The Critical Incident Technique consists of a set of procedures for collecting information from people about their direct observation of their own or other people's behaviors. Emphasis is placed upon incidents or events that are critical; that is, things that happen that are directly observed or experienced, and that significantly affect outcome (Woolsey, 1986a).

In this study, the aim was psychosocial preparedness for surgery. Participants that were selected for interviews had been in a position to observe, or experience, events that help or hinder the given aim. Upon completion of interviews, critical incidents were extracted from tape recordings of accounts, and then grouped upon the basis of similarity to form a set of categories that encompassed the events. This category system, as stated, provides a conceptual map of what elements facilitate, or hinder, the given aim, a map that can then be used in theory development, test construction, and practical programs (Flanagan, 1954).

Flanagan (1954) developed this technique while working as a researcher in the Aviation Psychology Program of the United States Army Air Forces during World War II. His procedure helped to establish factors as effective and/or ineffective in helping pilots learn to fly, develop good leadership capabilities, and acquire mastery in a variety of other specific activities. For instance, Flanagan asked combat veterans to describe incidents significantly helpful or harmful to their mission, analyzed the descriptions, and devised a list of behaviors critical for task performance.

After the war, Flanagan (1954) utilized the Critical Incident Technique in the aviation industry to select, classify, and evaluate personnel.

Subsequently, this technique has been used as a research tool for varied purposes. In counseling psychology, the Critical Incident Technique has been used to define behaviors that are effective for telephone crisis intervention (Delfin, 1978), investigate perceptions of school counsellors regarding their effectiveness (Gora, Sawatzky, & Hague, 1992), investigate the experience of unemployment (Borgen & Amundson, 1984), explore high school counseling trends (Neely & Iburg, 1989), describe the meanings occupational therapists derive from their work (Hasselkus & Dickie, 1990), and analyze the facilitation of healing for the First Nations People of British Columbia (McCormick, 1994).

Studies examining the credibility of the Critical Incident Technique have declared it a reliable and valid research method.

In one such study Anderson and Nilsson (1964) found that:

- a. collection procedures were reliable (the number and structure of incidents did not significantly vary across different interviewers);
- b. categorization of incidents was reliable (categories did not differ significantly across different coders);
- c. data were comprehensive and reached saturation;
- d. the categories were important as confirmed by questionnaires and other literature in the field.

Ten years later Ronan and Latham (1974) also subjected the critical incident technique to several different tests of reliability and validity and results were found to be satisfactory.

The decision to employ Critical Incident Technique for the proposed study was guided by several considerations.

Firstly, the purpose of the proposed study is to understand, and describe, the experience of women with breast cancer while undergoing preparation for breast cancer surgery. A qualitative, descriptive approach is appropriate when the primary interest of the researcher is not to predict and control, but rather to "understand the meaning of events and interactions to people in particular situations" (Bogdan & Biklen, 1982, p.31). As with other qualitative methods, the Critical Incident Technique focuses on obtaining a comprehensive description of the activity under study.

Secondly, the Critical Incident Technique is congruent with a philosophy of counseling emphasizing the importance of inner experience and personal meaning (Woolsey, 1986b). The interview approach respects participants' uniqueness and trusts that participants themselves are "in the best position to provide accurate accounts of the events under investigation" (Brown & Canter, 1985, p.222).

Thirdly, the approach to the interview in the Critical Incident Technique is flexible enough to enable researchers to stimulate participants' recollections of their experiences under investigation. The interview also allows researchers to react, and form questions, to clarify

certain data. This enables participants to confirm or correct the researchers' perceptions of their responses.

Fourthly, the research findings from the Critical Incident Technique are not preconceived and emerge from the data itself, allowing researchers to get close to the data and develop analytical, conceptual, and categorical components of explanation from the data itself (Filstead, 1970).

Fifthly, the Critical Incident Technique has been used repeatedly in many different fields, and demonstrated itself as a reliable and valid methodology (Andersson & Nilsson, 1964, Ronan & Latham, 1974).

Lastly, the interviewing procedures of Critical Incident Technique are more personal than alternate methods of obtaining data from participants (e.g., questionnaires) and therefore may enhance and stimulate participants' cooperation.

#### Flanagan's critical incident study

Flanagan (1954) describes five steps to conducting a critical incident study: (a) determine the aim of the activity to be studied; (b) set plans and criteria for the information (elements) to be observed, (c) collect data, (d) analyze data, and (e) report findings.

The first step identifies the aim of the study in a clear and simple way, which is typically done by consulting related theoretical and empirical literature, as well as experts in the field being investigated (Woolsey, 1986a). This primary step is fulfilled in the literature review of this document.

The second step refers to identification of who observes, which individual and activities are observed, and which specific behaviors are

observed. These are discussed in the "Specification" section of this chapter.

The third and fourth steps refer to the collection of data (incidents), with the designated interview and analytic techniques. These two steps are discussed in the "Interview Procedures" and "Data Analysis" sections of this chapter.

### Description of Participants

Thirty participants were selected according to five main criteria. Firstly, each woman had undergone breast cancer surgery. Secondly, their operation had been performed six to twelve months prior to involvement in this research study, which assured some emotional distance from the surgery, but enough closeness in time to relate detailed, rich memories.

Thirdly, women selected were willing, and able, to articulate their experiences. Fourthly, participants were selected in rough proportion from two different surgeons, and from two different oncologists. Lastly, care was taken to assure that some participants had been involved with breast cancer support groups.

After consultation with people involved with women with breast cancer, participants were recruited from two different breast cancer surgeons and two different oncologists. Each breast cancer surgeon and oncologist was contacted personally by the investigator, and given a letter describing the study in detail (Appendix B). A similar letter was given to selected patients who met the study's criteria. Interested patients contacted the investigator.

Flanagan (1954) considered the size of the sample to be the number of critical incidents obtained from the interviewing procedure, rather than the number of people interviewed. Therefore, after a discussion with my supervisor and other researchers we decided that a test for saturation would be employed to ensure data collection was not terminated too soon, before all significant categories were generated.

With this in mind, 17 women were initially recruited from the eligible patients of two surgeons in Vancouver, and then another 13 women were chosen by two oncologists after being asked if they were willing to participate. A total of 30 women participated in the study. Subsequently, the participants were personally contacted and given an explanation of the study's purpose and scope. A pre-selection interview was completed over the telephone, or in person, in order to explain the confidential nature of the study to potential participants. In this interview the purpose and scope of the study were again explained, and an appointment time was designated for the taped interview.

A detailed discussion of informed consent occurred at the beginning of the taped interview, with emphasis placed upon confidentiality, and the potential emotional consequences of participation. After participants signed an informed consent form, audio-taping of the interview commenced.

A letter of consent from one of the breast surgeons endorsing with the research study is included as Appendix A.

### Protection of Participants

The following were precautions adopted to help ensure the protection of participants in the proposed study:

Firstly, participants were screened during the initial telephone contact, prior to participating in the study. The participants were informed that the research would focus on their experiences while preparing for breast cancer surgery. The purpose of this screening was to identify, and then include in the study, only those participants for whom involvement in the study would not create any undue hardship (Koehn, 1995).

Secondly, participants were fully informed of the objective of the study, the method of data collection, and how the collected information would be utilized. Participants were also informed that their participation in the study was voluntary and withdrawal or lack of participation would not adversely influence their medical treatment.

Thirdly, participants were informed the interview sessions would be audio-taped, and they could turn off the tape-recorder whenever they wished.

Fourthly, participants were informed of their rights to confidentiality and that confidentiality would be maintained through the omission of any personal references, and by recording only the first initial of participant's first name on the interview transcript.

Fifthly, a period of debriefing occurred at the end of the interview in order to discuss any feelings the participant might have experienced during the session.

Lastly, a resource list of agencies, and groups, providing counseling for breast cancer patients was made available to any participant who wished it.

### Specifications

According to Woolsey (1986a), within a critical incident study the researcher must determine (a) the aim of the activity to be studied, (b) who will be observed, and (c) which behaviors and experiences will be reported. These issues were addressed according to Woolsey's delineation.

#### Aim of the Activity

The aim of counseling is to assist clients in making positive changes in their behavior, feelings, thoughts, and attitudes. With this definition as a frame of reference, the aim of the study was to describe and assess psychological preparedness of women with breast cancer for surgery. Participants were asked to describe incidents which occurred prior to their operation for breast cancer perceived as either especially helpful, or hindering. Described incidents were regarded as "critical incidents" if they:

- a. led to a change (temporary or permanent) in participant's behavior, feelings, thoughts, or attitudes;
- b. were recalled in detail by the participants.

### Participant Demographics

The participants in this study ranged in age from early forties to early eighties. The mean age of participants was 59 years. Geographically, 28 participants lived in the Greater Vancouver area and two were from Vancouver Island. Participants were employed in a wide variety of occupations, such as housewife, secretary, administrator, nurse, university professor, and laborer. Fifteen participants were married, 3 divorced or separated, 5 were widows, and 7 women were single. Participants had, on average, 1 child. More specifically, one woman had five children, two women had three children, six women had two children, seven women had one child and fourteen women did have not any children.

### Experiences Reported

Participants were asked to describe their own behavior, feelings, attitudes, and thoughts, as well as their interpretation of the behavior, feelings, and attitudes of their families, friends, medical practitioners, clergy, counselors, co-workers, and people they accidentally met. In addition, participants described anybody, or anything, they found helpful/hindering to the process of coping with their diagnosis of breast cancer, and their preparation for breast cancer surgery.

A request was made for participants to describe specific experiences they found either helpful, or hindering, to their preparation for breast cancer surgery. More specifically, participants were asked to describe what events led to each experience. The summary of the incident outcome involved a description of how participants reacted in terms of their behavior, feelings, thoughts, and/or attitudes.

Prior to a primary interview, a short demographic questionnaire (Appendix C) was administered. This questionnaire collected data about the participant's type of operation for breast cancer, age, occupation, and marital and social status, along with other background information.

#### Data Collection and Interview Procedures

Woolsey (1986a), suggested writing a detailed direction of interview procedures (interview guide) and doing a pilot test of the interview (with two or three non-participants) before starting data collection. The detailed guide of interview procedure is described in this section. The pilot testing was conducted with three student volunteers. The results of this pilot study were discussed with the research supervisor, Dr. Larry Cochran, and utilized to further refine the interview procedure described in this section.

To ensure data collection was not terminated before all significant categories were generated, a test for saturation was employed by randomly selecting incidents and placing them into different categories. Andersson and Nilsson (1964) suggested that saturation and comprehensivness were safely assumed if 95% of identified categories appeared after two-thirds of the incidents had been classified into results: 95.7% of the categories showed after 100 incidents (27.6%) had been classified thus satisfying the criteria for saturation and comprehensivness.

### Interview Guide

For this study, the critical incident interview involved four parts:

1. Recruitment and orientation of participants;
2. Collection of data: an elicitation of events affecting preparedness, and the drawing of a time line of participant experience;
3. An examination of the time line in detail, with emphasis on specification of events influencing decision-making process regarding type of operation (mastectomy versus lumpectomy).
4. A debriefing, and disengagement for final analysis.

During the first part of the interview, care was taken to describe the aim of the study clearly and to allow time to establish rapport with the participant. In order to avoid the danger of collecting answers not based on the study's aim, I remained aware of the importance of clarifying the aim statement to all participants. The following statement was used to orient participants to the purpose of the study.

**Hello, Mrs. (Ms.). Thank you very much for coming today. As I mentioned to you on the phone the purpose of this study is to find out what helps women with breast cancer to prepare themselves for the operation, and also what hinders their preparation. My intention is to meet with experts like you so**

**that you can tell me what has helped and/or hindered this process, and find out what enabled you to respond to different events in a helpful way. My goal is to come up with a comprehensive map of what helped you so that other women can learn and benefit from your personal experiences and perhaps prevent them from going through some rough times that could possibly be avoided. In order to do that I need your help, and I really appreciate your being here today to give me a chance to talk to you about your experience. I am looking forward to working with you.**

In addition, we discussed with the participants the nature of the study, clarified the nature of events to be reported, and I presented participants with a consent form explaining the purpose of the study, confidentiality, their right to refuse to answer any questions, and their option to withdraw from the study at any given time without prejudice of any kind. It was also explained that withdrawal or lack of participation would not influence their medical treatment. Upon reading this form I offered to clarify any questions the participant might have. Then the consent form (Appendix D) was signed by both, after all details were addressed and discussed to the satisfaction of the participant.

Woolsey (1986a) suggests it is important to gather relevant descriptive biographical data about respondents in the Critical Incident Technique studies. Therefore, after giving informed consent, the participant was asked to complete a demographic questionnaire (Appendix C).

The second part of the interview consisted of an elicitation of critical events pertaining to the study. Interviews were approximately 60 to 90 minutes in length, and were tape-recorded with an audio recorder. The time and location of the interviews were arranged at the convenience of the participants. Approximately half of the participants (14) found it convenient to be interviewed in their homes, twelve participants chose the office in the Counselling Psychology Department on the UBC campus, and four participants preferred to be interviewed in a specifically designated office in a medical building in down-town Vancouver.

The interview began with the following question:

**Think back to a time before the operation, when you first noticed, or learned that you had breast cancer, and tell me what helped/hindered the process of preparation for surgery.**

**How did you prepare to decide on the type of your surgery for breast cancer?**

After this question was asked, participants were allowed time to recollect their memories. Questions found in Appendix E needed to be specific enough to get to the study's purpose, but also vague enough to give the participant enough space to describe what was pertinent and meaningful to her experience. Throughout this part of the interview, participants were asked to place, on a chronological line (time table), the major events influencing their preparedness for surgery. Through active listening, I

gradually encouraged the participant to recollect different events, and temporally order them. However, not every participant was able to do so. In this event, the participants were asked to do the ordering approximately.

In the third part of the interview, after participants indicated all major events had been included, they were asked to explain the first event of the time line, describing what led up to it, what helpful or hindering events actually happened, and what was the outcome of the event relevant to preparedness for breast cancer surgery. Participants were encouraged to continue on, describing each experience in turn.

During the interview it was acceptable for the participant to ask questions for clarification. I also asked questions to obtain further clarification concerning responses made by participants. However, throughout the interview, care was taken to ensure that leading questions or hints were not given to the participant.

Some examples of clarification questions frequently asked during the interview include:

**What exactly happened that was helpful/hindering?**

**How did you know that it was helpful/hindering?**

**What has changed for you?**

In this part of the interview participants were also asked to describe how they came to a decision on the surgery desired, and what influenced their decision-making process regarding the type of operation (mastectomy versus lumpectomy). Participants were encouraged to provide a personal

account of the decision made, elaborating important events, circumstances, and influences.

In the final part of the interview, I summarized all the critical incidents from the time table and my notes and checked with the participants if the meaning of the critical incidents was a true reflection of what really happened. This was followed by debriefing and disengagement of participants. This included questions like:

**If I feel like I have missed something, is it O.K. to call you back?**

**Or would you prefer another way of contacting you?**

In three cases I felt that it would be helpful to offer a list of agencies and groups providing counseling for breast cancer patients. In nine cases I had to call back to clarify some data with the participants in order to get to the meaning of particular incident.

### Data Analysis

Data analysis involved three steps:

1. the extracting, and recording, of critical incidents from audio-tape onto individual index cards (one incident per card) with the help of my notes and the time tables (chronological lines with participants' incidents);
2. the grouping of incident cards, according to similarity, to form categories;

3. the subjection of these categories to several tests, (assessing reliability and validity).

### 1.Extraction of the Incidents

The aim of critical incident data analysis is to provide a comprehensive and valid description of the activity studied (Woolsey, 1986b). All 30 of the interviews conducted were recorded on tape, and each was assigned a number. From the participants' time tables, my notes, and the tape recordings of each interview, events were extracted and recorded on index cards, with each card providing a description of one event (including what led up to the incident, what happened, and how the incident turned out). Each event was then subjected to an intense examination. In this examination the following criteria were considered:

- 1) can a source be determined for the event described? (example of source type: person, place)
- 2) can the story be stated with reasonable completeness?
- 3) can an outcome be found with bearing on the aim of the study?

I chose to disregard 12 vague statements, and to polish the occasionally unclear language of participants.

The following are two examples of incidents, or events described, that were not included in the study:

My summer holiday is the most important thing for me in the whole year. We were walking and enjoying the beautiful sunny

days in the mountains. It didn't rain for the whole vacation, it was just great summer.

I love my husband a lot. He was always nice and generous to me. He never failed me.

In the above two examples it was not evident to me what exactly happened to facilitate, or hinder, the participant's preparation for breast surgery. As well, the specific outcome of these descriptions was unclear.

After this extraction process, 362 complete incidents were identified. The incidents were then placed on the index cards, and each incident was divided into three component parts: source, action taken and outcome (which later facilitated the sorting of incidents into categories). Because of participants' differing educational levels, and their tendency to speak with varied degrees of clarity, I had to carefully use judgment in recording events, as well as paraphrasing the occasional event to convey fully the participant's message. However, whenever possible the words of the participants remained unchanged.

As a result of the above factors a heterogeneity of incidents, in terms of format, length and detail, developed.

## 2. Forming categories

According to Rosh (1977), categories are loose entities whose members share a family resemblance. In the next step all incidents were thoroughly examined, noting their similarities and differences, and sorted

into categories according to themes which group the incidents together. Throughout this process of categorization and critical reflection, it was important to become totally immersed in the data, and to obtain an intuitive sense for the essence of each incident in order to allow each category to crystallize and stabilize (Koehn, 1995).

Recorded incidents were sorted, systematically compared, and contrasted. The focus of sorting was placed upon the second part of the incident, more specifically, the action taken (or what happened). For each category a prototypical incident was selected, one encompassing as many characteristics of its category as possible. The selected incident best described and defined the category in question.

Certain incidents were borderline and could not be easily placed into a category. These incidents were put aside and reviewed later. The categorization of incidents was then examined by the research supervisor and accordingly revised and refined (utilizing the borderline incidents as well). The process of categorization was extensive, and included repeated consultation with my supervisor until stability of categories was achieved.

It should also be reiterated that the focus of the study was on "what" events occurred and not "why" each event occurred. Thus, meanings were not solicited from the participants with regards to the significance of different incidents. In most cases, however, meanings or outcomes of different incidents were volunteered by participants.

### 3. Validation Procedures

Following McCormick's (1994) suggestion, the categories were assessed using five different questions to establish the soundness, and trustworthiness of the category system.

