

Copyright is owned by the Author of the thesis. Permission is given for a copy to be downloaded by an individual for the purpose of research and private study only. The thesis may not be reproduced elsewhere without the permission of the Author.

# **DECIDING TREATMENT OPTIONS FOR BREAST CANCER:**

## **A GROUNDED THEORY OF THE WOMEN'S PERSPECTIVE**

by

**Lynn Harwood**

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

**Master of Arts in Nursing**

**Massey University**

**2000**



## **ABSTRACT**

### **The women's perspective on deciding treatment options for breast cancer**

Fallowfield and Hall (1991, p. 387) state: "Coping with the diagnosis and treatment of breast cancer is problematic for both the women with the disease and their doctors who must treat it". A variety of surgical techniques and types of adjuvant therapy are now available. As well as advances in medical and surgical care, marked cultural changes have also occurred in western health care over the past 30 years, with increasing concern for individual autonomy and consumer rights. Increasing emphasis is now placed on the provision of information to patients and on their participation in decision making about their prospective treatment. Questions remain, however, as to whether patients benefit from being offered choice, and evidence is currently limited.

The aim of the present study was to discover the women's perspective on having to make choices regarding their preferred treatment options for breast cancer. The Glaserian (after Barney Glaser) school of grounded theory was chosen as the research method. Fourteen participants were recruited. Each woman participated in a loosely structured interview lasting 1-1½ hours, which was taped and transcribed. Together these interviews became the data for analysis. Substantive codes and theoretical categories were developed from this data and finally a conceptual framework was constructed.

Three main categories were identified. These were:

- Detecting a cancer – the crisis evolves.
- Discerning value priorities.
- Reaching a point of salience and commitment to choice.

The over-arching or core category identified was "Unifying 'the self' with treatment choices".

It was identified in the present study that freedom of choice is part of the life project of 'choosing oneself'. The self is not a ready-made being but an existent always in the process of becoming, or as Macquarrie (1972, p. 145) states: "A unitary self as distinct from a series of unconnected acts". Women made their choices based on their past, their present life situation and their projection, for themselves, of their future. These decisions were made within the context of provisionality versus permanence; a diagnosis of cancer brought with it a renewed awareness life's uncertainty and also one's mortality.

## PREFACE

In the year 2000 breast cancer has reached almost epidemic proportions in western society. Although breast cancer is a greater risk in later years, younger women, and even men, can develop this condition. Owing to the pervasiveness and significance of this disease condition, extensive medical research has, and continues, to be undertaken. Although cure and prevention of this disease are the scientific community's primary focus, this is unlikely to be realised in the immediate future. Management and control of this disease therefore remain central concerns. To this end extensive clinical trials have been undertaken to determine how to best manage this disease.

Surgery, radiation, chemical and hormone therapy, remain the major treatment strategies for this condition. Unfortunately, as well as attacking the 'disease' these modalities impact on 'the person' inflicting their own morbidity in the quest for survival (or quality of life) advantage. Unsurprisingly, considerable psychosocial research has also been undertaken researching this morbidity. These have included studies comparing the psychological morbidity between such treatment options as mastectomy versus mastectomy and reconstruction versus conservative surgery. Quality of life studies have also investigated the impact on women of undergoing adjuvant hormone and chemotherapy.

In reviewing this literature on breast cancer, it was noticeable that there were few studies investigating the 'women's perspective' on having to make choices regarding their preferred treatment options for breast cancer. It was therefore decided to investigate the processes and factors women themselves describe as important in making their treatment choices.

As a nurse I have been involved with women undergoing treatment for breast cancer in both medical and surgical oncology for a number of years. In 1980-82 I was employed as a research oncology nurse caring for women undergoing adjuvant and treatment chemotherapy. From 1983 to the present date I have been involved with women having surgical treatment for breast cancer. It was this experience (and concern) that led me to choose this topic for my post-graduate research project.

## **ACKNOWLEDGEMENTS**

This research would not have been possible without the willing participation of the fourteen women who volunteered to be involved in the present study. I am deeply grateful to them for giving of themselves and their time. I am also very grateful to Gai Kidd, Coordinator/Breast Cancer Support Service, and Sandy Lyster, Breast Care Nurse for assisting me with recruitment of participants to the study. I would also like to thank my employer, Capital Coast Health, for granting me the required studies days to attend Massey.