Firstly, the question; "can different people utilize the categories system in a consistent way?" was addressed. Two different judges were asked to place a sample of 50 incidents within existing categories. Both judges, or evaluators, were students at the University of British Columbia, and possessed previous experience conducting research. By comparing the placement of incidents by judges with the original placement of incidents at formation of categories, the number of "hits and misses" were summarized statistically as a percentage of agreement (McCormick, 1994). A high level of agreement would indicate that different people could use the categories to group incidents in a consistent, or reliable way.

Secondly, the question; "is the category system constructed reasonably complete or comprehensive?" was addressed. As suggested by Andersson and Nilsson (1964), approximately ten percent of the incidents were withdrawn and not examined until the categories were formed. When category formation was completed the remaining incidents were examined and classified.

Thirdly, the question; "are the categories identified sound, or well founded?" was addressed. Although there are different ways to assess the soundness of a category, interpersonal agreement as a basic test of soundness was selected. Categories are formed when significantly similar groups of incidents reported by different people are identified by the

researcher. Often, participants independently report the same kind of event, however, if only one person, or a few persons, reported a type of event, the incident might be dismissed because this person might have fabricated or distorted the event. On the other hand, when many people report approximately the same kind of event, the chances of fabrication or distortion occurring are smaller. Agreement was obtained by assessing the participation rate for each category, which is the percentage of people reporting an event.

Fourthly, the soundness of categories can also be judged by the interpretation of qualified experts from the field of interest. Experts can assess the relevance and usefulness of the generated categories, based upon their experience related to the field of research.

Lastly, categories can be carefully compared with previous related research in order to determine consistency.

## CHAPTER IV

## RESULTS

Through interviews with 30 women, a total of 374 incidents were elicited related to what events facilitated, or hindered each woman's preparation for breast cancer surgery, and 362 of these incidents were included in the study. The incidents were organized into twenty-three categories. Table 1 illustrates the categorization scheme with the number of helpful incidents, the number of hindering incidents, and the total number of incidents for each category. A description of the categories generated is included in this chapter along with a description of the methods utilized to establish the reliability, validity, saturation and comprehensivness of the categories.

Eleven categories had both a positive and negative valence. Ten categories ( Discussing Problems with Loved One, Accompanied to Medical Appointments, Helping Others, Engaging Oneself in Physical or Creative Activities, Developing Helpful Habits, Experiencing Deep Emotional Closeness, Healing through Spiritual Experience and Visualization, Changing Perspective Through Comparison, Using Inspiring, Comforting Material, Getting an Approval/Recommendation of Medical Personnel) were comprised of only helpful incidents. By contrast, one category (Waiting for Medical Results) contained only hindering incidents. A description of all categories generated, including examples of helpful and hindering incidents, follows.

Table 1

The Number of Helpful, Hindering, and Total Incidents per Category

Name of Category	No. of Helpful	No. of Hindering	Total
1. Receiving Educational Materials and/or Information	39	7	46
2. Obtaining an Explanation of Medical Procedures or Problems	18	6	24
3. Discussing Problems with Loved One	12	0	12
4. Getting Support and Encouragement from Others	43	3	46
5. Being Accompanied to a Medical Appointment	10	0	10
6. Helping Others	22	0	22
7. Engaging Oneself in a Physical and Creative Activities	8	0	8
8. Developing Helpful Habits	9	0	9
9. Taking Action upon Realizing Own Mortality	7	2	9
10. Experiencing Physical Closeness	15	1	16
11. Experiencing Deep Emotional Closeness	7	0	7
12. Realizing Shift in Relationship with Loved Ones	6	4	10

13.	Healing Through Spiritual Experience and Visualization	16	0	16
14.	Changing Perspective Through Comparison	10	0	10
15.	Using Inspiring, Comforting Material	13	0	13
16.	Getting Alternative Treatment	1	5	6
17.	Establishing Professional Communication	11	7	18
18.	Waiting for Medical Results	0	5	5
19.	Sharing Experiences in Support Groups and Counseling	12	4	16
20.	Perceiving Professional Manners	10	3	13
21.	Experiencing Positive Medical Settings	4	1	5
22.	Getting an Approval/Recommendation of Medical Personnel	4	0	4
23.	Questioning Competence of Medical Care or Personnel	17	20	37

## DESCRIPTION OF CATEGORIES

### 1. Receiving Educational Materials, and/or Information (46 incidents)

This category refers to whether or not the woman received educational materials or information in a manner that was beneficial to them. The majority of women considered it very helpful when they received educational materials such as books, brochures, and/or audio/videocassettes, or when they watched an educational program on television, or listened to a radio program, to increase their knowledge about their disease. Participants identified this knowledge as helping them to better understand what was occurring inside of their bodies, and/or as assisting them in making informed decisions.

Educational materials were beneficial to the women for several reasons. Firstly, books and articles defined and explained breast cancer, and therefore helped the woman to better understand the breast cancer disease.

Example:

The disease was a devastating experience for me, I think I aged a thousand years. I don't think I would like to go through it again for a million bucks. On the other side, I have to admit that after reading the books a librarian recommended me, I felt that I was somehow happier with myself, I started to understand my body better and most of all I was more appreciative of what I have. I really am grateful for all of these books.

Secondly, the materials provided women with useful information (e.g., that it is not unusual for women with breast cancer to feel guilty).

Several women found it helpful to realize that they were not alone, and that other women with similar experience had experienced similar feelings.

Example:

I never paid any attention at the school in biology classes, so I didn't know too much about my body. When I was told that this was a cancer, I just knew that this is a fatal disease and that I must die. Well, I didn't want to, so I decided to read the book my surgeon recommended I read. Though it took some time (in the beginning I was so scared), I must admit it gave me a lot. I learnt about my disease and that I am not the only one and it was not as scary as in the beginning.

Thirdly, informative books, articles and tapes helped women to accept their feelings and behavior as normal. The knowledge that many women endure treatment for breast cancer, helped to assure women that they were normal, and shared similar experiences with other women.

Fourthly, books and tapes provided hope for successful recovery. Three women mentioned that the evening before the operation they were shown a detailed informative video: "dealing with breast cancer operation and what to expect after the operation. It (the information) was useful and it (the video) decreased my anxiety." However, one woman reported the video as a negative incident, since "it scared me more than helped."

Fifthly, educational materials helped women to decide what type of elective operation was best for them.

My surgeon gave me two options regarding my operation. At that time I did not know what type of operation to choose. A couple of days later I watched a program on TV about breast cancer. They

talked about the survival rate of breast cancer patients. They said that it is equal for patients who had mastectomy with chemotherapy and patients who had lumpectomy with radiation. It was exactly the type of program I wanted to see to get the information I needed. It helped me to decide. I made up my mind. I wanted only a lumpectomy and radiation.

Several women were extremely grateful when medical personnel recommended, or lent them, a book rather than instructing them to "find some literature by themselves". Some of the women commented that they either did not know where to find information, and/or resources, or that they lacked the energy to locate information in the library.

Four women mentioned specifically a book written by their personal physicians, Dr. Olivotto and Dr. Kuusk. They found it to be very important in their process of understanding, and preparing for breast cancer surgery.

I didn't know too much about breast cancer and I wanted to get some more information about it. I didn't know where I could get this type of information. I went to see my doctor and the secretary in her office offered me a book by Dr. Olivotto and Dr. Kuusk. Reading the book was an enlightening experience for me. I appreciated the availability of the book. In my situation - I didn't have any energy left and I was not able to look for it by myself.

On the contrary, it was hindering when women were given reading material which they did not feel ready for. Some women felt frightened or confused when they read certain books. For example, one woman said;

I read a lot of books. I remember particularly one of my first books by Susan Love. It was about her personal experience with breast cancer. For some reason the book frightened me. I tried to read it every evening before I went to bed. However, I was able to read only two, three pages and then I had to put it down. I connected her experience with mine and I was scared that I would not make it.

Some women actively sought more information. Others lacked the energy to do so: "I went to the hospital lacking any information whatsoever. I didn't know what was going to happen to me there. It was a fear of the unknown and the reality was not as bad as I pictured."

## 2. Obtaining an Explanation of Medical Procedures or Problems (24)

This category refers to whether participants received factual explanations regarding medical problems/procedures by medical personnel, or felt that such explanations were withheld, insufficient or inaccurate. This category differs from the category "Receiving Educational Materials, and/or Information" in that women in this category obtained an explanation of medical procedures or problems from medical personnel in person, not through books, or video. It was reported as helpful if medical personnel shared information (e.g., about the biopsy or operation). It was considered hindering if the participant did not receive information or the explanation that she thought she should have, or if she received insufficient or inaccurate information or explanations of medical procedures or problems. Five women reported related, and similar helpful incidents:

A couple of days before I was scheduled for my operation I was

asked to come to the St. Vincent hospital for an interview with an administrative nurse. I went not knowing what to expect. What a pleasant surprise! She explained to me in a detail, step by step the whole procedure, and what to expect after the operation. She also asked me what would I like to eat and showed me around the hospital. It was a very small hospital with a "homey" atmosphere. You wouldn't believe how great I felt. I wasn't as scared as I was before. It was a fantastic experience.

When the "unknown" became "known" the participants felt more comfortable with the hospital environment. They felt "better prepared for the operation" and two of them reported "decreased levels of anxiety". One woman mentioned, "I had anticipated everything and my stay in hospital turned out to be quite a pleasant experience."

Most of the women were eager to receive explanations of medical problems or procedures. Security existed in "knowing what to expect." Those women who were not informed properly (by their doctors) about their disease, and specifically, about what medical procedures they should anticipate, felt lost and scared. Women also appreciated straightforward, factual information when they requested it.

However, the problem they encountered quite often, was the "pressure for time". One woman characterized the situation in this way, "my doctor was very nice, I liked him a great deal, the problem was that he always seemed to be in a hurry and I didn't want to bother him with my problems."

Two other women reported that before the operation an anesthesiologist came to them and told them about their options regarding

their anesthesia. As one said: "he gave me a detailed information regarding my anesthesia. I felt I could make an informed decision and I was in control of the situation."

Some women were more active in obtaining an explanation of their medical problems:

For example:

I needed some medical procedures explained so I contacted the cancer clinic and asked them if I could talk to somebody who could explain some things I didn't understand about breast cancer and who could also tell me more about my options regarding my surgery. I got a nice, young doctor who explained everything I needed. It took him over one hour. I felt much better after.

Example of a negative experience:

I was hysterical the night before the operation. I was home and afraid that after the anesthesia I might not wake up. Nobody gave me any explanations about what to expect and what my options were."

### 3. Discussing Problems with Loved One (12 incidents)

This category involves the women discussing their problems with people close to them, such as husbands, girl-friends, and children and includes only helpful incidents. Women felt "relieved", "soothed and secure", or had their "spirit lifted up."

Examples:

I have a sister outside Vancouver. After the diagnosis I was a mess and needed to talk to somebody. I called her to come visit me and we had a long, open discussion about my cancer and all the

stuff around it. I was very, very open and able to tell her, I think, everything that was on my mind. I felt great and relieved- it was a liberating feeling to talk openly with her.

Four women mentioned helpful discussions with their partners.

After it was clear from all these examinations that I had breast cancer, my GP asked me to choose a surgeon from a list of doctors he gave me. My partner, who is a medical doctor, did his own "shopping" for the best surgeon as well. One evening we sat down in my living room, opened a bottle of wine and discussed together which would be the best one for me. It was a nice evening and I felt supported and, in a way, secure.

In two incidents, women mentioned that after they found out how much they liked discussing and sharing their problems with a loved one, they utilized this method of stress relief more often during their preparation for breast cancer operation.

I remember that my husband and I read the book by Dr. Kuusk together. He explained things I didn't understand and the best thing was that we were sitting in our living room together and openly discussing some important issues concerning my disease and our future. I felt relieved being able to tell somebody what was on my mind and "lucky" that I had him. Funny thing is that it has become sort of a habit and since then we talk and discuss about our problems more.

#### 4. Getting Support and Encouragement from Others (46 incidents)

This category includes incidents in which the women obtained support, or help, from another person through encouragement, comforting,

talking, or acceptance. This category does not include establishing social connections, nor establishing professional communication.

Many women mentioned that they had a tendency to withdraw from people throughout their experience with breast cancer. They described feelings of loneliness, anxiety and disbelief that this experience was happening to them, and feelings of being betrayed by their own body. These participants felt insecure, and were vulnerable to feelings of depression. Examples ranged from getting support from family members, extended family, friends, and coworkers to obtaining support from members of the community, or complete strangers.

Example of a positive incident:

After I got my diagnosis I didn't know what to do. I sat home and felt confused. I tried to decide what to do. "What on the Earth can I do?" The phone rang and it was my daughter. She was great! She talked to me with such an understanding and she also listened to all my worries. She helped me cope better with the disease. I felt supported and relieved. She made me feel so precious.

Because I got the disease I couldn't make it to my summer house. We have such a nice community there, everybody knows everybody. I love the place and the people and therefore I felt sad. I was surprised when my boss's wife showed up with a plane ticket to fly over there for at least a couple of days. She sat down with me, we had a cup of coffee and she told me that all the people from the summer house community put together money and bought me a plane ticket because they missed me so much. I felt so great. I felt loved, like I was a part of a community.

Just sharing things with somebody seemed to be helpful for many women.

Example of a hindering event:

My boyfriend's wife died 3 years ago of a cancer. It was a devastating event for him and his family. After I was diagnosed with breast cancer I told him and his reaction was an awful one. He looked at me and said: "I have a feeling of de ja vu!" Well, I didn't feel like I was going to die right away. His lack of any support what so ever and insensitive approach hurt me a lot.

Some participants reported that financial help from employers helped them in their preparation process for surgery. They did not have to worry about how to live after the operation when they might be disabled. This financial help was particularly important for single or divorced women with children.

I live in a small house, alone. I had to quit my job because of my cancer. I was quite concerned about whether I would have enough money to live on and be able to pay my bills. It worried me quite a lot. I sent a letter to the School Board and they decided to give me a paid sick leave as long as I would need it. It felt great! I felt appreciated, financially secure.

Two women found it very helpful when their employers suggested that they take a leave of absence for sickness. One woman said: "it was like having time to prepare for the battle."

We have a nice collective at work. During my illness I particularly appreciated the way they behaved- they were straightforward. I always knew where they stood. They were even so nice that they suggested that I would take a sick leave. They made me feel very special.

On the other hand some women preferred to continue working, like "nothing happened at all, just a small operation to come".

##### 5. Being Accompanied to a Medical Appointment (10 incidents)

This category includes incidents in which participants were accompanied to their medical appointments. This category consists of only helpful incidents. Visiting a medical setting or having an appointment with a medical doctor was a stressful event for most participants. Some of them mentioned that "my head was completely empty," or "all the questions I prepared home for my surgeon to ask, were gone." Therefore they found it helpful if somebody who was close to them accompanied them to the doctor's appointment, or to the medical procedure. The person who accompanied them seemed to act also as a "back up" for some of the participants, asking the right questions, "making sure that everything goes well."

I don't like to be the only one in a doctor's office, because I might forget something important. My lady-friend picked me up in front of my house and drove me to the doctor's office. She went there with me and stayed with me all the time. She also drove me back home. I felt safe and secure, I was not pressured to remember everything the doctor said.

After the diagnosis I was very emotional and distracted most of the time. My son suggested that I may need somebody to accompany me to my doctor's appointment because I may not remember everything. So I asked my friend of 22 years to accompany me for doctor's appointments. She went and it was much better. I knew that she would remember everything important the doctor said. After we came home we sat down and I made notes.

#### 6. Helping Others (22 incidents)

This category includes incidents in which women reported helping another person, or taking care of another person. In these events women decided to help others to "relieve the pressure inside which hurt and was preventing me to think clearly". By helping others women were perhaps able to shift their attention towards something productive, and therefore less stressful. They perceived the act of helping as a temporary relief from "an awful reality". In this category any form of helping another person, or taking care of another person was included.

Some women reported that helping others with daily shopping, sewing little fabric toys for children, or helping to baby-sit small children, made them feel better. In the following example a woman describes a feeling of usefulness:

I have always loved and enjoyed my job. In my job I am dealing with mentally challenged people. I decided to continue working as long as I could. It kept me busy and gave me the good feeling that I am useful, somebody actually needs me. I also didn't have time to think about my cancer as much. It helped me go through it.

Interestingly, some women helped others by intentionally concealing their own worries and negative emotions.

My son and I are very close. When he learned about my cancer, he worried about me a lot. So I decided to conceal my worries and feelings in front of him to protect him. It was quite a difficult task for me because we are so close. I didn't even tell him I went to hospital. It made me feel good that I could do at least something for him.

There was an old woman living in the house next to us. Her only son moved to Toronto and she felt lonely. She visited me occasionally, but I never returned her visit. After my diagnosis I stayed at home and had too much time on my hand. One day I went over to her house to return her visit. The old lady was sick recently and her house was quite a mess. I helped her to clean the whole house and took her in my car to do some shopping. We spent the whole day together and had a great time. Taking care of the old lady made me feel better for a while.

Other women engaged themselves in different non-favorable activities in order to allow others to feel that they were helping them. This activity, however, made them feel better about themselves.

I am single. Because I live in a community where people know each other I had a lot of visitors. Among my visitors was a priest, a psychologist, teachers, and social workers. They all wanted to help me, everybody had different advice for me to follow. I did what they asked me to do to put them at ease. Even if I didn't really want to do it (like the awful tea, I hated it!). For example I had to drink certain tea, read a certain book, swam twice a week, etc. I

had to help them feel better through letting them think that they are actually helping me. It shifted my attention from cancer to other things. I felt better and stronger as a person.

#### 7. Engaging Oneself in Physical and Creative Activities (8 incidents)

This category includes incidents in which participants engage in some form of physical exercise, creative work or relaxation. There were only positive incidents reported in this category. Participants often saw exercise as a way of releasing their negative energy. There were a couple of ways in which physical exercise, creative work or active relaxation helped women to feel better about themselves. Firstly, women were able to feel stronger and more capable when they exercised. Physical activity helped their bodies become stronger, and react better to the cancer treatment and related stress.

A couple of days after I was given the diagnosis, I couldn't stand being at home. I needed to do something. I was a mess and being home almost drove me crazy. I decided to do something for myself. So I did a lot of outdoors hiking by myself and it helped me in two ways. I was doing something for myself, and I was helping my body to become stronger to fight the disease.

Secondly, it helped many women "buy", or obtain some private time to sort things out in their own minds before making important decisions.

When they (the doctors) discovered that I had a cancer, we were in the middle of a renovation of our business. I was devastated, but I managed to keep myself busy- I was painting, cleaning and did all the construction work with my husband. It helped me. I didn't have to talk about my disease with anybody.

Thirdly, leisure, or physical or creative activity often shifted the women's attention to something other than their illness.

There were only two weeks between the diagnosis and my operation. Everything went so fast. Everything was in such a hurry. In the evenings I took my knitting and sat down for a while. I was working on a sweater with a difficult pattern. This required a lot of concentration. After working on that pattern for a while I realized that I felt better. It took away some tension from me. There I was, sitting, working and focusing on a knitting pattern. I was able to relax and sort things out.

Fourthly, two women reported discovering new resources within themselves. Leisure activities gave them a feeling of "something positive in an otherwise a sad story". One woman reported:

After my diagnosis of breast cancer I was close to a breakdown and I decided to quit my job. Because I had a lot of time on my hands, for the first time in my life, I was doing a lot of different things like painting, gardening, cooking. I actually enjoyed myself! I discovered a creative part of myself, which I was not aware of before.

I always knew that we have a nice collective at work. During my illness I particularly appreciated the way they behaved. For example, one girl, the youngest from our collective, asked me if I wanted to join her and go with her to the gym. Well, at the beginning I was quite skeptical, because I am not young any more, but I went with her a couple of times and it felt great. I couldn't exercise too much in the beginning, but I felt good. So we went at least twice a week. I got a lot of energy and felt more optimistic. I was quite proud of myself.

Fifthly, one participant reported being helped by engaging in a new sports activity; "I was able to focus on myself, on my needs and it felt great."

#### 8. Developing Helpful Habits (9 incidents)

This category encompasses incidents describing participants' development of helpful habits. Women in this study reported only positive incidents in this category. Most of these helpful habits persist in participants' lives for some period of time even after their operation for breast cancer surgery.

I was never a morning person. Since I am a teacher I must be at school every morning at eight o'clock sharp. I hardly ever went to sleep before midnight and consequently every morning I had to fight myself to stay in the bed " just five minutes longer". But everything was in a hurry and I had to run to school not to be late. It made me feel guilty and nervous. After learning about my cancer I started to be more "tuned into my body feelings" and I developed the habit to go into the bed every day between ten and eleven o'clock. This made my mornings much more pleasant and enjoyable.

Three women reported developing healthier eating habits while they prepared for breast cancer surgery.

I always had awful eating habits all my life. I could eat anytime I wanted and I just loved junk food. Since I learnt that I had breast cancer, this has changed. Because I wanted to be free of cancer as soon as possible, I took all the vitamins and supplements and I started to eat well. I believed that I was building up my immunity. It made me feel I was fighting the disease.

One woman, who used to be forgetful, became more organized when she developed the habit of bringing a pad and folder to her doctor's office:

I never got anything that my doctor told me right. I sometimes had to call his office to check his instruction with him or with one of his nurses. However, breast cancer is a serious business and I knew I had to get it right. I started to scribble down anything I needed to ask my doctor on a piece of paper so I was prepared to ask the doctor all these questions. And I always brought a pad and a folder to his office to make notes of whatever he said to me. It made me feel safer, I became more organized and felt that I was more in control of the situation.

Two women reported developing habits such as "actively trying to think positively." They both said that they still keep this attitude towards life. Another woman noticed a shift in the perception of her needs. Because she liked this shift, she decided to always prioritize the immediate needs in her life. She said for example: "when I am tired nothing else matters, I go to bed even with the dirty dishes in the kitchen sink."

#### 9. Taking Action upon Realizing Own Mortality (9 incidents)

This category includes incidents in which women decided to take some actions on realizing their mortality. There were seven positive and two negative incidents in this category. Two women spoke of writing a last will and taking care of other legal obligations. For example, one woman said:

My cancer made me realize that I may die tomorrow. It is not a nice feeling, but it's life. Therefore I decided that I had to show my

son (who isn't very practical) where I had all my money, I explained him his legal obligation and my last will and other necessities. After I had done that I felt relieved that he will know everything that needs to be done in the case of my death. It gave me peace of my mind.

One woman did not have any relatives. She lived alone in an apartment building. She felt that "it was important for me to let people in my neighborhood know about my disease so they could eventually help me if something unexpected would happen. I felt safe". Two other women worried about their pets because they felt responsible for them. They made arrangements for these pets in case of their death and that brought them peace of mind.

There were two negative incidents in this category.

Example:

I initiated a family gathering because of my birthday. It was couple of days after I was diagnosed positive with breast cancer. I felt my loved family felt uneasy when they congratulated me. I could read in their minds the question: How many birthdays are we going to celebrate with you? It was overwhelming, I felt sad knowing that maybe next year I will not celebrate with them. I realized that I may actually die and I can't do anything about it.

#### 10. Experiencing Physical Closeness (16 incidents)

In incidents included in this category women reported experiencing physical closeness. It was considered helpful when a person touched women in a nurturing, comforting way or expressed a desire to do so. They felt "cared for", "comforted", or "relieved".

Some women reported getting a hug from a medical person who delivered bad news about cancer, or cancer treatment, to them. One woman said that, "It made a big difference to me." Other women reported: "a sense of feeling not as alone" and "physically supported."

For some women, to be touched represented being worthy of love, "I felt so precious to him, deeply loved". This connects to the fact that some women blamed themselves for the disease, and therefore did not feel worthy of being loved. The meanings women derived from emotional, or physical closeness, included, " I matter," and "I am worthy of being loved." Two women reported that experiencing physical closeness helped them to start to feel physically better.

I am a widow and sometimes I miss a human touch. Especially after the diagnosis of breast cancer I felt vulnerable and missed physical closeness. I visited a retreat of our church group in lovely peaceful surroundings close to Vancouver. The nuns there were such wonderful, soft, lovely and kind human beings. After the lunch we walked along the river holding each other and it felt so great. What was very important to me was the kind of human touch I got from them. It gave me a feeling of deep human understanding without words, I felt relieved from all my worries about my disease. I got peace of mind.

In this category there was only one hindering incident mentioned:

Shortly after the doctor told me I had breast cancer my daughter had chicken pox. We are very close and I enjoy cuddling with her every day. But because I never had chicken pox, she had to be isolated

from me. I felt terrible not to be able to cuddle with her, I missed her hugs a great deal.

It is worth noting that most women responded to experiencing physical closeness with some kind of positive body reaction, described as, "my body felt relieved" or, "I didn't feel it (cancer) any more."

### 11. Experiencing Deep Emotional Closeness (7 incidents)

This category refers to the individual's experience of deep emotional closeness with someone from her family, extended family, friends or even a stranger. There are only positive incidents reported in this category. This category differs from the category "Obtaining Help or Support from Others" in that women in this category experienced deep feelings of emotional closeness and bonding with another individual.

Example:

I live alone and sometimes I feel lonely. Especially during the time after the diagnosis of breast cancer was made, it was difficult for me to go through the day. I remember particularly one day. It was a sunny day and my daughter left earlier from her work and drove directly to my house. We spent a beautiful afternoon sitting together on the bench in the garden and just talking. That afternoon I was able to forget all bad thoughts and had peaceful feelings inside myself. I felt loved. I enjoyed this feeling of closeness with my daughter.

One day I was sitting in the waiting room in the Cancer Clinic Center waiting for the results of my biopsy. I was very nervous and my husband did not feel any better. An older lady sitting next to me started to talk to me and we found out that we shared a very

similar fate. We were both diagnosed with breast cancer. She was such a nice, gentle and sweet old lady. She smiled at me all the time, and was listening to all my complaints, concerns and fears with understanding. We talked for almost half an hour and I had this funny feeling that I had known her forever. It felt so wonderful to be with somebody who could understand my most intimate thoughts, I felt very close to her and we met a couple of times after that, before she died.

A couple of women mentioned similar experiences occurring when they talked to somebody from their support group. However, most of these events, or experiences, happened outside of their regular meetings, in a more intimate and private environment. Usually, there were only two people present at the time of emotional bonding.

#### 12. Realizing Shift in Relationship with Loved Ones (10 incidents)

This category refers to incidents in which women noticed certain changes and shifts in their relationships with their loved ones (a family member, or friend). More specifically, incidents in this category do not imply starting, or developing, a new relationship. Most women in this category reported incidents in which they observed a relationship becoming stronger and more intense throughout their preparation for breast cancer surgery. Women found it important, and helpful, when people who were close to them demonstrated strong emotions for their well being (e.g.: "he made an extra effort to show me how he cares", or "I felt basically I could not go through this without him, and we were inseparable ever since", or "we became very close and connected since the biopsy experience").

Two examples of positive events include:

I always knew I could count on my husband. But during the whole process of my disease he became a backbone for me. He went everywhere with me, to the doctor's office, hospital, etc. I realized that when he went with me to visit my old girl-friend. He didn't like her too much, so he drove me there and waited in the car in front of her house. This made me very happy, we were like newlyweds again.

We have been married for over nine years and I have a great relationship with my husband. However, sometimes I think I took him for granted. Through all the hassle with my disease I started to appreciate him more and more. I had to decide what type of surgery I wanted. It was difficult for me. I did not want to be without one breast, but on the other hand I did not want to die either. So I went for the safe one, mastectomy. My husband supported my decisions. I felt that I could count on him. He became a source of strength for me. I could not have done without him, we became very close during the preparation for my surgery.

There are four negative incidents in this category. One woman admitted: "he did not show any interest in intimacy for two months, I realized that he didn't love me any more". Another woman, who was diagnosed with a colon cancer and six months later with breast cancer, reported:

We had a nice marriage for a couple of years. But when my husband learnt about my second cancer, he didn't want to talk about that. I guess it was a sort of overwhelming experience for him. He did not speak to me and became sulky. This made me angry, because I

needed him and he was not there for me. We became estranged for a while.

Most women expected support and encouragement from their partners and family members. However, for some it seemed as though their partners had difficulty coping themselves with the new situation.

### 13. Healing Through Spiritual Experience and Visualization (16 incidents)

This category refers to women having spiritual experience or using visualization to prepare themselves for breast surgery. There were only positive incidents reported in this category. Two women spoke about receiving positive energy from other people. For example:

The day before surgery was a critical one for me. I was afraid of the operation and my spirit was quite low. My friends organized a surprise dinner for me the evening before my surgery. We all stood up and made a spiritual "healing circle", holding each others hands. I felt overwhelmed being in the center of this loving attention and went to sleep happy, knowing how many people care about me. I felt deep connection with all my friends and this gave me a strength to "survive" my operation.

Most of the time (after the diagnosis was made) I felt sad and a little helpless. One day I opened the window and found a folded paper on the balcony. The paper contained a message: "Whoever will read this paper I wish you the best and love." I believe that this was a message from my recently deceased girlfriend. This wonderful experience gave me more hope for the future and reassurance that I am on the right track, that I am going to make it.

Some women mentioned visualization prior to surgery as a helpful incident or experience.

One of the activities we did in a support group which helped me most was a visualization. As a part of our healing we tried to visualize our cancer. It was team work. We made a circle and we held hands. It was a powerful spiritual experience-it made me feel stronger.

Another women reported:

Learning that I had a cancer made me tense. I didn't want any strange things inside my body. I like to play golf. However, this was a special ritual for me. Every time I looked at the golf ball, I visualized it was a cancer in my body. I said some naughty things to it and hit the ball as much as I could. It was a big sigh of relief. It took tension off me, like someone lifting a weight from my shoulder.

One woman described another incident:

I wanted to get in touch with my cancer, so I wrote to my cancer. Through formulating all my negative feelings I was able to feel relieved and less pressured.

#### 14. Changing Perspective Through Comparison (10 incidents)

This category includes incidents in which women reported learning to better accept their situation, and to cope with their disease through comparison with another person in a similar situation. Learning about the experiences of other people in similar situations helped them to change their negative or pessimistic perspective of breast cancer, and adopt a more optimistic, or at least hopeful outlook, perspective, that was

considered helpful for their preparation for breast cancer surgery. There are only facilitating incidents included in this category.

A couple of days after the diagnosis I was having a coffee with my girlfriend who is originally from Great Britain where she had both her breasts removed because of breast cancer. She told me that a couple of decades ago, when you used the word "cancer" in Great Britain it was perceived as "plague", and therefore people did not talk about it at all. Hence she could not tell anybody about her operation. It was sad for her and she felt lonely. I realized that I should be more appreciative of these days when breast cancer is discussed openly and I can talk about my disease with everybody. This gave me a little different perspective of my cancer.

Immediately after the diagnosis I felt awful because I just could not come to terms with the fact that I had a breast cancer. I pitied myself. A couple of days later, I talked to my Romanian colleague, who told me "You are so lucky that you live in Canada. In my country they do not have the means yet to diagnose breast cancer at such an early stage". Somehow I didn't pity myself anymore. On the contrary, I felt really lucky and privileged to live in Canada.

Learning about the situation of women in different countries made participants realize how privileged they were to live in Canada. It gave them positive feelings of confidence and trust in their treatment in a country that as one participant mentioned "has one of the best health-care systems in the world". This showed to be an important aspect for them.

Another type of comparison was with somebody who was successfully coping with a similar disease (e.g., another cancer, leukemia) and served as an example, or a role model.

I had a friend who has had leukemia for years. One day she told me: "This was one of the best things that ever happened to me". It helped me change my negative attitude toward my cancer. I told myself, if she could find something positive about the disease, maybe there is something positive in this experience, and I started to look for it.

#### 15. Using Inspiring, Comforting Material (13 incidents)

This category includes incidents in which participants reported using different inspiring or comforting material to facilitate their preparation for breast cancer surgery. Women reported only helpful incidents in this category. Incidents ranged from reading a beloved book from childhood, to listening to a favorite radio station or classical music, to using different types of audio and videotapes with relaxing exercise, and to autohypnosis. There are only positive incidents in this category.

Examples:

After I was given the diagnosis I felt overwhelmed and thought that I could die sooner than I expected. I remember one day coming home sitting in a chair and feeling completely drained. I took out photo album of my family. I am very old, I don't have any family left. They all are dead. Just looking at their pictures I felt somehow quite peaceful and relaxed.

I have used different relaxation techniques, usually on tapes. For example: E. Muller: "Letting go off stress." It helped me. Later I listened to :"Preparing for surgery" by the same author. These tapes helped me to heal, I felt relaxed, I could let things go for a while.

Through the use of inspiring, comforting material participants were able to relax. The leisure activity also seemed to give women time to ponder their situation, and see it from a better, or renewed, perspective.

#### 16. Getting Alternative Treatment (6 incidents)

This category includes the alternative treatment experiences of women diagnosed with breast cancer. All of the women in our study received regular medical treatment, and the alternative treatment they reported was supplementary. One facilitating event (one participant went to see a special dietologist/macrobiologist and she considered it to be helpful for her) and five hindering events were reported.

Examples of hindering incidents:

I went to see a naturopath. I was surprised when she told me that doctors are too quick to do the surgery. She also expressed an opinion that only alternative medicine is the right choice for breast cancer. I was confused and upset. I believe she just wanted to sell her products.

I wanted to get the best treatment for my cancer. I went for a second opinion for Integrated therapy offered by a private MD. He gave me a lot of information which I already knew. I had learnt it in groups and from my readings. He did my examination and gave me a chart to fill in to help me watch my diet. I was irritated, annoyed that I wasted my time and money.

Because I had decided to try every treatment reasonable and available on the market I went to see a Chinese doctor here, in

Vancouver. He did something with his hand and said he gave me some energy. He added also shark cartilage to help the body deal with the cancer. However, my tumor markers went up and blood sugar went up and down, my body didn't like the treatment. It didn't work for me.

One woman had an experience with sinobiology. However, she found it "a very abrasive method because they asked us to dismiss other alternatives."

It is interesting to note that in all events participants sought alternative treatment without recommendation of their medical doctors.

#### 17. Establishing Professional Communication (18 incidents)

This category refers to whether women were able to establish professional communication with medical personnel in a way identified as helpful or hindering to the process of preparation for breast cancer surgery. Good communication between medical personnel and patients seemed to be of great concern to participants.

Example:

When I went to see a doctor because of my "sore" breast, I was scared to death. I was scared more than when I went to see my dentist. I did not know what would I tell him, so I wanted to be seen by a woman. What was my surprise when the appointment turned out to be quite a pleasant thing! She asked me a couple of simple questions and she seemed to understand everything I told her. She was also very patient, waiting for me to dress up, before we sat down and talked. I felt relieved I have chosen her to be my doctor.

Certain factors, as outlined by participants, obstructed the establishment of professional communication between medical personnel

and participants. For example, a limited amount of time in a doctor's office was perceived by many participants as very distressful. For some women a limited amount of time with their doctors helped to create an upsetting environment. As one woman said: "The doctor seemed to be so busy that I was more looking at the clock on the wall, than asking him the right questions".

Some women reported having a difficult experience while interacting with medical personnel over the telephone. Women expressed a wish to have their results, information, and instructions explained to them in person.

An example:

In the middle of March I got a phone call from my surgeon. She told me over the phone that I need a needle biopsy. I was not prepared for that. I didn't like the fact that she told me that on the phone. I did not have enough time to ask her about my options. I would had preferred to be told that in person.

Two women reported experiencing some difficulties when they expressed a wish for a second opinion. One of them reported; "I had this strange feeling that she might have thought that I did not trust her any more".

The use of excessive medical terminology seemed to be another factor obstructing the establishment of effective communication between medical personnel and their patients.

I went to school just for ten years, so I know I did not get enough education. But I had got a good job and I enjoyed it for almost fifty years. But when my doctor told me what I had, I thought I was going to die tomorrow. That was how awful it sounded. I didn't understand him well, but I was afraid to ask.

Some other women expressed the feeling of being ashamed, or being afraid to ask for explanation, when they did not understand an aspect of their disease. Women found it helpful if their doctors checked with them regularly, or even occasionally, to be sure that they understood the instructions, or information, they were receiving.

#### 18. Waiting for Medical Results (5 incidents)

This category consists only of negative incidents. Women all dealt with the excruciating experience of waiting for the results of a medical examination (such as biopsy or mammogram). One woman said; " it was (waiting for five days) unbearable, I was a nervous wreck."

Two negative experiences:

The needle biopsy was an awful experience for me. So I hoped I would be able to get my results as soon as possible. However, I had to wait three long weeks for my results, because my surgeon went on vacation. It was a torture for me. I felt absolutely terrible not knowing what to expect.

To cope with cancer was difficult. But the time I spent waiting for results of my biopsy test was excruciating. One minute I had my hopes up, the other down. I was devastated, it drove me crazy.

All women spoke very negatively of this waiting period, citing the experience such as; "It was tiring", "it drove me crazy", "it was a torture for me, I felt absolutely terrible, not knowing what to expect." One woman considered the waiting period to be; "the worst thing from the whole process."