Special thanks to my supervisor, Martin Woods, for his continuous support, advice and guidance, and patient reading and critique of the various draft stages of this report. I would also like to thank my family (especially Rick, Mum and Peggy) for 'putting up with me' over this time and my four (now three) Pekingese for their constant (and precious) companionship over this time. Also, special thanks to Rick for his speedy 'technical support' when the occasional 'computer crisis' occurred.

# TABLE OF CONTENTS

<b>ABSTRACT</b>	ii
<b>PREFACE</b>	iv
<b>ACKNOWLEDGEMENTS</b>	v
<b>TABLE OF CONTENTS</b>	vi
<b>CHAPTER ONE: INTRODUCTION AND OVERVIEW</b>	<b>1</b>
BACKGROUND TO PRESENT STUDY	2
PSYCHOLOGICAL MORBIDITY ASSOCIATED WITH THE TREATMENT OF BREAST CANCER	3
AIMS OF THIS STUDY	4
METHODOLOGY	4
ORGANISATION OF THESIS	5
SUMMARY	9
<b>CHAPTER TWO: BACKGROUND AND LITERATURE REVIEW</b>	<b>10</b>
INTRODUCTION	10
CONTEMPORARY BIOLOGICAL UNDERSTANDING OF BREAST CANCER	11
(1) THE MEDICAL PERSPECTIVE	11
(2) THE PSYCHO-SOCIAL PERSPECTIVE	17
THEORIES ON DECISION MAKING	29
THE WOMEN'S PERSPECTIVE	36
SUMMARY	38
<b>CHAPTER THREE: RESEARCH METHODOLOGY</b>	<b>39</b>
INTRODUCTION	39
THE EVOLUTION OF NURSING AND NURSING RESEARCH	40
QUALITATIVE RESEARCH	42
GROUNDED THEORY	44
OBJECTIVES OF THE PRESENT STUDY	49
PROCEDURES ADOPTED FOR RECRUITING PARTICIPANTS AND PROCEDURES FOR OBTAINING INFORMED CONSENT	49

PARTICIPANTS, DEMOGRAPHICS AND ETHICAL CONSIDERATION.....	51
ETHICAL ISSUES.....	54
SUMMARY .....	55
 <b>CHAPTER FOUR: THE HISTORICAL-SOCIAL PERSPECTIVE ON 'AUTONOMY OF CHOICE' IN HEALTH CARE DECISION-MAKING</b>	 <b>56</b>
INTRODUCTION.....	56
THE HISTORY OF PATIENT PARTICIPATION IN HEALTH CARE DECISIONS	57
PATIENT DECISION-MAKING: THE ETHICAL PERSPECTIVE.....	63
A BRIEF HISTORY OF THE EVOLUTION OF INFORMED CHOICE AND INFORMED CONSENT .....	65
SUMMARY .....	68
 <b>INTRODUCTION TO THE DATA .....</b>	 <b>69</b>
 <b>CHAPTER 5: DETECTING A CANCER – THE CRISIS EVOLVES</b>	 <b>70</b>
INTRODUCTION.....	70
EMERGING THE PROBLEM .....	71
Finding a lump .....	71
Screening detected breast cancer .....	73
“Feeling devastated” .....	74
 THE ‘BAD NEWS’ CONSULTATION .....	 75
Receiving the ‘bad news’ .....	76
Facing a breast cancer diagnosis – hearing treatment alternatives.....	77
‘Flashbulb’ recall .....	79
Receiving and telling ‘bad news’ difficult.....	80
Concentrating on detail ‘difficult’ .....	82
Feeling “out of control” – “a roller-coaster”..	83
Grieving potential losses and asking: “Why me?” “Why this?”	84