#### 19. Sharing Experience in Support Groups and Counseling (16 incidents)

Within this category women reported of their participation and sharing experiences in support groups, and counseling. Women seemed to gain a sense of empowerment, as though they all shared the same fate (cancer), and were giving each other strength to "fight the disease". Four women described their similar positive experiences with the Cancer Center as follows.

One of the activities we did in a support group which helped me most was sharing our experiences with breast cancer. I felt that I am not the only one to suffer and that made me feel better. I remember one older lady, who told us about her sister living without her breasts quite happily for over fifteen years. I could still remember the feeling of relief that there is actually a life after the operation.

A couple of women emphasized "sharing experiences" as "the very beginning of my healing." One woman talked of her experience in Hope group: "it was important for me to hear from other people that they had the same worries and problems as I did. It was like somebody removed part of the burden from my shoulders". A couple of women reported seeing a

counsellor or psychologist. Most of the time it was perceived as a helpful incident.

After I learnt about my diagnosis, I needed some help. I went to see the therapist-grief counselor. She helped me through feeling my own body and its pain. I felt that I was able to understand my body better, it was not a "stranger" to me any more. I made connections to it and we became a unit.

By contrast, there were four hindering incidents reported. Two of them were identified by women who were visited in their home by a volunteer from Reach to Recovery: "the woman (who came to visit her) was a survivor, but was very calm and distant, not the kind of person I would have expected." In the second hindering incident, "the lady (volunteer/breast cancer survivor) used a lot of personal details, I didn't want to hear that/personal details/, neither did I want to talk about my situation with a stranger." Both participants said they understood good intentions to be behind these visits, however, they seemed to believe that such a sensitive issue was not handled properly.

#### 20. Perceiving Professional Manners (13 incidents)

The incidents reported in this category refer to women's perceptions of the professional manners of medical doctors, nurses, technical personnel and receptionists in medical settings as helpful or hindering in their preparation for breast cancer surgery. Women who reported incidents in this category were very perceptive of subtle nuances in the presentation and behavior of medical personnel, such as their choice of words, voice

tone, facial expressions, and/or posture shifts. Women assigned to medical personnel who appeared gentle and attentive to their needs, yet efficient throughout their interaction, felt better than women interacting with medical personnel who displayed cold and distant mannerisms.

Example of a positive incident:

I went for my regular mammogram and the doctor found something she didn't like. She decided that I needed an ultrasound and a needle biopsy and therefore she arranged for that and did both the same day. She was so efficient and had great professional manners. I was very impressed. She was behaving very nicely. The way she spoke -gently, kindly. I trusted her. Although it was a life-threatening situation, she made me feel good.

One of the most frequently cited helpful incidents in this category involved the doctors' approach to their patient. Four women mentioned " a matter of fact" approach. They all liked this kind of professional manner and they found it very helpful for their preparation for breast cancer surgery.

On the second visit in my surgeon's office we discussed what was going to happen to me next. My surgeon told me with a matter of fact approach that they have to remove the lump from my breast right away. Her attitude was wonderful, she didn't make a fuss around it. I felt that I was in good hands and nothing wrong was going to happen to me.

One woman appreciated the "straightforward " manners of her surgeon.

I went for an appointment with my surgeon. He was straightforward with me, looking in my eyes all the time, and told me that I had a cancer and that I need an operation. It suits my character if somebody is like that. If people are too emphatic, or hiding something (like they aren't telling the whole truth), it does not work for me.

Some participants were appreciative if the medical personnel were "open" with them:

After my mammogram I had to see a surgeon. She told me: "Something suspicious is there. Let's open it and we will see." I appreciated her openness. She was not hiding anything from me.

Other women were very perceptive as to whether, or not, the medical personnel treated them equally and with respect. Three participants mentioned that they liked the medical person if he, or she, was "respectful". One woman mentioned:

The attitude of people I am dealing with is very important to me. I realized how lucky I was with my surgeon. She was open and respectful even when I called her a couple of times in the late afternoon, when my worries escalated. I felt that she was treating me as an equal. Though not everybody from the medical community does. She gave me a lot of self-confidence.

The same woman, however, also reported a negative experience:

When I went for my biopsy I was scared what to expect. They put me in the bed in a big room. Next to me was another bed separated from me by a curtain. I heard the lady screaming from that bed, obviously I heard "operation procedures." It took a while and I was so scared that I couldn't talk to ask them to put me somewhere else. It was very insensitive and unprofessional to put me next to somebody who went through the same procedure before me. What did they (medical personnel) think this is going to do with me? It was awful and inconsiderate.

In this category some women also reported incidents in which they were observing the manners of nurses and receptionists. The women considered their relationship with support personnel very important. One woman mentioned that; "It was not so embarrassing for me to ask the receptionist. I felt more comfortable asking her instead of asking a doctor".

#### 21. Experiencing Positive Medical Settings (5 incidents)

This category refers to the women's positive or negative perceptions of their medical settings or environment. It was considered helpful when the setting appeared warm, cheerful and comfortable.

One example of a helpful incident is quoted below:

Every time I see a doctor it is a stressful event for me. I remember my three appointments with my surgeon before the operation. I was devastated. However, I can still see the waiting area of my surgeon office. It was quite a cheerful place to sit down. Especially the color of the furniture and carpet was appealing to me. The chairs were very comfortable. I cannot say that it was a pleasant experience for me to be there, but I think that it relaxed me a bit, I wasn't so tense.

Other two women reported similar experiences, "I entered the waiting room of my surgeon and it had a cozy, friendly atmosphere, and I was able to relax a little bit and look at my disease from a more positive perspective." One woman reported a negative incident:

I think that everybody deserves privacy. When I came first time to visit my surgeon, I noticed that the way the office was set up really bothered me. There was no privacy, because all the tests and appointments were discussed with the secretary in the middle of the waiting room, so everybody could hear. I felt not so much embarrassed, I felt more exposed. I didn't want people to feel pity for me. They might also recognize me in the street.

For some women, the medical settings, or environments were perceived as very important places. They reported that in cozy, cheerful and comfortable environments they were able to relax and view their illness from a different perspective.

#### 22. Getting an Approval/Recommendation of Medical Personnel (4 incidents)

Women who reported incidents in this category obtained the approval or recommendation of the medical person who was treating them. This category consists of only four positive incidents.

I went to see my GP. We talked about my further treatment. He recommended me a surgeon. He told me that this one is the best I can get. I felt completely confident and from then on I trusted my surgeon 100%."

The other three incidents were similar in nature: "they all told me he is a great surgeon", and "the nurse in the hospital came to me and without asking spontaneously told me: 'You so lucky to have Dr. X'". Women were comforted to know that their surgeon was highly respected by others. They trusted their doctors and it made them feel safe, as though they were "in the right hands". One woman reported a decreased level of anxiety prior to surgery as a result of this type of approval.

### 23. Questioning of Competence of Medical Care/Personnel (37 incidents)

This category includes incidents in which women reported their perception of competent medical care, and/or medical personnel, in a way that was helpful, or hindering, to their preparation for breast cancer surgery. The third largest category includes 17 helpful and 20 hindering incidents. This category does not include events involving establishment of relationships with medical personnel, their perceptions of medical settings, their observations of professional manners, or their experiences while waiting for medical results (discussed as separate categories). In this category women were more "judging" of medical care they received, and the medical personnel involved with their therapy and treatment. As well, women commented about how medical personnel handled their individual cases.

For example:

Before I learnt I got breast cancer I used to have good rapport with my GP. However, it changed after I was diagnosed with breast

cancer. I felt he did not give me enough information I needed. He was very distant, cold and did not explain to me what I was supposed to do or anything about my prognosis either. It seemed to me that he didn't know too much about breast cancer. I felt that I was not prepared for my surgery.

Several other women also reported negative incidents in which they accused medical personnel of negligence, or incompetence:

Before Christmas 1994 I felt a lump in my breast and went to see my GP. She couldn't find the lump and sent me home with: "We will keep an eye on it." She did not order any further examination, nor mammogram. I was uncomfortable with that, worried for next six months till the next mammogram showed the lump and breast cancer was diagnosed. I was angry and I do blame her.

After the mammogram was positive they wanted to clarify the diagnosis and I was scheduled for a needle biopsy. My doctor showed a great deal of uneasiness doing the biopsy. It took him for ever to do the biopsy. Judging from his performance it was his first biopsy. I was scared and at the same time I felt annoyed, I didn't trust him any more.

Some women felt that they didn't obtain enough time with, or information from, their doctors to make a proper and correct decision regarding the type of breast cancer surgery elected.

I was given two options regarding the type of operation for breast cancer. My surgeon booked the operation room prior to my decision about the type of my operation. It made me feel uncomfortable,

rushed and pressured. It also prevented me from reading more about breast implants.

Another woman reported:

He ( GP) just handed me a list of surgeons and told me to pick one. He didn't give me any more information or support, neither did he show any interest in my decision.

Women who made an observation of, or questioned the competence of medical care or medical personnel, identified certain important elements as inadequate and/or insufficient. For example, one woman noticed a lack of flexibility, and an inability to handle individual cases differently. As another woman said: "Every patient is distinct and has different needs and my doctor just did not seem to take it into the consideration."

Two women had a very critical view of the medical community as a result of their experience. One of them explained as follows: " I was angry, because they (medical personnel) were rude and couldn't care less that somebody was suffering." She went on to explain that after her mammogram was done and the results were indicating a lump in her breast, she wanted to talk to a radiologist, but the nurses in a waiting room were rude and didn't let her talk to him. They told her that she was supposed to discuss these findings with her GP, not the radiologist.

Women quite often reported on behavior of medical support personnel, such as; "the person who actually did the ultrasound was in a terrible mood and very, very unpleasant," or "the doctor was explaining the pathology report and all the time he was looking at my husband. He didn't look at me at all. I felt like I didn't exist for him, like an object, completely

"unimportant". By contrast, many helpful incidents were also recorded in this category with regard to the behavior of medical personnel. For example:

In January my GP sent me for a mammogram. I went to a clinic and a young doctor took care of me. She didn't like the results of my mammogram and persuaded me to stay for another test. She insisted on needle biopsy. She was very competent and at the same time caring person. I was grateful for all her care and I felt I was in good hands.

It was important for me to have a good doctor I could trust and would give me the best treatment. My surgeon (woman) came across as a confident, but also very caring doctor. Because she was very concerned with my swollen ankles, she ran all these tests to find out more about it- something even my GP didn't do. She made the impression on me that she is skillful (good with needlework). I liked the care she gave me, I felt more at ease.

I think I got a very good surgeon. She probably saw how scared I was when I got the lump in my breast. Although she must have seen hundreds of women like me, she was very nice. As a woman she knew about all my concerns. She even did some drawings for me. I trusted her, I knew what was happening to me and it made me feel better.

Another sensitive issue involved participants' follow up with medical personnel. Some women reported disappointment when their GP did not keep in touch. One woman said: "He promised, but he actually never showed up and never called to find out about the results of my operation". This kind of behavior made them feel abandoned, or even betrayed. Other women were really impressed by their GP's follow up. Some GP kept in

touch with participants throughout the entire process. A considerable number of women reported how important it was for them to have somebody who was there for them all of the time. As one woman said: "he never took his eye off me."

A couple of events in this category dealt with the very sensitive issue of time pressure during doctors' appointments. One woman, for example, mentioned that within two minutes of the first meeting with her oncologist she was told that she was "too young to die". Prior to the comment she had not considered the possibility, and the comment frightened her.

### **Decision-Making Processes**

The literature about breast cancer and its treatment is vast. Women these days can access not only general information about breast cancer and its treatment, but also precise survival statistics for breast cancer and each mode of breast cancer treatment. However, consulting physicians may offer different interpretations of the data available from studies that compare mastectomy and breast-preserving surgeries. Therefore the dialogue between physician and the patient regarding breast cancer diagnosis and its treatment seems to be the most crucial for women facing their decision-making task. On the one hand it eases some of women's stress to discuss their treatment of breast cancer, however, it also poses a new psychological burden of feeling responsible for making the "right" decision, often with incomplete or ill-understood information and at a time when anxiety is already great. My aim was to establish psychological preparedness of women with breast cancer for their choice of surgery type (mastectomy vs. lumpectomy).

According to the study's data, participants could be divided into four categories according to the type of operation they underwent, and according to who made the decision about the type of their surgery.

#### **1. Women with lumpectomies who made their own decisions (10 participants)**

Here are some examples of how some participants decided upon breast-preserving surgeries:

My first reaction was to have a mastectomy. However, after some thinking I decided to opt for a lumpectomy and radiation. The librarian told me that a lumpectomy and radiation are as effective as a mastectomy. My friend who had a mastectomy said to me: "I wish I hadn't done that." This was crucial for me to opt just for a lumpectomy.

My surgeon gave me two options: mastectomy, or lumpectomy with radiation. I had to make up my mind immediately because of time constraint. I didn't want to lose an important part of my body. The way I look at it is, that my breasts are more important for me than the need to clean my body from everything (cancer). Besides, my surgeon didn't tell me that one option is better than the other one.

My decision was based on my surgeon's recommendation, which I carefully discussed with my partner, who is also a medical doctor. I also did a lot of reading before I made the decision.

I was given the option of only lumpectomy with chemotherapy or lumpectomy and radiation. My surgeon let me decide. I went to the Cancer Clinic library and read some books and articles. I also called my son who is an emergency doctor and asked him. He did some research and recommended me to get a second opinion. However, the decision was mine.

After the biopsy of my breast I discussed with my surgeon what kind of operation would be best for me. He gave me two options regarding my surgery: mastectomy or lumpectomy followed with radiation. However, he did not recommend one option, or the other. Actually, I felt he did not give me enough information to make the informed decision. I was upset, and didn't trust him any more.

I did not do too much reading about breast cancer, but I read one article in the Readers Digest about a mastectomy having the same results in survival rates as a lumpectomy with radiation. It was important for me to know that because I kept switching from one decision to the other one until I read that article. I think that it really helped me to decide for what my new surgeon (her surgeon went for a vacation) suggested- to have only a lumpectomy.

2. Women with lumpectomies who did not make their decisions ( 8 participants)

The following examples illustrate how other women made decisions regarding their lumpectomy surgery:

I didn't have to make any decision, my surgeon just told me that I needed only a lumpectomy. I never challenged his decision, it suited me well. I didn't want my breast to be removed, anyway.

I was never given an option between mastectomy and lumpectomy. I was always recommended a lumpectomy with radiation. And it was fine with me.

We never discussed the option of my breast being removed with my surgeon. I assumed that my cancer was in an early stage.

3. Women with mastectomies who made their own decisions (.8 participants)

The following are some examples which demonstrate how eight women from the study arrived at the decision of having a mastectomy:

I learned through the literature (participant did not specify

what kind of literature she used) that I have 30-40% chance to survive five years if I have only a lumpectomy with radiation or chemotherapy. With a mastectomy I would need radiation but not chemotherapy and would have only 10% chance of recurrence. I wanted a simple mastectomy (without reconstruction or lymphatic glands removal). Presently, I do not feel less as a woman. I have come from a very close knit and traditional family and I feel very close to my son and husband. It did not change my life at all.

I made the decisions (regarding the type of surgery) on my own. Because I am strictly an academic person, I decided to do all the readings about a "flap" reconstruction. I realized also that because I am a very thin person I could have a problem after this (reconstructive) operation, and will not be able to do my "sit ups". My surgeon recommended me a breast removal operation, although he told me of other options. I went for a second opinion and only after that I opted for a mastectomy with a reconstruction with an implant.

Because of the positive family history of breast cancer, I wanted to make sure that "everything" (breast cancer) was gone. A lady in our street had only a lumpectomy and went through hell. She died, anyway. I made up my mind before the biopsy, because my priority was the safest treatment. I also talked about the operation with my husband and he agreed with me.

I went to see my surgeon who told me that I needed an operation, that it is not dangerous and that everything would be fine. As a person who wants to know what is going on, I asked him a lot of questions about other treatments and possibilities for my operation. But I felt that my questions were not properly answered. I didn't feel in control of my disease, somebody else made all the decisions and I did not like that. Because I needed more information than I got from my GP and my surgeon, we contacted the Cancer Clinic in Vancouver. We asked them if we could talk to somebody who could

explain things I did not understand and who could tell us more about my options. We got an appointment with a young oncologist, who answered us all the questions. Finally, I felt relieved that I got all the answers I needed and that I could make the right decisions regarding the type of operation for breast cancer surgery. I decided for a mastectomy with a reconstruction.

Making a decision was a little easier for me because my husband was dead. I wanted the safest operation which was recommended to me by my doctor. I did not have any problem to adjust. I believed that my doctor did the best to help me to get rid of the disease.

#### 4. Women with mastectomies who did not make their own decisions ( 4 participants)

Here are some examples which illustrate why some women, who did not make their own decision regarding the type of operation for breast cancer surgery, underwent mastectomy:

I was told by my surgeon that the mastectomy is the only option for me. I didn't really care, because of my age. I guess it would have been different for me thirty years ago.

My surgeon told me that because of the stage of my disease a mastectomy would be the right option for me. I had a hard time to deal with the image of my body without my breast, I was scared and needed to talk to somebody about it. But I guess, it is better to live without a breast than to be dead.

Since there is a lot of breast cancer in my family, I wanted to play it safe. I wanted to get rid of it all. I did not mind a mastectomy which was strongly recommended by my surgeon. I wanted to have my

breast removed from the moment I had learned about my cancer.

The largest category of participants reported in the category of "women with lumpectomies who made their own decisions" (10 participants). Two categories ranked as second largest: "women with mastectomies who made their own decisions" and "women with lumpectomies who did not make their own decisions". Both categories had eight women each. The category with the smallest number of participants were women who did not make their own decisions, and were recommended for mastectomies. This category included four participants. In most cases participants who did not make their own decisions were recommended a specific operation by their surgeons.

Although women presently have access to survival statistics for each mode of treatment, most participants in our study seemed not to be aware of the plurality of existing views concerning primary breast cancer treatment. A few women recognized that no "best" treatment exists, and that there is a multitude of treatment options. It should be considered that most participants in our study at the time of their diagnosis did not have any previous knowledge of breast cancer, except for some information from the media like television or radio.

Many participants in our study struggled simultaneously to keep distressing emotions of anxiety and fear within tolerable limits, while they were making the difficult decision about treatment for a potentially fatal disease. For many of them the experience was overwhelming. Some participants admitted that the level of anxiety they experienced in the

physician's office coupled with perceived information overload was overwhelming and might have further impaired their decision-making ability for a while.

A finding in this study also supports Petrisek's (1995) study. Older women with breast cancer who were less likely to desire participation in the decision-making processes of their treatment, were also less interested in obtaining educational material and information about breast cancer and showed considerably less anxiety in the possibility of recurrence when making treatment decision.

More than half the women in our study expressed the wish that their doctors had spent more time with them and thoroughly explained all their treatment options. These concerns highlight the importance of health professionals understanding the emotional responses of women to the diagnosis of breast cancer and the factors which assist them in making an informed decision about breast cancer treatment.

The patient-physician relationship seemed to be the most important factor in a participant's decision-making process and for some participants, information given verbally by their physician played a key role in their decision-making process regarding treatment options.

From participants' comments and suggestions regarding their decision-making process prior to breast surgery some observations can be drawn:

Firstly, it was evident that a majority of women welcomed the development of open dialogue between themselves and their physicians with regards to their disease and its treatment. By contrast, a few women

mentioned that medical doctors could facilitate preparation for surgery by refraining from delivering information that might be overly worrisome. Thus, the physicians' first task might be to evaluate a woman's coping ability, and based on this, then determine the best way to convey treatment information to their patients.

Secondly, most women welcomed their physicians' detailed information about what to expect regarding different breast cancer operations, and what to anticipate after their surgery (e.g., regarding wound healing, possibility of plastic surgery reconstruction, prosthesis, etc.).

Thirdly, a surprisingly large number of women mentioned feeling pressured for time. Those women described the experience of not having enough time to properly make an informed decision about breast surgery.

Fourthly, current legal and ethical constraints regulating patients' independent choice place additional demands on some women who feel uncomfortable about treatment decisions made without their input. More specifically, twelve women in the study assumed a passive, or indifferent role in treatment decision-making. However, some of these women stated that they would have appreciated more control over their treatment decision. Some women felt that they did not have access to enough information to make their own decision about breast surgery.

Currently, physicians adopt a "single approach" for all women, however, this approach fails to accommodate the varied reactions of women to the decision-making process. Ideally, information should be conveyed in ways that are responsive to each patient. (Patients' responses

to treatment information can be organized into different categories, each of which require a different physician "approach", or intervention.)

Increased dialogue between physician and patient regarding diagnosis and care is recommended to ease these women's distress. These dialogues require not only medical expertise, but also psychological sensitivity (on the part of the physician) in order to help the women understand their treatment options and make a reasoned and informed decision about which type of surgery best meets their medical and emotional needs, all at a time when they are experiencing great anxiety.

In addition, we anticipate that through comparative analysis, we can understand the process of decision as one of empowerment or disempowerment, perhaps determining the significance of a decision for one surgical treatment over another. Lastly, and perhaps of most importance, the method used gives women a voice on their experiences during a trying period of time.

## TESTING OF THE CATEGORIES

To ensure the confident utilization of a generated category scheme, it is important to determine the validity of the scheme. In this study several methods of testing were implemented in order to be assured of an acceptable level of soundness and trustworthiness.

### Participant Validation of Incidents

All participants were asked at the end of their interview to validate the observations they had reported. A summary of the incidents they reported was read to participants, in chronological order, and the participants were then asked to make any additions, changes, or deletions necessary for the recorded data to accurately reflect their experiences. With the exception of two women (one that remembered two additional incidents and another who added some missing details) the data was validated as presented.

### Reliability of Categorizing Incidents

According to Anderson and Nilsson (1964), a good way to establish category reliability is to measure the degree of agreement between independent evaluators using, or "sorting" within, the category scheme generated. In this study reliability of categories was determined by the extent to which two independent evaluators were able to accurately place a sample of incidents within existing categories. One evaluator was a doctoral student in the Department of Counseling Psychology, and the other was a masters student. Both evaluators were students at the

University of British Columbia. As well, both evaluators had prior experience conducting research. They were independently given a one hour training session to learn about critical incident data analysis (although both evaluators possessed previous knowledge about the technique).

As previously stated, the evaluators were then asked to organize a sample of 50 incidents into appropriate categories. By comparing the evaluators' placement of incidents with the original placement of incidents at the time of category formation, the number of "hits and misses" could be summarized statistically as a percentage of agreement (McCormick, 1994). For example, if an evaluator had 50 hits out of his/her placements, the percentage of agreement would be 100%. Flanagan (1954) recommends a 75% level of agreement (or more) in order to consider a category system sufficiently reliable. Andersson and Nilsson (1964) suggest an acceptable level of agreement between evaluators' and researcher's categorization of incidents to be between 75% and 85% .

The first evaluator agreed 92% of the time with the original categorization of incidents. The level of agreement between the second evaluator and the original categorization (for the same incidents) was 88%. The average percentage of agreement was 90% for the sample categories and incidents.

The high level of agreement noted after evaluation indicated that different people could likely use the generated categories system to organize incidents in a consistent and reliable way. Later discussion revealed that the evaluators' misplacement of incidents could perhaps be

attributed to the evaluators' focus upon certain words from the incidents recorded, rather than upon the entire incident.

Table 2

The % of Agreement Between the Evaluators' and the Researcher's Categories

	% of Agreement
Evaluator 1	92%
Evaluator 2	88%
Average %	90%

Note: n = 100 incidents, 50 incidents per evaluator

### Comprehensiveness of Categories

Another important test establishing the soundness of the category system assesses whether the category system is reasonably complete, or comprehensive. As suggested by Andersson and Nilsson (1964), approximately ten percent of the incidents from this study (or, 39 incidents from the last three participants) were withdrawn, and not examined until after categories were formed. When category formation was completed, these incidents were examined and classified. Because all withheld incidents were easily placed within the generated category system it can be reasonably stated that the categories generated were comprehensive.

### Participation Rate for Categories

In order to form a category, a significant similarity among a group of incidents must be reported by various people, and identified by the researcher. Participants often independently report the same kind of event. However, if only one person, or a few persons, report a type of event, the incident might be dismissed as insignificant based upon the belief that the incident might be fabricated, or distorted. However, when many people report approximately the same kind of event, the likelihood of fabrication or distortion decreases. Agreement among independent observers is an important test to determine soundness of research data (McCormick, 1994). Agreement is obtained by taking the participation rate for each category (e.g., the number of participants reporting a category of events) and dividing it by the total number of participants (see Table 3). The categories with the highest participation rate are therefore, the categories

with the highest amount, or level of agreement. The category participation rates ranged from as low as 13%, (Obtaining Approval of Medical Personnel, and Experiencing Positive Medical Settings) to as high as 90% (Getting Support and Encouragement from Others).

Categories with a participation rate of 50 % or higher included: Getting Support and Encouragement from Others (27), Receiving Educational Materials, and/or Information (26), Obtaining an Explanation of Medical Procedure/Problems (18), Helping Others (16), and Questioning of Competence of Medical Personnel (16).

Although many categories could be classified as "highly rated", three categories, Obtaining Approval of Medical Personnel, Taking Action upon Realizing Own Mortality and Experiencing Positive Medical Settings had a relatively low participant rating of only 13%. Only four participants reported events, or incidents, related to these categories. After careful reexamination of these particular incidents, it was concluded that these categories should remain unchanged because of the clarity, and the distinctness of the incidents reported.

#### Expert Validation

The soundness of categories can be judged by experts qualified in the field of study. Experts can assess the relevance and usefulness of the generated categories based upon their individual levels of experience and understanding. Experts are asked to bring their relevant experience to bear (Cronbach, 1971) by explaining whether or not the findings of a particular study are in agreement with what they have found from their own experience. Expert validations are significant for soundness of categories

because the experts have extensive practical experience in their field, and thus can provide collaborative evidence and content validity to the results of an investigation (McCormick, 1994). In this study, the opinions of three experts were sought. The first person was a medical doctor-surgeon working with women with breast cancer. The second person was a psychologist practicing in a medical field, and the third expert was a counselor practicing in the field of Health Psychology and presently working in a university teaching hospital.

The purpose and rationale of this study was explained to these experts, and each received a written description of each category and related category themes. They were asked to evaluate the usefulness of each category, and the group of categories as a whole. Later, each expert was interviewed. Comments from these experts conveyed the message that the generated categories were reasonable and meaningful. They agreed that the categories accurately reflected the experiences of women diagnosed with breast cancer throughout their preparation for breast cancer surgery. This expert examination contributed positively to the soundness and validity of the study.

Table 3

Categories Ranked According to Participation Rate

	Categories	Frequency	Participation Rate
1.	Getting Support and Encouragement from Others	27	90%
2.	Receiving Educational Materials and/or Information	26	87%
3.	Obtaining an Explanation of Medical Procedures or Problems	18	60%
4.	Helping Others	16	53%
5.	Questioning of Competence of Medical Care or Personnel	16	53%
6.	Establishing Professional Communication	14	47%
7.	Sharing Experiences in Support Groups and Counseling	10	33%
8.	Experiencing Physical Closeness	9	30%
9.	Using Inspiring, Comforting Material	9	30%
10.	Perception of Professional Manners	8	27%
11.	Discussing Problems with Loved One	8	27%
12.	Engaging Oneself in a Physical and Creative Activities	7	23%
13.	Being Accompanied to a Medical Appointment	7	23%
14.	Realizing Shift in Relationship with Loved Ones	7	23%

Table 3 (cont.)

Categories Ranked According to Participation Rate

Categories	Frequency	Participation Rate
15. Developing Helpful Habits	6	20%
16. Healing Through Spiritual Experience and Visualization	6	20%
17. Experiencing Deep Emotional Closeness	5	17%
18. Changing Perspective Through Comparison	5	17%
19. Getting Alternative Treatment	5	17%
20. Waiting for Medical Results	5	17%
21. Experiencing Positive Medical Settings	4	13%
22. Getting an Approval of Medical Personnel	4	13%
23. Taking Action upon Realizing Own Mortality	4	13%

### Comparison of Results with Related Literature

The categories and major findings of the study were compared in relation to related clinical and research literature in order to determine a level of consistency between the study and related research findings. This comparison represents an additional method of evaluating category soundness. If a category, or group of events, is new, neither confirmed or disconfirmed by previous research, the category stands alone as a possible finding to be confirmed, or validated, by future research. If a category represents a finding in discord with previous research, the category should not be dismissed, although there would then be good reason to question the validity of the category. As no mention could be found for the remaining six novel categories (Being Accompanied to a Medical Appointment, Helping Others, Taking Action upon Realizing Own Mortality, Experiencing Physical Closeness, Changing Perspectives Through Comparison, Getting an Approval/Recommendation of Medical Personnel) they stand alone as a possibility to be confirmed or disconfirmed by future research.

However, I would like to stress that the majority of published studies of women with breast cancer extend through the whole period of time after women's diagnosis with breast cancer was made. Therefore these studies have limited relevance as the focus of this study was on the period of time before their operation.

### Receiving Educational Materials and/or Information

It was important for all women in this study to received information and educational material. However, women varied in the degree and extent of information they wanted.

Fallowfield (1999) pointed out that women should have access to precise survival statistics for each mode of treatment. Yet some women in this study found it hindering (they felt frightened and confused) when they were given reading material (e.g. survival statistics) which they did not feel ready for. This finding is in congruence with Ashing-Giwa (1997). In her study she also noticed that some women with breast cancer received inadequate information to help them through initial diagnosis and treatment phases of the breast cancer experience.

The findings of this study are also in corroboration with Carey (1999). He went even further to suggest that anxiety and information overload may comprise a woman's ability to make a correct decision regarding her treatment for breast cancer.

There are books written specifically for women with breast cancer that provide information and assist them with their decision-making processes (Olivotto, 1995; Love, 1992).

van Wersch (1997) developed a multidisciplinary care-protocol, combining a continuous flow of information on medical and nursing matters with information about psychosocial aspects of breast cancer and its treatment. The protocol describes the sequential steps of care process during the initial treatment of breast cancer and recommends which information should be given to patients at various points of the disease

continuum. It builds on the expertise and experience of a multidisciplinary team, as well as of (ex) patients. The protocol contains no guidelines for medical treatment and offers no recommendation for clinical decision-making. The protocol was positively evaluated by health-care professionals and patients. It proved possible to use it as an informational instrument which acquainted both health-care professionals and patients in a full and detailed manner about the entire line of care.

#### Obtaining an Explanation of Medical Procedures or Problems

To ease some of the stressors or demands faced by women in this study, an increased dialogue between physician and patient regarding diagnosis, explanation of medical procedures and problems was suggested by some of them. This observation is supported by findings of Valanis and Rumpler (1985). Their study provided a thoughtful review of many issues faced by women when choosing between breast cancer treatment alternatives and the importance of a detailed explanation of medical procedures.

Schofield (1995) developed and tested guidelines for preparing cancer patients for threatening medical procedures. In his study he underlined items in which a significant discrepancy existed, namely, consistency of information and explanation of medical procedures, and involvement of others in preparation and assistance to the patient in coping with treatment for breast cancer. In his opinion these issues should be given more prominence in undergraduate and specialist medical training, as well as in continuing medical education.

### Discussing Problems with Loved One

Participants in this study found that discussing problems with somebody close to them was relieving and "soothing" experience for them. All incidents in this category were rated as helpful. This study lends support to some clinicians' suggestion that the patients' complaints of marital difficulties, loss of functioning, exacerbated emotionality, and reactivation of feelings of victimization should be treated in individual, couples, or group therapy to improve communication skills and therefore improve women's adaptation processes to the breast cancer diagnosis (Carter, 1994).

As well, Pistrang (1995) suggested that the partners play an important role in the breast cancer patient's adaptation, and that interventions aimed at couples may be an effective way of reducing their psychological distress. In her study of 113 women with breast cancer she stressed that good communication with the partner was characterized by high empathy and low withdrawal. What is interesting to note, is that even though most women had a good relationship with another person, this did not compensate for a problematic communication with the partner.

### Getting Support and Encouragement from Others

The results from this category are in congruence with the Komproe's (1997) study. Support and encouragement from others had direct beneficial effects on depression of women recently diagnosed with breast cancer.

Hoskins (1996) and Roberts (1994) in their studies also emphasized the importance of support from others on the emotional and physical adjustment to breast cancer.

In her study Suominen (1993) analyzed the support that 125 nurses offered breast cancer patients before, during and after their hospitalization. The nurses reported that patient support was inadequate before and after hospitalization, however most nurses maintained that the patients were well supported in the hospital by the health care staff.

#### Engaging Oneself in Physical Activities

All incidents reported in this category were perceived as helpful in preparation for breast cancer surgery. These results are consistent with findings in Greer's study (1992). Results of her study revealed its effectiveness in reducing indicators of various sorts of psychological stress after eight weeks of implementing a program with physical activities.

#### Experiencing Deep Emotional Closeness

All women in this category reported only facilitating incidents. This is consistent with findings in Classen's (1996) study. In her study of 107 women with breast cancer emotional expressiveness was associated with better adjustment to diagnosis of breast cancer.

Kahane (1995) underlines the importance of having somebody emotionally close to women diagnosed with breast cancer. She also mentioned that this concern is not often shared or spoken of, and that it is

not unusual for women with breast cancer to worry about being abandoned or unloved.

#### Realizing Shift in Relationship with Loved Ones

In addition to worrying about the effect of breast cancer treatment on their bodies, women in the study were often concerned about the effect that treatment will have on their relationship with those whom they were intimate with. When a life crisis occurs significant others are thought to help alleviate distress and resolve practical problems. Life crises may overwhelm significant others, eroding their ability to provide effective support and a shift in relationships with significant others could be detected (Bolger, 1996).

#### Healing Through Spiritual Experience and Visualization

Carver and Scheier (1990) proposed that when people see desired outcomes as attainable, they engage in continued efforts to reach their goals, and positive feelings result. Some women in this study intentionally focused themselves on positive thoughts, sometimes using meditation methods, some of them seeking positive activities to engage them (e.g., playing with grandchildren, using positive topics in a conversation, reading books with a happy-ending).

Ashing-Giwa (1997) in her study of African-American women stated that a primary source of support and coping for women with breast cancer was their spiritual beliefs.

#### Using Inspiring, Comforting Material

All incidents reported in this category were perceived by women in this study as helpful in their preparation for breast cancer surgery. This finding was consistent with findings in Predeger's (1996) study. She explored the use of photography, water color, poetry, audiotapes and music for healing 18 women with breast cancer over a six month period to refocus on positive and the present, and to develop and maintain connectedness with others.

#### Getting Alternative Treatment

It should be mentioned that there is usually small time left for women to seek alternative treatment before their surgery. Most women seek alternative treatment after their medical treatment is finished. All women in our study used alternative treatment as a second option after their medical treatment was implemented.

Gray (1997) mentioned that the popularity of unconventional therapies has grown dramatically in recent years and in his study physicians were interested in having information available about these. They also expressed a desire to be supportive of patient choices in this area, however, like in our study there was little interest in initiating communication about unconventional therapies, with most seeing such discussion as a poor use of their time.

#### Establishing Professional Communication

Siegel (1986) provided one of the first examples of the active, committed teamwork that may exist between holistic health professionals

and clients to aid in optimizing patients' life-styles. Gilbar (1991) also discussed the application of an holistic approach, as conducted by multidisciplinary team members who helped women with breast cancer to cope more effectively with the disease, the trauma of surgery, and with chemotherapy or radiation treatment.

Fallowfield (1999) suggested that an increased level of dialogue between physician and patient regarding diagnosis and care eases the emotional distress experienced by the women with breast cancer. From my own observations women were often overwhelmed as they coped simultaneously with distressing emotions of anxiety and fear, while making difficult decisions about treatment for a potentially fatal disease.

Valanis and Rumper (1985) indicated that the influential factors in treatment selection included a woman's past experience, her personal and demographic characteristics, as well as the experiences and demographic characteristics of her social support network and her physician. The influence of two important factors--anxiety and the physician-patient relationship--on the decision-making process was highlighted.

#### Waiting for Medical Results

All incidents reported in this category were considered by women as hindering. This finding is in congruence with Caplan (1995). In his study he suggested the need to reduce the time required to get an appointment with a physician or a diagnostic test, as well as to educate physicians and the women themselves regarding the importance of prompt evaluation, diagnosis and treatment.

### Sharing Experiences in Support Groups and Counseling

Sharing experiences in support groups and counseling was perceived by the majority of women in this study as facilitating their preparation for breast cancer surgery. These findings are in congruence with Spiegel's (1997) findings. He documented both medical and psychological improvements with treatment for women with breast cancer and concluded that psychotherapy is an important treatment modality for women with breast cancer, that it has been shown to reduce morbidity, prolong life and decrease medical cost.

The enhancing effect of psychosocial intervention on the psychological and biological functioning of breast cancer patients is stressed also in van der Pompe's (1996) study. Provision of psychosocial intervention can improve a woman's coping abilities, and reduce emotional distress and feelings of isolation. She provided some evidence that psychotherapy may prolong survival of women with cancer.