DEVELOPING KNOWLEDGE OF CLINICAL OPTIONS .....	86
Seeking information - gaining expertise... ..	87
Researching the literature .....	87
Talking with others who had encountered breast cancer... ..	89
Discussing options with family and friends .....	90
‘Statistics unhelpful?’ .....	90
‘Statistics helpful?’ .....	91
Choosing not to seek information... ..	92
Deciphering the jargon - getting it all together .....	93
SUMMARY .....	94
 <b>CHAPTER 6: DISCERNING VALUE PRIORITIES</b> .....	<b>95</b>
INTRODUCTION .....	95
MAXIMIZING CHANCE OF SURVIVAL - CONTAINING THE CRISIS .....	96
Surviving the disease priority: preserving ‘body wholeness’ integral .....	96
Defying disembodiment .....	99
Accepting adjuvant therapies .....	101
<i>Hormone therapy</i> .....	101
<i>Chemotherapy</i> .....	102
<i>Radiotherapy</i> .....	104
SITUATING BREAST CANCER WITHIN THE CONTEXT OF ONE’S LIFE.....	106
Reflecting on one’s personal life situation:	
Past, present and projected future .....	106
Living in the community with others... ..	109
Timing: too much – too little - rarely right... ..	111
SOLICITING EXPERT GUIDANCE.....	113
Seeking expert advice... ..	114
Developing helping-trusting relationships with other ‘experts’	116
SUMMARY .....	117

## **CHAPTER 7: REACHING A POINT OF SALIENCE AND COMMITMENT**

<b>TO CHOICE</b> .....	<b>118</b>
INTRODUCTION.....	118
MAKING DECISIONS – TAKING THE PLUNGE.....	119
Just ‘wanting rid’ .....	120
Deciding instantly.....	121
Sub-conscious decision making .....	123
Protecting body image .....	124
‘Fielding the knocks’ .....	125
REVEALING THE PARADOXICAL NATURE OF CHOICE.....	127
Choosing (is never easy) .....	128
Deciding (when choices are restricted) .....	129
Weighing (the ‘pros and cons’) .....	131
Wanting (a definitive answer) .....	134
Accepting (there are no perfect solutions).....	135
SUMMARY .....	137

## **CHAPTER 8: CORE CATEGORY: UNIFYING ‘THE SELF’ WITH TREATMENT CHOICES: CONTOURS OF EMBODIMENT**.....

INTRODUCTION .....	138
MAKING CHOICES AND LIVING WITH THEM .....	139
‘Buying in’ to personal choice .....	139
Struggling to preserve unity and body wholeness.....	141
ACCOMMODATING THE FACT OF CANCER: RE-INTEGRATING SELFHOOD .....	145
Facing one’s mortality.....	145
Integrating the personal and social self: disclosing the fact of breast cancer.....	147
UNIFYING ‘THE SELF’ WITH TREATMENT CHOICE.....	149
Contours of embodiment.....	149
Embodiment and breast reconstruction.....	152



Integrating choice and self .....	153
Core category: “Unifying ‘the self’ with treatment choice” .....	154
SUMMARY.....	157
THEORETICAL MODEL (PART ONE).....	158
THEORETICAL MODEL (PART TWO) .....	159
THE WOMEN’S PERSPECTIVE ON DECIDING TREATMENT OPTIONS: THE MODEL .....	160
<b>CHAPTER 9: LITERATURE COMPARISION, DISCUSSION AND IMPLICATIONS FOR PRACTICE.....</b>	<b>162</b>
INTRODUCTION.....	162
DETECTING A CANCER – THE CRISIS EVOLVES.....	163
DISCERNING VALUE PRIORITIES.....	168
REACHING A POINT OF SALIENCE AND COMMITMENT TO CHOICE .....	175
CORE CATEGORY: UNIFYING ‘THE SELF’ WITH TREATMENT CHOICES .....	180
IMPLICATIONS FOR NURSING PRACTICE.....	185
IMPLICATIONS NURSING EDUCATION .....	190
SUGGESTIONS FOR FURTHER RESEARCH.....	191
LIMITATIONS OF THE PRESENT STUDY.....	192
CONCLUDING STATEMENTS .....	193
<b>GLOSSARY OF TERMS .....</b>	<b>194</b>
<b>APPENDICES .....</b>	<b>195</b>
APPENDIX A: INTRODUCTION AND INFORMATION SHEET .....	196
APPENDIX B: CONSENT FORM .....	199
APPENDIX C: RESEARCHERS REFERENCE QUESTION LIST .....	200
<b>REFERENCES.....</b>	<b>201</b>

# **CHAPTER ONE**

## **Introduction and Overview**

### **Deciding Treatment Options for Breast Cancer**

*It is the history of silence with respect to patient participation in decision making that I wanted to document.*

Jay Katz, 1984, p. 3-4.

#### **INTRODUCTION**

Contemporary breast cancer treatment has become an experience that rests on a woman's personal decisions regarding what treatment alternatives she prefers. The chosen option(s) will probably be most consistent with her priorities regarding health, body integrity, and general well being. Medical and surgical treatment of breast cancer is increasingly complex because it involves multiple options regarding treatment choices, all retaining an element of uncertainty with regard to final outcome. For some women choices will be more limited, related to the presentation of their disease. However, in this era of informed consent, women will necessarily be required to participate in their treatment plan and consider the options available to them.

This chapter will provide a brief background to these issues, an overview of the aims of the present study, the research methodology, a summary of the findings and an overview of the format of this report. It is arranged in the following sections:

- Background to present study.
- Treatment options to be decided.
- Psychological morbidity associated with the treatment of breast cancer.
- Aims of the present study.
- Methodology.
- Organisation of thesis.
- Summary.

## **BACKGROUND TO PRESENT STUDY**

Thirty years ago, the selection of therapy for breast cancer was simple; treatment equalled mastectomy (Cady & Stone, 1990). However, over the past three to four decades, a different understanding of the biology of breast cancer has evolved. It is now known that the details of local resection do not govern survival (Fisher, 1996). Survival is governed by the ability of the individual tumour to spread (its invasiveness) either via the blood stream or lymphatic channels, and secondarily by its ability to implant itself, undetected (immunologically) by its host.

Over the past 20-30 years another important fact has been established. A variety of prospective clinical trials, in various parts of the world, have come to the same conclusion; survival is identical for periods as long as 10 years or more between groups of women randomly assigned to mastectomy (breast amputation) or breast preservation (local excision and radiation therapy, or local excision alone). The details of local resection may have considerable bearing as to whether there is local recurrence in the breast, but not long term survival (Cady & Stone, 1990).

The two major local surgical options for breast cancer are currently mastectomy and axillary dissection versus conservative surgery (local tumour excision and axillary dissection). For women choosing mastectomy, breast reconstruction (immediate or delayed) may be a further option to be decided. In either surgical option, histology will determine whether further surgical (in the case of conservative surgery) or medical adjuvant<sup>1</sup> therapy is indicated: cytotoxic, hormone, radiation therapy or combination of these. Radiotherapy is almost universally recommended after conservative surgery without which there is a 30% risk of local recurrence (Nixon, Troyan & Harris, 1996). Ultimately it will be the women's decision whether she wishes to proceed with further treatment.

---

<sup>1</sup>The term adjuvant therapy refers to chemotherapeutic or hormonal treatment for post-surgical breast cancer patients who have, as yet, no clinically detectable disseminated disease (Siminoff & Fetting, 1991).

Historically, it was the physician or surgeon who decided the treatment plan for patients with a breast cancer. In recent years that imbalance of power between the patient and the professional has changed (Biley, 1992). Women have become much more active participants in deciding their treatment choices. Greater knowledge of healthcare issues and the development of bodies to protect the interests of the patient have all contributed to women having a much more active role. There are also ethical, legal and social reasons for this change occurring. Legally, the area of informed consent has required healthcare professionals to fully explain treatment choices and obtain informed consent. Socially, there is a growing movement advocating the view that the patient is a health care consumer with rights to information, interaction, and participation in his or her care and treatment plan.

All of the above adds to the immensity of a diagnosis of breast cancer. Not only is the women faced with the awareness that she has a potentially fatal disease, but she must also make important treatment decisions which may affect her life, and her body, irrevocably.

### **PSYCHOLOGICAL MORBIDITY ASSOCIATED WITH THE TREATMENT OF BREAST CANCER**

Over the past 15-20 year's considerable psychosocial and medical research, has investigated the impact on women's psychological, sexual and social well being associated with the different treatment options for breast cancer. Studies generally agree that mastectomy is more likely to result in problems related to body image (Schain & Fetting, 1992). Studies that have assessed the affects of surgery on psychological morbidity, however, show similar levels of anxiety and depression regardless of treatment chosen (Fallowfield and Hall, 1991). Irrespective of the type of primary treatment, at least one fourth of breast cancer patients will develop clinically significant anxiety or depression (Maguire, 1989). A literature search (1980-2000) reveals considerable quantitative research investigating women's choice of treatment in relation to breast cancer whilst it appears minimal qualitative research has been undertaken and few studies directly explore women's personal perspective. Yet Williamson (1996, p. 506) states that "research that picks up trends

in patients' views and detects new issues as professional practices, or patients' expectations change, is a necessary complement to professional assumptions and aspirations". This is a focus of the present study.