### Perception of Professional Manners

I strongly agree with Penman and colleagues who demonstrated in their study in 1984 that information conveyed verbally by the physician played a principal role in the patient's efforts to arrive at a decision about treatment. An idea of how the patient-physician relationship remains crucial to a woman's decision-making process can be gained from an understanding of the primary reason cited for accepting treatment: namely "trust in the physician who discussed this treatment with me (the patient)".

### Experiencing Positive Medical Setting

Women in this study perceived it helpful when their medical setting appeared warm, cheerful and comfortable. Crook (1995) stated that:

"The office where a woman consults a doctor often sets the dramatic stage for the attitude behind the closed doors. Nurses stand behind high counters, creating a division between the professionals and the patients. Stacks of patient files with color-coded numbers are overwhelming and depersonalized evidence that the patient is one of hundreds.

She also mentioned that small things like magazines in the examining room were evidence for some women that the doctor appreciated the problem of waiting in the room.

### Questioning of Competence of Medical Personnel

Caplan (1996) studied the reasons for the prolonged intervals between initial medical consultation and establishment of breast cancer diagnosis. In about 45%, medical personnel and the health-care system were said to be responsible for the delay through difficulties in scheduling or physician inaction.

The results of this study are congruent with Fallowfield (1999), who emphasized the importance of health professionals understanding the emotional response of women to the diagnosis of breast cancer, as well as factors that contribute to this multifaceted response, and how to best assist women with their coping.

Ashing-Giwa (1997) found that women in her study received inadequate medical care, particularly those with less education and lower incomes.

Herman (1996) raised in her study concerns regarding limited opportunity for cancer education for public health nurses.

Burton (1994) examined breast cancer patients' satisfaction with their medical and psychological care at the time of their surgery and one year later. The findings of our study are consistent with Burton's study: the complaints that were recorded suggested that physician-patient communication needs to be improved.

## EXAMINATION OF THE OUTCOMES

### Themes Across Categories

The focus of this study was on what incidents (events or experiences) facilitate or hinder women's preparation for breast cancer surgery. Participants in this study provided 362 critical incidents of what they experienced, and what actions were taken to facilitate or hinder their preparation. A scheme of categories was designed and established in order to organize these data in a form useful to both theorists and practitioners. In this section the outcome of actions taken to facilitate or hinder patient preparation is discussed. From a psychological and medical point of view, understanding this process is fundamental in helping facilitate women's preparation for breast cancer surgery, and to reduce hindering factors throughout this process.

By examining the outcomes women emphasized in reported events, and then by organizing these into categories, it was possible to construct a framework of trends found throughout the preparation process, and subsequently formulate recommendations for practice.

After thorough examination, six themes emerged. These themes extended across all categories and, therefore, there is an inevitable degree of overlap amongst the categories. Themes serve as exploratory themes or concepts to provide a tentative organization for the study's outcomes and they are not necessarily conclusive findings of the study.

A brief description of each theme follows; together with an indication of the type of events reported, and some illustrative examples.

### 1. Validating Experience (59 incidents)

This large category refers to whether, or not, the woman perceived the people around her as validating, or invalidating, her emotions, and self-concept. It was helpful when a participant felt validated as a person, as a patient, or as a mother, wife, sister, co-worker or friend. Most women found it particularly helpful when their emotions about their experience with breast cancer were validated.

I am not a rich person. I am a working person, therefore I was concerned about my financial security. I talked to a friend of mine at work and she told me to speak to my boss. So I went to see him and explained to him my situation. He was wonderful, he told me that he understood my situation and felt sorry for all the pain I had to go through. He also gave me a full salary. I felt great, appreciated and understood.

My surgeon was a woman and she was a wonderful person. She was very empathetic, practical and had a good sense of humor. When she told me about my diagnosis, she did it in a very gentle way. I could even sense that it hurt her as well. I felt that I was a person to her, not just a patient:

My friend came to visit me a couple of times. She would just sit quietly on a chair and listened to all my worries, fears and concerns. I found her visits became important to me, actually I was very much looking forward to have her over in my house. I felt that I was important to her.

The women, after being diagnosed with breast cancer, were very sensitive. Some of them were going through the most difficult part of their

lives. Certain participants reported the behavior of judgmental individuals around them as hindering, for example, "he told me that things could have been different if I had not smoked". Being judged invoked strong emotional reactions for participants. Women reported feeling angry, embarrassed, or hopeless and misunderstood.

Example of negative incident:

I got a phone call inviting me for a second mammogram. So I went. After this mammogram I was told by a "brisk" MD to stay for an ultrasound right away. I was not prepared for that, I felt angry and humiliated.

Another woman reported a negative reaction to the medical personnel in her doctor's office:

When I came for the first time to see my doctor, I felt vulnerable. The receptionist was in a bad mood. She asked me in an annoyed voice: "Where is your card?" It was important for me to be treated with respect at that time, not the way she treated me. I was hurt.

Some women felt that they were blamed directly, or indirectly, for their disease. They found this experience profoundly hurtful and emotionally damaging. Some women reported the disrespectful behavior of their families or friends. For example, one woman described how her husband failed to demonstrate any respect for her experiences and emotions:

I had an appointment in the hospital to have my biopsy done. My husband was supposed to pick me up from a hospital after that. But I had to wait for him in front of the hospital for almost three hours. He said that he had an unexpected meeting. I felt terrible, I could almost not speak about how angry I was. He didn't even bother to call to arrange something else.

The majority of participants perceived the use of language they did not understand as very "negative".

I went to school just for ten years, so I know I did not get enough education. But I had got a good job and I enjoyed it for almost fifty years. But when my doctor told me what I have, I thought I was going to die tomorrow. That was how awful it sounded. I didn't understand him well, but I was afraid to ask.

Women perceived this behavior from medical personnel as highly disrespectful, however, very few of the women actually asked medical staff for an explanation. Women often felt ashamed of asking questions, or showing that they did not understand. As well, very few women were vocal about expressing their negative perception of these incidents, or experiences.

## 2.Empowerment/ Feeling in Control (44 incidents)

In this category participants reported being empowered in some way. The outcomes of incidents included in this category shifted the women's perceptions of themselves and their situation toward something more positive. Women felt better, more optimistic, and stronger about

themselves. This provided them with self-confidence, self-respect, motivation, and hope.

Empowerment was experienced either through personal actions or the actions of others. Two examples of women empowered through actions of others follow:

My doctor is a woman and she was wonderful. She told me everything I needed to know about my disease. She took all the time she needed to explain everything, answered all the questions I had. I felt confident that together we could make it. It also gave me enough self-confidence to make some important decisions regarding my operation.

I didn't want to go for a doctor's appointment by myself. My coworker, who is also my friend, went with me to the very first appointment with my surgeon. I felt better. Her presence gave me the strength I needed.

Other women experienced empowerment through their own actions, for example, getting literature about breast cancer from the library, deciding to quit smoking, joining a support group, or developing new healthier eating habits.

Other examples were:

My daughter has four children and lives in Quebec. We are very close. As much as I wanted to tell her about my breast cancer (just to feel a relief of sharing it with her) I decided not do it. I did not tell her about my cancer till after my operation was done. It was difficult but it gave me a lot of strength, and self-confidence.

Another aspect of the empowerment theme was feeling in control. Most women considered it helpful when they felt in control over the process of preparing for their surgery, and felt in charge of their lives, diseases, or decisions about treatment options (e.g., the choice of surgeon and type of operation).

Some examples that demonstrate experiences of feeling in control:

My surgeon was very straightforward with me. When I went to see her she explained everything to me and gave me a chance to see another doctor so I could get a second opinion. I did not use this chance, but because I was given the choice, and the decision was on me, I felt better, like I was controlling, at least a little bit, the situation.

After they told me that I have a breast cancer I was devastated. I knew that I needed the most current information about breast cancer and the library in the Cancer Clinic was recommended to me. An attentive librarian in this clinic supplied me with the newest material about breast cancer and answered all my questions. Somehow I felt more in charge of my disease. I felt that I had the newest information available and that I could make better informed decisions regarding my operation.

Conversely, it could be hindering when somebody else seemed to be attempting to exert control. The same woman reported a negative incident:

I went to see my surgeon who told me that I needed an operation, but that it was not dangerous and that everything would be just fine. As a person who wants to know what is going on I asked him a lot of

questions about different treatments and possibilities for my operation. But the surgeon didn't seem to pay a lot of attention to my questions. He was looking at his papers most of the time and I felt that my questions were not properly answered. I felt that somebody else wanted to make an important decision for me and I did not like that.

### 3.Organizing Oneself/ Active Approach/ (34 incidents)

Participants who started to organize themselves in preparation for breast cancer surgery are included in this category. Some women established new rules in their lives, or made some substantial changes in their lives. For example, they imposed self discipline and exercised or participated in physical activities. For some women the incentive came from within (e.g., "I thought I was too fat to endure the operation without any complication", or " I wanted to be in a good shape"), and for other women the motivation was external (e.g., " The doctor told me I have to be healthy and have a positive attitude"). To better accommodate their needs some women decided to actively change their priorities, to seek new information in books and/or articles, or actively make plans for their future. As a result of these activities, they felt happier ("I felt actually happy to be back in the library and study again"), or they were proud of their accomplishment, (" getting up early morning to do my exercise made me feel stronger", or "I had more respect for myself). Another woman reported that: "I got a confidence that I might actually deal with my disease." Some examples:

I was an overweight and sort of lazy person all my life. It never really bothered me. When I learnt about my diagnosis of breast cancer

I became desperate and I didn't really know what to do. One day my husband came across an article about a woman who runs three kilometers every day to help her deal with the death of her daughter. He (my husband) thought that this would not be such a bad idea to start to actively exercise. We started to walk regularly every evening and I felt better. I also started to organize my time better to have time to exercise during the day. It was difficult in the beginning to find a strength to do it, but it paid off.

Interestingly, quite a few women organized themselves to begin "a healthy living style", starting with a healthy diet, and/or a regular physical exercise.

Physical exercise and eating well helped me. It actually toughened me to deal better with my everyday problems. It was not easy in the beginning, sometimes I wanted to skip it, like to eat this wonderful stuff in KFC, or just sleep in the morning instead of exercising, but it became part of my life. Because I am a fighter by nature, I stayed with it and felt much, much better.

Although organizing themselves often represented a physical challenge, it also manifested on mental, spiritual or emotional levels.

I felt tired during the whole time after my diagnosis and I needed more rest. There was a shift in my perception of my needs and I decided to prioritize them. For example, when I felt tired, nothing else mattered -I went to the bed (even with the dirty dishes in the sink). I became better organized and had a more active approach towards my body's needs.

#### 4. Belonging (31 incidents)

In this category the participants reported achieving a sense of belonging, for example, in the family, the community, a support group, or a collective at work. Some women stated that it was very important for them to somehow feel connected to their families, friends, or coworkers. As one woman put it: "This gave me peaceful feeling like flowing on the lake. I didn't have to worry, somebody else was guiding my little boat."

We moved quite recently into our house. When people in my neighborhood learnt that I have a cancer (although I don't know how), some of them came to visit me in my house. First I was a little uneasy, but later I enjoyed their visits. Particularly one nurse from my neighborhood was helpful. She came to visit me a couple of times. She also gave me a lot of important information from the medical field, (like statistics of breast cancer in British Columbia) which I found hopeful. Quite often, when I went for a walk or shopping, I felt more like returning home.

I have a big family. When they learned that I had breast cancer they all called and expressed their sympathy and support. They offered their help and some of them came over to our house and brought me all these wonderful get-well cards and gifts. I felt great. This sense of belonging to this great family gave me a lot of strength in my fighting off the disease.

One woman described the benefit of belonging as "feeling that I belonged somewhere made me feel safe, I didn't have to be in charge for anything for a while. Or at least, somebody is going to help me because my life is right now just too much for me to deal with on my own."

I told my coworkers about my problems. They were very supportive. They actually tried to be around me when the GP called with results of my ultrasound. It felt good, somehow as we were all connected, we were in the same boat.

### 5.Adapting (29 incidents)

This category includes incidents ranging from outcomes like "I thought that it was a mistake", "I thought the lump in my breast would go away", to incidents in which women were coming to terms with the disease, accepting the situation, perceiving that "it is really happening to me, etc.

Women in this study went through different stages of adaptation, which was possibly because the time span between the diagnosis and operation differed for each woman, ranging from two weeks to five months. Almost every woman reported experiencing "disbelief", when they felt: "It is not happening me," or " there must be some mistake in these results." It took some time to grasp and comprehend that "it is really happening to me." Two women from the study were still feeling disbelief when the interviews were held.

One example of a woman's disbelief:

I remember the day my surgeon told me about the result of my biopsy. It was positive, he told me. I recall thinking, this must be some mistake, they just mixed up names. I was calm, I was so sure that the result was wrong. I even felt sorry for the other woman.

Another example of women coming to terms with the disease:

As an artist, I am working with my hands, creating things, and therefore expressing my emotions through my work. After the diagnosis was made I could not believe it was happening to me. I was stressed out most of the time, and I spent a lot of time at home, doing nothing, just worrying. However, one day I started to work again and it helped me to get used to the idea that I had breast cancer, to understand what was happening and realizing that this was actually happening to me.

When I went for my biopsy in the hospital I was scared. I felt numbed, or even didn't feel anything. But the staff in the hospital gave me a lot of "positive energy" - they were cheerful and understanding and I started to accommodate the idea that I had breast cancer.

It is interesting to note that these two participants acknowledged that they experienced disbelief for quite a long period of time after the diagnosis.

#### 6.Changes in Feeling-Relief/Anger (77 incidents)

There were 77 incidents outcomes that did not fit into existing categories, but rather had to do with change of emotional responses. Rather than create other categories, it seemed more accurate to describe the range of these emotions. Examples of these outcomes ranged from: "It made me happy", to "somebody took a burden off my shoulder", or "I felt somehow quite peaceful". Conversely, some participants reported negative emotional changes: "I felt absolutely terrible not knowing what to expect", or "I thought I was going to die tomorrow". Many of the changes in feelings were illicited in incidents describing the excessive use of medical

terminology by doctors, or the incompetence of medical personnel responsible for their care.

One of the activities we did in a support group which helped me most was sharing our experiences with breast cancer. I felt that I am not the only one to suffer and that made me feel better. I remember one older lady, who told us about her sister living without her breasts quite happily for over fifteen years. I could still remember the feeling of relief that there is actually a life after the operation.

The needle biopsy was an awful experience for me. So I hoped I would be able to get my results as soon as possible. However, I had to wait three long weeks for my results, because my surgeon went on vacation. It was a torture for me. I felt absolutely terrible not knowing what to expect.

## CHAPTER V

### ORGANIZATION AND ANALYSIS OF CATEGORIES

The previous chapters introduced twenty-three categories of incidents that facilitated or hinder women's preparation for breast cancer surgery along with a preliminary presentation of incident outcomes. In this chapter, three complete narratives are examined in order to present individual contents and thus provide meaning and action for the categories. Based upon this examination, a preliminary organization of the categories is presented and the themes that emerged from these narratives.

#### Narrative Accounts

The following stories were related by three women in the study. A commentary is provided after each incident in order to emphasize and outline the most important ideas.

#### Narrative Account #1

My GP sent me for a mammography because of a lump in my left breast. He gave me an appointment the next day and told me that, unfortunately, the results are positive. He was very empathic, he had tears in his eyes. I was touched, I saw that he was a caring person. It was a bad time for me, but somehow his concern and empathy made it easier for me.

Although this woman received bad news regarding her health, the way her GP told her- showing her his empathy- made her feel supported and cared for. She appreciated his professional manners.

I always knew I had a great GP. When my mammography turned out positive his referral to a surgeon was quick and efficient. I didn't have to wait like some other women. I trusted him and felt I was in right hands.

Again, this woman appreciated her GP's quick and efficient referral and liked the fact that she did not have to wait like other women she knew.

I didn't want to go for the doctor's appointment by myself. My coworker, who is also my friend went with me to the first visit with my surgeon. I felt better. Her presence gave me a strength I needed.

Having an appointment with a medical doctor was a stressful event for the participant. Therefore, she found it helpful if somebody who was close to her accompanied her to the doctor's appointment. The person accompanying her seemed to act as a "back up" for her.

To cope with cancer was difficult. But the time I spent waiting for results of my biopsy test was excruciating. One minute I had my hopes up, the other down. I was devastated, it drove me crazy.

Like most women in the study, the participant felt devastated not knowing how the results turned out. For some of them it was the most difficult period in the whole process of preparation for breast cancer operation.

After the diagnosis was made I told my boss about my breast cancer. After I told him, I couldn't help myself, and started to cry. I think I made him cry as well. I know that it was selfish. But I appreciated that he felt for me and showed me so much empathy. His support made me feel precious and worthy.

By telling her boss about breast cancer, the participant felt not only relieved, but also "precious" and "worthy" as a result of his empathic reaction.

I also told my coworkers about my problems. They were very supportive. They actually tried to be around me when the GP called with the result of my ultrasound. It felt good, somehow as we were all connected, we were on the same boat.

By being with the participant when she was waiting for the result of her ultrasound, coworkers expressed their support. It was important for the woman to receive an encouragement from others. It made her feel included, part of a collective.

A couple of days after the diagnosis I was having a coffee with my girlfriend who is originally from Great Britain where she had both her breasts removed because of breast cancer. She told me that a couple of decades ago, when you used the word "cancer" in Great Britain it was perceived as "plague", and therefore people did not talk about it at all. Hence she could not tell anybody about her operation. It was sad for her, she felt so lonely. I realized that I should be more appreciative of these days when breast cancer is discussed openly and I can talk about my disease with everybody. This gave me a little different perspective of my cancer.

Learning about the situation of women in different countries made the participant realize how privileged she is living in Canada. She could talk freely about her disease. The woman felt great relief to be able to talk about her problems, share them and not conceal them. It seemed to

alleviate a lot of pressure for her. There has been a huge attitudinal change towards breast cancer in the last 20 years, not just in Canada.

I always knew that we have a nice collective at work. During my illness I particularly appreciated the way they behaved. For example, one girl, the youngest from our collective, asked me if I want to join her and go with her to the gym. Well, at the beginning I was quite skeptical, because I am not young any more, but I went with her a couple of times and it felt great. I couldn't exercise too much in the beginning, but I felt good. So we went at least twice a week. I got a lot of energy and felt more optimistic. I was quite proud of myself.

This participant saw exercise as a way of releasing her negative energy and shifting her attention to something else. Exercising also gave her a feeling of something positive in her life and it empowered her.