### **AIMS OF THIS STUDY**

The present study sought to explore the women's perspective on deciding their treatment options. The goal was to illuminate the issues the women themselves identified as significant in influencing these decisions. The central aims of the present research were therefore to:

- Ascertain the central issues women describe in deciding their preferred treatment options for breast cancer.
- Report how the women interpreted this experience.
- Develop a theoretical model of the factors and issues women relate as significant in deciding personal treatment choices.
- Advance the knowledge of women's experience of a breast cancer diagnosis, and the significance of deciding their personal treatment choice.

### **METHODOLOGY**

The grounded theory method was chosen for this study. Grounded theory is an inductive approach meaning that the researcher generates theory from the data. There are no pre-conceived hypotheses to be investigated. Constant comparative analysis of the data, right from the beginning of the research, emerges into theory development as reflection and analysis of the data progress. It is achieved by exploring and uncovering the relationships between the various codes and categories that the data generates. It consistently asks the question "What is happening here?" and therein the grounded theory method strives to be both descriptive and predictive. Although the researcher must necessarily interpret, make sense of, the data, the grounded theory method dictates that one must remain true to the data; theory emerges directly from the data. Rigour is maintained by remaining true to 'the canons and procedures' of the grounded theory method (Glaser, 1992).

Fourteen women were recruited to the study and each participated in a semi-structured interview lasting 1-2 hours. The interviews were recorded, transcribed and analysed as described above. Substantive codes and categories were developed from the data and one over-arching or 'core category' evolved.

## **ORGANISATION OF THESIS**

To achieve the aims of this study, this thesis is arranged into nine chapters. The first four chapters pertain to the introduction and overview of the thesis topic and objectives. Chapter one has outlined the background and purpose of the present study, and the chosen methodology. It has discussed how although there is considerable medical and social science research regarding the treatment options, and the affects of these treatments for breast cancer, few studies have investigated how the women themselves describe this experience.

### **Chapter two: Background and literature review**

This chapter provides an overview of the relevant literature relating to the present study. It begins by discussing the contemporary medical understanding of breast cancer followed by a sample of psycho-social research that has been undertaken. A section discussing decision-making theory (including 'feminist' theory in relation to women with breast cancer and decision making) follows this.

### **Chapter three: Research methodology**

This chapter begins with a brief discussion of the evolution of nursing as a profession, and nursing research. It reflects on the nursing professions increasing adoption of qualitative nursing methodologies, and a discussion of grounded theory, which was the method chosen for the present study. The philosophical background of this method is discussed along with the reasons why it was chosen for the present study. Chapter three also describes the research process undertaken for this study (including the objectives of study, participant eligibility and selection, informed consent, data collection and analysis).



#### **Chapter four: The historical-social perspective on ‘autonomy of choice’ in health care decision-making**

This chapter provides an overview of the social and historical perspectives on the doctor-patient relationship and patient participation in treatment decision making. It discusses such issues as medical dominance in health care decision making, the affects of ‘consumerism’ and information technology, and the influence of activist groups such as the women’s rights movement. It also discusses legal and ethical issues including that of ‘informed consent’.

The next four chapters (chapters five to eight) are devoted to the presentation of the concepts elicited from the data. The final chapter, chapter nine, provides an overview of the study relating it to selected, relevant literature that either concurs, or disagrees, with the present study’s findings. Description is by means of theoretical coding, with sub-codes generally using gerundial (a verbal noun ending in *ing*) term for description. The three main categories that were elicited, and which serve to ‘link’ the many substantive codes, are as follow:

- Detecting a cancer – the crisis evolves (Chapter 5).
- Discerning value priorities (Chapter 6).
- Reaching a point of salience and commitment to choice (Chapter 7).