After my first visit in my surgeon's office I needed some information about breast cancer. I bought a book which was displayed in the reception area of the surgeon's office. My surgeon was also one of the co-writers. I found everything I needed there, it was very helpful in many ways.

The participant realized that she did not know very much about breast cancer and decided to buy a book. The book she bought defined and explained breast cancer, and helped her to better understand her disease.

The attitude of people I am dealing with is very important to me. I realized how lucky I was with my surgeon. She was open and respectful even when I called her couple of times in the late afternoon, when my worries escalated. I felt that she was treating me as an equal. Though not everybody from the medical

community does. She gave me a lot of self-confidence.

The participant's perception of her surgeon's professional manner was positive and appreciative. The women with breast cancer were aware of subtle nuances in the presentation and behavior of medical personnel, such as their choice of words, voice tone, facial expressions, posture shifts, and so on. It was important that her surgeon treated her as an equal, was attentive to her needs, and was open and respectful. It helped her to feel good about herself and gave her self-respect and self-confidence, which she needed in this difficult time.

I was scared of my operation. My friend insisted on driving me to hospital for my surgery. I was happy he did, it was a great support.

The operation was a stressful event for the participant. To have her friend accompanying her to a hospital seemed to reduce her anxiety, which was important for the operation.

#### Narrative Account #2

I got a phone call inviting me for a second mammogram. So I went. After this mammogram I was told by a "brisk" MD to stay for an ultrasound right away. I was not prepared for that, I felt angry and humiliated.

The participant referred to the professional manner of a "brisk" medical doctor. She did not like the way she was spoken to, even though it was

probably in her best interest to immediately have the ultrasound. Perhaps, if more had been explained to her, she would not have been as angry and scared.

After the mammogram was positive they wanted to clarify the diagnosis and I was scheduled for a needle biopsy. My doctor showed a great deal of uneasiness doing the biopsy. It took him forever to do the biopsy. Judging from his performance it was his first biopsy. I was scared and at the same time I felt annoyed, I didn't trust him any more.

The doctor performing the needle biopsy, which was quite a painful and distressing experience for the patient, was perceived as incompetent. Her anxiety escalated and her trust in the doctor was undermined.

After the stressful needle biopsy experience, I came home and my hands were shaking, I felt terrible. I called my daughter. She came over in my house and we had a long discussion about what happened. She went step by step with me through everything what happened that day. She was very matter of fact and relaxed me. I had to admit that talking to her, discussing problems helped me normalize the situation. I felt much relieved and even got some sleep that night.

Discussing the stressful experience with her daughter helped the participant to relieve some of the stress and relax little bit.

After it was clear from all these examinations that I had breast cancer, my GP asked me to choose a surgeon from a list of doctors he gave me. My partner, who is a medical doctor, did his own "shopping" for the best surgeon as well. One evening we sat down in my living room, opened a bottle of wine and discussed together

which would be the best one for me. It was a nice evening and I felt supported and, in a way, secure.

From this event we can see how important it was for a participant to discuss her problems with somebody she loved and felt comfortable with. Talking and sharing made her feel supported and secure. It was helpful in her preparation for breast cancer surgery.

The surgeon we have chosen told me about my option regarding my mastectomy, but I had to decide by myself. With my partner we went to the library in the Cancer Clinic in Vancouver and they gave me some literature to read. I learned from some articles that there is a 30-40% chance to survive 5 years if I will have only lumpectomy with radiation or chemotherapy. With mastectomy we learned that I do not need radiation or chemotherapy and have only 10% chance of recurrence. So I decided I want simple mastectomy (without reconstruction) and presently, I do not feel less as a woman.

The participant had to make some decisions and it was important for her to get some information and base her decision on it.

I think I got a very good surgeon. She probably saw how scared I was when I got the lump in my breast. Although she must have seen hundreds of women like me, she was very nice. As a woman she knew about all the concerns and carefully explained everything to me and asked if I did understand it and went through some problems with me again. She even did some drawing for me. I trusted her, I knew what was happening to me, I felt better.

Because the medical procedures were explained, the woman knew what to expect. She could anticipate things to a certain extent. When the unknown

became known, fear and anxiety were reduced. She also appreciated that her doctor was a woman like her, and believed that the doctor would better understand a woman's body and mind.

Every time I see a doctor it is a stressful event for me. Yet, the waiting area of my surgeon's office is a cheerful place to sit down and relax. Especially the color of the furniture and carpet was appealing to me. Chairs were very comfortable. I cannot say that it was a pleasant experience for me to be there, but I think that it relaxed me a bit, I wasn't so tense.

The participant identified the importance of relaxing in the cheerful environment of the doctor's office.

I was open and talked about my cancer at work. People were very nice to me, though very respectful. They were bringing different small and funny things to me, articles to read (just the positive ones!) and tried to cheer me up. I was moved. Till then I did not know how many friends I had. I felt precious. They just spoilt me.

This woman emphasized the importance of being supported and encouraged at her work. She felt comfortable in such an environment.

Sometimes I felt I was just a "case " or "number" for medical personnel. The receptionist in my surgeon's office was somehow different. Every time she called my name she gave me a "special" smile. She also lowered her voice, when she was asking me some personal questions or explaining to me where to go for a biopsy, so the other people could not hear us. I liked the way she treated me, it made me feel as if I was a precious patient for her.

The participant's perception of the receptionist's sensitivity and professionalism made her feel like an important person.

Shortly after the doctor told me I had breast cancer my daughter had chicken pox. We are very close and I enjoy cuddling with her every day. But because I never had chicken pox, she had to be isolated from me. I felt terrible not to be able to cuddle with her, I missed her hugs a great deal.

The participant missed the physical closeness with her small daughter, which was so important to her.

I had a friend who is afraid of anything even loosely connected with medicine, disease, etc. I thought he would never come to the clinic. What was my surprise when he showed up at the clinic after my doctor's appointment. He made me feel really special.

The participant felt supported by her friend when he surprised her by visiting her in the clinic. She appreciated it, especially given his fear of a medical environment.

Another friend has had leukemia for years. I remember one day she told me: "This is one of the best things that ever happened to me". It helped me change my attitude toward my cancer. I told myself, maybe there is something positive in this experience.

The participant started to view her experience differently. Maybe there was something positive in her experience with breast cancer and maybe having cancer was not just a negative experience. Her perspective of cancer

started to change through comparison with her friend's experience. Her friend made her look for something positive in her experience.

### Narrative Account #3

Before Christmas 1994 I felt a lump in my breast and went to see my GP. She couldn't find the lump and sent me home with: "We will keep an eye on it." She did not order any further examination, nor mammogram. I was uncomfortable with that, worried for next six months till the next mammogram showed the lump and breast cancer was diagnosed. I was angry and I do blame her.

The delay in the diagnosis of breast cancer was attributed to the woman's GP. The participant was angry and questioned the competence of her medical doctor.

There was a suspicious lump on my mammogram and the radiologist suggested a needle biopsy to verify the diagnosis. He explained what this meant for me and the whole procedure I would have to go through. He also handed me a list of surgeons he prepared for me to choose from. Although I was terrified, I thought he was nice and considerate. He treated me with respect and seemed to understand my fear.

The radiologists explanation of the medical procedure she faced and his list of surgeons to choose from reduced her fear of the unknown and prepared her for the needle biopsy.

After my incident with my GP I was quite reluctant to trust anybody from the medical community (with the exemption of the radiologist). The relationship my surgeon and I built during the process of my disease was, however, excellent. I liked her gentle but professional

manners, her empathy, and down to earth approach. I was able to trust medical doctors again. My husband liked her too.

It was very important for her to build a good relationship with her surgeon and to trust doctors again. The doctor's professional manners were perceived as helpful in preparing for breast cancer surgery.

After my diagnosis of breast cancer was confirmed I went back to my GP to confront her. I asked her why she didn't send me for more examinations after I told her about the lump I felt in my breast. She checked my file and told me: "I do not have it in my file that you told me about the lump in your breast". She made me feel that I made it up. I was upset and my trust was broken.

The doctor's denial of being told about the lump really upset the participant.

I wanted some information about breast cancer. I found that there are just too many books to choose from. I didn't know which one was the best for me considering the level of my education and type of my cancer and treatment. I also wanted some books on non-medical treatments of breast cancer. I was desperately lacking some sort of guidance about which books to choose.

In this negative event the participant described her confusion about finding the right book about breast cancer. She was overwhelmed by the abundance of literature on the subject of breast cancer. She was lacking some direction to choose the proper one for herself.

The news of my cancer spread among my friends quite fast. I remember particularly two of my girlfriends coming to our house and cooking for me. I was sitting at the kitchen table, talking and they

were busy around the stove, cooking, joking. We laughed a lot, we also cried. It was so lovely. It was a catharsis for me, I felt precious and loved by my friends.

Having friends over in her house made this woman feel loved and supported. It was also important for her to feel as a part of them. By crying and laughing together, her feelings were validated, and some tension and pressure she felt were relieved.

I have a great relationship with my parents-in-law. When they learnt about my cancer, they both came from Victoria to visit me the very next day. I felt supported, and an important part of our big family.

The immediate visit of her parents in law made her feel supported and connected to her family.

I didn't want to go to a doctors' appointment by myself. I asked my parents in law, who came to visit me. They accompanied me to every appointment I had. I felt better to have them with me, they were my back-up if something unexpected would have showed up.

By accompanying her daughter-in-law to every medical appointment they made her feel safe. The environment in a medical setting can be perceived by some patients as unfriendly and stressful. It was important for this participant that somebody who cared for her was there with her.

I am very close to my daughter. Soon after my diagnosis was made she found out that she is pregnant with a child with Down's syndrome. She was terrified and didn't know what to do. I spent a lot of time with her. We cried together, and talked a lot, trying to find

the best solution for her. I spent less time worrying about my cancer, I worried more about her. I also realized how close are we.

By helping her daughter to cope with her pregnancy the participant focused more on her daughter's fear and pain than on hers. This was helpful in diluting her own anxiety and brought her some relief from thinking about her own situation all the time.

I have four sisters. They all got concerned after I was diagnosed with breast cancer that this could be genetic and that they could also get breast cancer. We all phoned each other, talked for hours about our relatives and what are their chances of getting breast cancer. Sharing the same fate made us a cohesive group, we felt protective towards each other.

The participant derived relief through helping her sisters manage their concerns and fears about getting the same diagnosis. It made her feel more connected to them as well.

I have an older step sister, who I refer to as "cold ". She likes her space and never really showed her emotions. I called her and told her about the cancer. What was my surprise when I got a "get well" card from her in which she actually offered me help. It never happened before. It felt great to matter to her again. I think the disease brought us together.

By sending a "get well" card, her "cold" step sister demonstrated that the participant was important, which made her feel good about herself and more self-confident.

I was with my GP for 17 years. After I confronted her I did not go

back to see her anymore. She also never called me back to ask me about my breast cancer or just how am I doing. I felt hurt and angry. I didn't understand why she didn't care. I wanted to call her but I was not ready to do so.

Her GP disappointed her again by showing no interest in the progress of participant's disease.

I went to see a naturopath. She told me that doctors are too quick to do the surgery. She also expressed the opinion that only alternative medicine is the right choice. I was confused and upset. I think she just wanted to sell her products.

The participant's experience with the naturopath was upsetting. The naturopath seemed to undermine medical treatment, which created confusion and anger for the participant.

### Summary

By thoughtfully examining the themes that emerged in the three narratives better insight is gained which may deepen knowledge about what helps or hinder in the preparation for breast cancer surgery. Since the process is examined from the beginning until the end, a rationale and logic is revealed. Therefore the division of categories presented in previous chapters can be followed.

## **CHAPTER VI**

### **DISCUSSION**

This final chapter will summarize the results of the study, discuss limitations and implication for theory, along with recommendation for further research and practice, as well as personal reflections.

Through interviews with 30 women a total of 362 incidents were elicited relating to what events facilitated, or hindered each woman's preparation for breast cancer surgery. There were 294 positive incidents (87.2%), and 68 negative incidents (18.8%). These incidents were organized into twenty-three categories: Receiving Educational Materials and/or Information, Obtaining an Explanation of Medical Procedures or Problems, Discussing Problems with Loved One, Getting Support and Encouragement from Others, Being Accompanied to a Medical Appointment, Helping Others, Engaging Oneself in Physical or Creative Activities, Developing Helpful Habits, Taking Action upon Realizing Own Mortality, Experiencing Physical Closeness, Experiencing Deep Emotional Closeness, Realizing Shift in Relationship with Loved Ones, Healing Through Spiritual Experience and Visualization, Changing Perspective Through Comparison, Using Inspiring, Comforting Material, Getting Alternative Treatment, Establishing Professional Communication, Waiting for Medical Results, Sharing Experiences in Support Groups and Counseling, Perceiving Professional Manners, Experiencing Positive Medical Settings, Getting an Approval of Medical Personnel, and Questioning of Competence of Medical Personnel.

Eleven categories had both a positive and negative valence. Ten categories ( Discussing Problems with Loved One, Being Accompanied to a Medical Appointment, Helping Others, Engaging Oneself in Physical or Creative Activities, Developing Helpful Habits, Experiencing Deep Emotional Closeness, Healing through Spiritual Experience and Visualization, Changing Perspective Through Comparison, Using Inspiring, Comforting Material, Getting an Approval/Recommendation of Medical Personnel) were comprised of only helpful incidents. By contrast, one category (Waiting for Medical Results) contained only hindering incidents.

A description of these categories is included in Chapter IV, along with a description of the methods utilized to establish the reliability, validity, saturation and comprehensivness of the categories.

Because the study focused on "what" events occurred and not "why" each event occurred, meanings were not solicited from the participants with regards to the significance of different incidents. However, examination of the outcomes women stressed in reported events, and preliminary organization of these outcomes into categories, helped to construct a framework of trends and a better understanding of women's experiences throughout their preparation for breast cancer surgery.

In the previous chapter three complete narratives were examined in an attempt to provide meaning and action to the categories. Based upon this examination a preliminary organization of the categories was also presented.

### Limitation of the Study

Both the significance and the generalizability of the research are limited by a number of factors. Firstly, the study relied on the retrospective viewpoint of its participants. Participants were selected according to the criterion that their operation was performed six to twelve months prior to involvement in this research study. A frequent criticism of retrospective accounts is that the information may not be accurate due to distortion in memory. However, the criterion used to assess the accuracy of reporting is the quality of the incidents themselves. If the details are full and precise, the information is assumed to be accurate. If the events are vague, some of the data may be incorrect (Flanagan, 1954). Only those incidents which were reported with sufficient details were included in the study.

The purpose of the study was not to establish what actually happened to facilitate or hinder the preparation for breast cancer surgery, but rather to determine what the client perceived to be helpful or hindering. Therefore the time lapse may allow for a much fuller description because the participant has had an opportunity to reflect back on the experience, process it, and integrate it consciously and verbally (Hycner, 1985). It actually may provide for much more rich and meaningful data than a method which would collect immediate information from current experience.

Secondly, because of the age difference among the participants, there is a broad range of different factors (events) helping or hindering their preparation for surgery. As a result, younger women being in a different, more productive stage of their lives reported more incidents connected to

their work and family environment. Older women, who were usually retired, were focused more on their friends and living environment.

Thirdly, the categories were derived from self reporting rather than from direct observation. Critical incidents obtained through self-reporting were limited to the events that participants were able to remember during the interview. It is likely that some events were forgotten and not mentioned in the interview.

Fourthly, the demographics of the group of research participants precluded extensive generalization to the population at large. Although participants were quite varied in terms of age, family background and individual factors, there was no balanced distribution of these factors nor were they used in the data analysis. As well, participants were selected from a narrow pool: they were all patients of female surgeons and two male oncologists. Therefore some events could be attributed to the fact that these women has chosen a woman surgeon.

Fifthly, there was the possibility of researcher's bias during the data collection. This might have occurred if nonverbal and verbal responses to certain disclosures encouraged participants to report some incidents and not others. Likewise mentioning certain aspects of the experience may have been inadvertently encouraged or discouraged by the interviewer. Due to these factors, caution is necessary in interpreting research results. On the other hand, the meaning of "objectivity" in qualitative research is different from that in quantitative research. Objectivity in qualitative studies is largely concerned with the quality of observations made by the researcher (Hycner, 1985). It involves being as comprehensive as possible

in responding to the broad range of experiences described by participants and applying a research method that will be "faithful" to the phenomenon (Giorgi, 1970). In contrast with quantitative studies, qualitative research (including the Critical Incident Technique) requires the researcher be close rather than distant from the data.

Lastly, there was a range of articulation as well as reflection from the different participants. This necessarily meant that some reports were both descriptive and more illuminated with meaning than others and this may have excluded some events from being revealed. However, it should be remembered that this study did not explore the question of "who" was helpful in facilitating preparation for breast cancer surgery or "why" they were helpful, but on "what" was done to facilitate it. The focus was on the scope of facilitating or hindering events.

### Implications for Theory

The results of this study are unique in their contribution to literature on women with breast cancer because they focused on the relatively short period between a woman's diagnosis and her operation for breast cancer.

This study provided a broad range of factors presented in theories of women's experiences with breast cancer (e.g., Fallowfield & Roberts, 1992; Spiegel, 1992, Taylor, 1983), specifically their preparedness for breast cancer surgery. In general, most factors found in this study were confirmed with present research. However, the category system generated in this study also provides some factors, which are not mentioned in the literature (e.g., Being Accompanied to a Medical Appointment, Helping Others,

Taking Action upon Realizing Own Mortality, Experiencing Physical Closeness, Changing Perspectives Through Comparison, Getting an Approval/Recommendation of Medical Personnel). These factors should be included in theory of preparedness for breast cancer surgery if confirmed by future research.

#### Recommendations for Further Research

The demographics of the group of research participants precludes extensive generalization to the population at large. Participants varied in terms of age, family background, type of breast cancer and type of surgery. As well, participants were selected from only two different female surgeons and two different male oncologists and there was no balanced distribution of these factors, nor were they used in analysis of the data. There was also most likely some researcher bias on the part of the interviewer during the data collection, as I see the need to replicate this study with a larger group of women with breast cancer.

As mentioned above, the present study generated some new factors which were not found in related clinical and research literature. They stand alone as a possibility to be confirmed or disconfirmed by future research. These factors should be put in a survey questionnaire and tested on a broader population of British Columbia breast cancer patients. It could be beneficial to know if the factors are relevant for the larger population.

### Recommendation for Practice

The findings of the present study inspired me to outline some general recommendations for counseling practice and for the medical community to consider when working with women diagnosed with breast cancer:

1. Open communication regarding the disease and its treatment tempered with sensitivity to giving information that generates unnecessary worry.