The over-arching or core category identified was “Unifying ‘the self’ with treatment choice” (Chapter 8). A brief overview of chapters one to nine follows.

#### **Chapter five: Detecting a cancer – the crisis evolves**

As the women were invited to describe their experience of breast cancer and how they decided their treatment options, they generally began their narratives with how their breast cancer was discovered. This chapter therefore describes how the women encountered their breast cancer and their preliminary discussions with their breast cancer specialist(s) regarding their treatment options.

#### **Chapter six: Discerning value priorities**

This chapter discusses how the women decided their value priorities in relation to the different treatment options they were required to consider. For most of the

women, 'maximizing survival – containing the crisis' was their major priority (at least initially) but preserving body integrity was also integrally important. Decisions regarding adjuvant therapy were also discussed in this chapter. The contextual determinants of the women's lives – their families and careers – were all-important factors in their decision making. The significance of timing in relation to their finding a lump (or diagnosis of cancer) and their definitive treatment is discussed. This chapter also related the importance the women placed on having confidence in their clinicians. They needed to be able to trust that they would guide them, or advocate in their best interest, in making 'medically safe' decisions.

#### **Chapter seven: Reaching a point of salience and commitment to choice**

This chapter provides a retrospective look at how the women felt about their treatment choices and the experience of having to decide their options. It discusses how there is always paradox inherent in choice; there are inevitably positives and negatives in all choices. Choices were always both enabling and limiting in one way or another. Involvement in decision-making, however, appeared to help the women commit to their choices.

#### **Chapter eight: 'Unifying 'the self' with treatment choices'**

Chapter eight discusses what was identified as the core or over arching category, "Unifying 'the self' with treatment choices". It discusses how issues of mortality and personal physical integrity are not separate but integral components of women's decision making regarding treatment options. It also relates the significance of 'personal meaning' as opposed to measurable treatment outcomes (calculated in years of disease free survival and mortality figures) which are the important quantitative end-points of treatment choice. Chapter eight relates how the women chose the options that they could cope with in the present and best live with in their projected future. Whatever their treatment choice, the women had to work at committing themselves to that choice, of integrating their experience of breast cancer into their lives, and of regaining a sense of selfhood, be it altered selfhood, having experienced such a crisis as breast cancer. The women often related that this experience had given them a new appreciation of life and the things that were really



important to them. They remained, however, a sense of provisionality versus permanence; breast cancer had touched on their mortality. For some this was viewed positively (more so those with a very good prognosis), for others it was an immense burden.

Chapter eight also related the concept 'contours of embodiment' and the fact that a woman's breasts contribute to her sense of wholeness and feelings of womanliness. Breast cancer touches at the very core of what it means to have an 'intact' body, a sense of unity and feminine wholeness. The women appeared to have to re-integrate the altered self into their personal self-concept. This occurred over time.

Chapter eight concludes with a discussion of the theoretical model that evolved in this study and provides an overview of the linkages of the various theoretical categories and substantive codes.

#### **Chapter nine: Discussion and recommendations**

Chapter nine discusses the findings of the present study in relation to a sample of the relevant scientific, psychosocial and philosophical literature. It also prescribes a theoretical proposition in relation to each major category that emerged in the study. Chapter nine then discusses the implications for nursing practice of the theoretical model that emerged in this study and its potential for wider application in other areas of healthcare decision-making (both a general and specific example are provided). It also discusses the implications of this study for nursing education and offers suggestions for further nursing research.

#### **SUMMARY**

The present study indicates the complexity of women's decision making with regard to deciding their preferred treatment options. As well as facing the crisis of a diagnosis of breast cancer they also have to cope with making important decisions regarding their choice of treatment. Their personal value priorities and life situations necessarily affect these.

The nursing profession has considerable involvement with women undergoing treatment for breast cancer. Nurses have an important role in assisting patients through the various treatment phases (in both surgical and medical oncology) and helping them to be self-determining in their choices. In the new age of both specialization and consumerism, specialist breast cancer nurses have an important role to play in the multi-disciplinary team involved in the care of women with breast cancer. It is hoped that this research will be a resource for nurses who are involved in helping women faced with a diagnosis of breast cancer.