Women with breast cancer need to know what to expect of treatments and medicines and need to spend time with professionals who convey an optimistic attitude, instill realistic hope, and include the women in decisions related to their treatment.

2. Approaching the women as an "equal". The women in this study seemed to favor consultation rather than being told what to do. This egalitarian type of relationship can be demonstrated through language and behavior, as well as through the arrangement of the medical setting. For example, this can be accomplished through ensuring privacy when arranging for medical appointments with secretaries, or being spoken to in a friendly and respectful manner, and not from behind the desk.

3. Respecting and being sensitive to issues of control. Autocratic behavior may be negatively perceived as controlling and can be prevented by regularly checking with a woman how she feels and what she thinks.

As much as possible, women need to feel in charge of their preparation for breast cancer surgery. This is facilitated when comprehensive, understandable information on treatment options are provided and she makes the final decision.

4. Helping women to empower themselves. Helping women with breast cancer achieve a sense of autonomy, self-efficacy, and personal responsibility is desirable. This also includes being attentive to the dynamic within the therapeutic relationship. It is understandable that every woman goes through a process of adaptation to the breast cancer and in some point of this process she goes through denial. At this point women are extremely vulnerable and they need to be helped.
5. Using language that is understandable. Complex medical terminology can be confusing and should be avoided. The women seemed to find it difficult to ask for explanations when they did not understand. Checking to ensure comprehension of the information is important.
6. Making referrals to counsellors, psychologists, and/or support groups. Attending physicians should assess each woman's ability to cope and consider making referrals to counselors, psychologists, and/or support groups.
7. Finding ways to communicate empathy. This includes medical personnel spending time and being available. The women were extremely sensitive to any sign of time pressure because it made them feel guilty that somebody needed the doctor more than they did. Being accompanied to the waiting room, or other gestures that demonstrated caring were noticed and appreciated by the participants in this study.

#### Personal Reflection

Being a medical practitioner myself, I am only too aware of time constraints on a doctor's ability to provide the optimal clinical, professional

and psychological assistance that a breast cancer patient ideally needs. Although some doctors provide a superior level of patient care, it would be helpful to many doctors and patients if a facilitator (or advisor, or coordinator) in hospitals or clinical settings would be assigned. It is my hope that this study has provided enough information to demonstrate the need for such a person.

Because medical professionals usually focus on the somatic and physiological aspects of cancer, psychological factors are often not addressed in their approach, or in their treatment of patients. I strongly believe that the treatment of breast cancer patients needs to be more holistic, and should include a variety of physiological, behavioral, emotional, and cognitive aspects. Yet, to my best knowledge, there are very few programs in the hospital or clinical settings implemented.

## REFERENCES

- Andersson, B., & Nilsson, S. (1964). Studies in the reliability and validity of the critical incident technique. Journal of Applied Psychology, 48(6), 398-403.
- Ashing-Giva, K.; & Ganz, P. A. (1997). Understanding the breast cancer experience of African-American women. Journal of Psychosocial Oncology, 15(2), 19-35.
- Bartlett, K. G. (1991). Management of breast cancer pain in the home setting. Unpublished master's thesis, University of British Columbia, Vancouver, British Columbia, Canada.
- Berkow, R., & Fletcher, A. J. (1987). The Merck Manual (15th ed.). Rahway, NJ: Merck, Sharp & Dohme Research Laboratories.
- Blichert, T. M. (1992). Breast-conserving therapy for mammary carcinoma: Psychosocial aspects, indications and limitations. Annals of Medicine, 24, 445-451.
- Bogdan, R., & Biklen, S. (1982). Qualitative research for education: An introduction to theory and methods. Boston, MA: Allyn & Bacon.
- Bolger, N., Foster, M., Vinokur, A.D., & Ng, R. (1996). Close relationship and adjustments to a life crisis: The case of breast cancer. Journal of Personality and Social Psychology, 70(2), 283-294.
- Borgen, W., & Amundson, N. (1984). The experience of unemployment. Scarborough, Ontario: Nelson.
- National Cancer Institute of Canada: Canadian Cancer Statistics 1999, Toronto, Canada, 1999.

- Caplan, L.S., Helzlsouer, K.J., Shapiro, S., & Wesley, M.N. (1996). Reasons for delay in breast cancer diagnosis. Preventive Medicine: An International Journal Devoted to Practice and Theory, 25(2), 218-224.
- Carey, M. S. (1999). Coping styles of breast cancer patients and spouses: The effect on patients' psychological well-being and quality of life. Dissertation Abstracts International: Section B: The Sciences and Engineering, 59(9-B).
- Carver, C. S., & Scheier, M.F. (1990). Origin and functions of positive and negative affect: A control-process view. Psychological Review, 1997, 19-35.
- Classen, C., Koopman, C., Angell, K., & Spiegel, D. (1996). Coping styles associated with psychological adjustment to advanced breast cancer. Health Psychology, 15(6), 434-437.
- Cobliner, W. (1977). Psychosocial factors in gynaecological or breast malignancies. Hospital Physician, 10, 38-45.
- Craig, T. J., Comstock, G. W., & Geiser, P. B. (1974). The quality of survival in breast cancer: A case-control comparison. Cancer, 33, 1451-1456.
- Cronbach, J. (1971). Test validation. In R L. Thorndike (ed.) Educational Measurement. Washington, D.C.: American Council on Education.
- Crook, M. (1995). My body: Women speak out about their health care(pp. 142-144). New York: Insight Book
- Delfin, P. (1978). Components of effective telephone intervention: A critical incidents analysis, Crisis Intervention, 9 (2), 50-68.

- Edgar, L. N., Rosenberger, Z., & Nowlis, D. (1993). Coping with cancer during the first year after diagnosis. Cancer, 69, 817-828.
- Erickson, F. (1986). Qualitative methods in research on teaching. In M. C. Wittrock (Ed.), Handbook of research on teaching (3rd ed., pp.119-161). New York: Macmillan.
- Esterling, B. A., Kiecolt-Glaser, J. K., Bodnar, J. C., & Glaser, R. (1994). Chronic stress, social support, and persistent alterations in the natural killer, cell response to cytokines in older adults. Health Psychology, 4, 291-298.
- Fallowfield, L., & Roberts, R. (1992). Cancer counselling in the United Kingdom. Psychology and Health, 6(1-2), 107-117.
- Feuerstein, M., Labbe, E. E., & Kuczmierczyk, A. R. (1986). Health Psychology: A psychobiological perspective. New York: Plenum Press.
- Flanagan, J. (1954). The critical incident technique. Psychological bulletin, 51, 327-358.
- Fotopoulos, S., & Cook, M. R. (1980, September). Psychological aspects of breast cancer: Age. Paper Presented at the American Psychological Association Meetings, Montreal, Quebec, Canada.
- Frank, A. W. (1992). The pedagogy of suffering: Moral dimensions of psychological therapy and research with the ill. Theory and Psychology, 2, 467-485.
- Friedman, L. C., Nelson, D. V., Baer, P. E., & Lane, M. (1990). Adjustment to breast cancer. A replication study. Journal of Psychosocial Oncology, 8, 27-40.

- Gilbar, O. (1991). Model for crisis intervention through group therapy for women with breast cancer. Clinical Social Work Journal, 19, 293-304.
- Giorgi, A. (1970). Towards phenomenologically based research in psychology. Journal of Phenomenological Psychology, 1, 75-78.
- Glanz, K. (1992). Psychological impact of breast cancer: A critical review. Annals of Behavioral Medicine, 14, 204-210.
- Gora, R., Sawatzky, D., & Hague, W. (1992). School counsellors' perceptions of their effectiveness. Canadian Journal of Counselling, 26(1), 5-14.
- Gorzynski, J. G. Holland, J., & Katz, J. I. (1980). Stability of ego defenses and endocrine responses in women prior to breast biopsy and ten years later. Psychosomatic Medicine, 42(3), 323-329.
- Gray, R. E., Fitch, M., Greenberg, M., & Voros, P. (1997). Physician perspectives on unconventional cancer therapies. Journal of Palliative Care, 13(2), 14-21.
- Greer, S. (1992). Adjuvant psychological therapy for women with breast cancer. Boletin dr Psicologia, 36, 71-83.
- Haber, S. (1993). Breast cancer: A psychological treatment manual. Phoenix, Az: Division of Independent Practice.
- Hannum, J. W., Giese-Davis, J., Harding, K., & Hatfield, A. K. (1991). Effects of individual and marital variables on coping with cancer. Journal of Psychosocial Oncology, 9(2), 1-20.
- Hardin, K. N., & Hailey, B. J. (1993). Health care professionals' perception of seriously ill women. Health Care for Women International, 14, 7-16.

- Hasselkus, B. R., & Dickie, V. A. (1990). Themes of meaning: Occupational therapist' perspective on practice. The Occupational Therapy Journal of Research, 10(4), 195-207.
- Herman, C.J., Tessaro, I.A., Shaw, J.E., & Giese, E.A. (1996) Knowledge, attitudes and practices of public health nurses regarding breast and cervical cancer. Family and Community Health, 19(1), 73-82.
- Holland, J. C., & Mastrovito, R. (1980). Psychological adaptation to breast cancer. Cancer, 46, 1045-1052.
- Holland, J. C., & Rowland, J. H. (1989). Handbook of psychooncology: Psychological care of the patient with cancer. New York, Oxford University Press.
- Hoshmand, L. L. S. (1989). Alternative research paradigms: A review and teaching proposal. The Counseling Psychologist, 17, 3-79.
- Hoskins, C. N. (1995). Adjustment to breast cancer in couples. Psychological Reports, 77(2), 435-454.
- Hoskins, C. N., Baker, S., Budin, W., & Ekstrom, D. (1996). Adjustment among husbands of women with breast cancer. Journal of Psychosocial Oncology, 14(1), 41-69.
- Hoskins, C.N., Baker, S., Sherman, D., & Bohlander, J. (1996). Social support and patterns of adjustment to breast cancer. Scholarly Inquiry for Nursing Practice, 10(2), 99-123.
- Hycner, R.H. (1985). Some guidelines for the phenomenological analysis of interview data. Human Studies, 8, 279-303.

- Komproe, I.H., Rijken, M., Ros, W.J.G., & Winnubst, J.A.M. (1997). Available support and received support: Different effects under stressful circumstances. Journal of Social and Personal Relationship, 14(1), 59-77.
- Koehn, C. (1995). Sexual abuse survivors' perception of helpful and hindering counsellor behaviors. Unpublished doctoral dissertation, University of Victoria, Victoria, British Columbia, Canada.
- Lee, E., & Maquire, G.P. (1975). Emotional distress among patients attending a breast clinic. British Journal of Surgery, 62(2), 162-169.
- Levy, S. M., Haynes, L.T., Herberman, R., & Lee, J. (1992). Mastectomy versus breast conservation surgery: Mental health effects at long-term follow-up. Health Psychology, 11, 349-354.
- Lippman, M. E., Lichter, A. S., & Danforth, D. N. (1988). Diagnosis and management of breast cancer (pp. 439-454). Philadelphia, PA: W. B. Saunders.
- Maguire, G. P., Lee, E. G., & Bevington, E. J. (1978). Psychiatric problems in the first year after mastectomy. Journal of Psychiatry, 1, 963-969.
- Margolis, G., Goodman, R. L., & Rubin, A. (1990). Psychological effects of breast-conserving cancer treatment and mastectomy. Psychosomatics, 31, 33-39.
- Martin, R. P., & Curtis, M. (1980). Effects of age and experience of consultant and consultee on consultation outcome. Journal of Community Psychology, 8, 733-736.

- McCormick, R. (1994). The facilitation of healing for the First Nation People of British Columbia. Unpublished doctoral dissertation, University of British Columbia, Vancouver, British Columbia, Canada.
- McGinn, K. A., & Haylock, P. J. (1993). Women's Cancer. Alameda, CA: Hunter House.
- Meyerowitz, B. E. (1980). Psychosocial correlates of breast cancer and its treatment. Psychological Bulletin, 87, 108- 117.
- Neely, M. A., & Iburg, D. (1989). Exploring high school counselling trends through critical incidents. School Counsellor, 36 (3), 179-185.
- Olivotto, I., & Gelmon, K. U. (1995). Intelligent patients' guide to breast cancer. Vancouver, B.C.: Intelligent Patents Guides.
- Penman, D. T., Holland, J. C., & Bahna, G. F. (1984). Informed consent for investigational chemotherapy: Patients' and physician's perceptions. Journal of Clinical Oncology, 2, 849-856.
- Pistrang, N., Barker, CH., & Rutter, CH. (1997). Social support as conversation: Analysing breast cancer patients' interactions with their partners. The Social Science and Medicine, 45(5), 773-782.
- Pellissier, J. M., & Venta, E. R. (1996). Introducing patient values into the decision making process for breast cancer screening. Women and Health, 24(4), 47- 67.
- Petrisek, A., Laliberte, L. L., Allen, S. M., & Mor, V. (1995). The treatment decision-making process: Age difference in a sample of women recently diagnosed with nonrecurrent, early-stage breast cancer. Annual Meeting of the Gerontological Society. Los Angeles, California, US.

- Polkinghorne, D. E. (1991). Two conflicting calls for methodological reform. The Counseling Psychologist, 19, 103-114.
- Predeger, E. (1996). Womanspirit: A journey into healing through art in breast cancer. Advances in Nursing Science, 18(3), 48-58.
- Ronan, W. W., & Latham, G.P. (1974). The reliability and validity of the critical incident technique: A closer look. Studies in Personnel Psychology, 6(1), 53-64.
- Rosh, E. (1977). Human categorization. In N. Warren (Ed.), Advances in cross-cultural psychology. New York: Academic Press.
- Rosser, J. E. (1981). The interpretation of women's experience. A critical appraisal of the literature on breast cancer. Social Science and Medicine, 15, 257-265.
- Royak-Schaler, R. (1991). Psychological processes in breast cancer: A review of selected research. Journal of Psychosocial Oncology, 9, 71-89.
- Schain, W. S. (1985). Breast cancer surgeries and psychosexual sequelae. Implication for remediation. Seminar of Oncological Nurses, 7, 200-203.
- Schofield, M.J., Walkom, S., & Sanson-Fisher, R. (1997). Patient-provider agreement on guidelines for preparation for breast cancer treatment. Behavioral Medicine, 23(1), 36-45.
- Schottenfeld, D., & Robbins, G.F. (1974). Quality of survival among patients who have had radical mastectomy. Cancer, 26, 650-659.
- Siegel, B. S. (1986). Love, medicine and miracles. New York: Harper.

Spiegel, D. (1992a). Effects of psychological support on patients with metastatic breast cancer. *Journal of Psychosocial Oncology*, 10, 113-120.

Spiegel, D. (1992b). The need for psychotherapy in medically ill. *Psychoanalytic Inquiry*, 45-50.

Strauss, A. L. (1987). *Qualitative analysis for social scientists*. Cambridge, England: Cambridge University Press.

Strauss, A., & Corbin, J. (1990). *Basic of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage.

Taylor, S. E. (1983). Adjustment to threatening events. A theory of cognitive adaptation. *American Psychologist*, 38, 1161-1173.

Valanis, B. G., & Rumpler, C. H. (1985). Helping women to choose breast cancer treatment alternatives. *Cancer Nurse* 8(3), 167-172.

Van Heeringen, C., Van Moffaert, M., & de Cuypere, G. (1990). Depression after surgery for breast cancer: Comparison of mastectomy and lumpectomy. *Psychotherapy and Psychosomatics*, 51, 175-179.

van der Pompe, G., Antoni, M., Visser, A., & Garssen, B. (1996) Adjustment to breast cancer. The psychbiological effects of psychosocial intervention. *Patient Education and Counseling*, 28(2), 209-219.

van Wersch, A., Bonnema, J., Prinsen, B., & Pruyn, J. (1997). Continuity of information for breast cancer patients: The development, use and evaluation of a multidisciplinary care-protocol. *Patient Education and Counseling*, 30 (2), 175-186.

Veronesi, U., Saccozzi, R., & Del Vecchio, M. (1981). Comparing radical mastectomy with quadrantectomy, axillary dissection and radiotherapy in patients with small cancer of the breast. New England Journal of Medicine, 305-316.

Waxler-Morrison, N., Hislop, T. G., Mears, B., & Kan, L. (1991). Effects of social relationships on survival for women with breast cancer: A prospective study. Social Science and Medicine, 33, 177-183.

Wellisch, D. K., DiMatteo, R., Silverstein, M., & Landsverk, J. (1989). Psychosocial outcomes of breast cancer therapies: Lumpectomy versus mastectomy. Psychosomatics, 30, 365-373.

White, M. (1989). The externalizing of the problem and re-authoring of lives and relationships. Dulwich Centre Newsletter, 3-21.

Woolsey, L. K. (1986a). The critical incident technique: An innovative qualitative method of research. Canadian Journal of Counselling, 20, 242-254.

Woolsey, L. K. (1986b). Research and practice in counselling: Conflict of values. Counselor Education and Supervision, 26, 84-94.

Zemore, R. R., Rinholm, J., Shepel, L. F., & Richards, M. (1989). Some social and emotional consequences of breast cancer and mastectomy: A content analysis of 87 interviews. Journal of Psychosocial Oncology, 7, 33-45.

**Appendix C  
DEMOGRAPHIC QUESTIONNAIRE**

**Name:**

**Age:**

**Address:**

**Telephone:**

**Occupation:**

**Status (married, divorced, single, common law partner):**

**How many children you had:**

**Date of your diagnosis:**

**Date of your operation:**

**Was your surgeon woman or man:**

## Appendix E

THE UNIVERSITY OF BRITISH COLUMBIA  
FACULTY OF EDUCATION  
DEPARTMENT OF COUNSELLING PSYCHOLOGY  
2125 MAIN MALL  
VANCOUVER, B.C.  
V6T 1Z4

TITLE OF PROJECT:

PSYCHOLOGICAL PREPAREDNESS FOR BREAST CANCER  
SURGERY

**List of suggested questions for interviews:**

"Think back to the time before the operation, what helped you to facilitate or hinder the preparation for surgery?"

"Could you describe how did you anticipate such events?"

"What did you do or what happened to make you feel this way?"

"What actually happened when this event took place?"

"How important was this incident at the time?"

"What did you consider most helpful from the health-care personnel?"

"What made this incident so helpful?"

"What made this incident hinder your preparation to the surgery?"

"What did you learn about yourself from this event?"

"What was meaningful about these incident?"

"What are the resources that help you in your preparation to the surgery?"

"Was this event /incident helpful/hindering enough to change your attitude towards other people, your disease, or yourself? Maybe for some time only?"

"If you would have the option to do it again, what would you like to change about the preparation?"