## **CHAPTER TWO**

### **Background and Literature Review**

*"The body has become unfaithful."*

Van Den Berg (1980, P. 66).

#### **INTRODUCTION**

This chapter will discuss the contemporary understanding of breast cancer as reflected in the literature over the past few decades with a particular emphasis on the changing understanding of the nature of this disease and its treatment. As breast cancer (and women with breast cancer) has been widely studied, this review is necessarily selective and aimed at providing an overview, as opposed to an in-depth analysis.

Chapter two begins with a reflection on the medical perspective and current 'state-of-the-art' management of breast cancer. The psychosocial literature in relation to breast cancer and treatment choice is then examined. As the central focus of this study is the women's perspective on deciding treatment options, this is followed by a section considering the psychological theories on decision making. This includes a brief section on the 'Kohlberg-Gilligan debate' and its relevance to women deciding treatment options for breast cancer. The goal of this review is to situate choice and decision making within the wider context of a breast cancer diagnosis. This is the situation in which the woman is poised. In relation to this, chapter two will conclude with a very brief reflection on the women's perspective of a breast cancer diagnosis.

The section topics in this literature review are:

- Contemporary biological understanding of breast cancer:
  - (1) The medical perspective.
  - (2) The psychosocial research perspective.
- Psychological theories on decision-making.
- The women's perspective.

Sub-sections relating to these topics will be identified at the beginning of each segment.

## **CONTEMPORARY BIOLOGICAL UNDERSTANDING OF BREAST CANCER: (1) THE MEDICAL PERSPECTIVE**

### **Introduction**

Laboratory and clinical experience over the past half century has evolved a new paradigm of understanding as to the nature of breast cancer (Fisher, 1996). Up until the 1950s, breast cancer was considered to be a local disease confined to the chest wall, whose recurrence, spread, or both, could best be prevented by aggressive surgical dissection; notably the 'Halsted radical mastectomy'. This involved aggressive dissection of the breast, local muscle and the surrounding tissue. It is now understood that breast cancer is a much more complex disease process involving a response between the tumour and host (Fisher, 1996). There is an increasing awareness that metastases grow as a consequence of both anatomic access plus a 'fertile field' effect in which local tissue conditions actually encourage or support growth through release of growth, and other, mediating factors (Hudis & Norton, 1996). It has also been identified that breast cancer is more commonly a systemic, as opposed to local, disease. Dissemination from a primary cancer occurs by haematogenous and lymphatic routes simultaneously. The 'new biology' (demonstrated over the past decades by both laboratory and clinical research) indicates that the details of local resection do not govern survival. Once the primary invasive cancer has been removed (either by local excision or mastectomy), and its potential for shedding cells into the haematogenous and lymphatic channels has been eliminated, "the fate of the patient has been determined" (Cady & Stone, 1990, p. 1048-9). Other details of local therapy will not exert a controlling influence on that prognosis. Systemic therapy, however, may offer some survival advantage. These issues will be discussed in the following sections, in this sequence:

- Breast cancer statistics.
- Mastectomy versus conservation surgery .
- Scenario: A lump in the breast.
- Adjuvant therapy.

### **Breast cancer statistics**

Breast cancer is the most common cancer in women in western society accounting for 28-32% of all newly diagnosed cancers (McCool, Stone-Condry, & Bradford, 1998). In 1994, it was estimated that world wide more than 850,000 new cases of breast cancer were diagnosed and approximately 250,000 died (Moore & Kinne, 1995). In the United States it is estimated that 184,200 new cases of female breast cancer will be diagnosed in the year 2000, and more than 40,000 deaths will be attributed to the disease (Greenlee, Murray, Bolden & Wingo, 2000). During the 1940s until the 1960s, the incidence of breast cancer was 1 in 20, whereas in 1970 it was 1 in 13 (Scott, DiSaia, Hammond, Spellacy, 1994). Today the American Cancer Society estimates that, for the general population, 1 in every 8 women in the United States who lives to the age of 85 will develop breast cancer at some time during her life (Kelsey & Berstein, 1996). In New Zealand approximately 28-30% of all cancers diagnosed in women is breast cancer. It is estimated that between 1997-2001, there will be 3,951 deaths from breast cancer (Public Health Commission, 1995, p. 47). These figures serve to illustrate the significant 'burden' breast cancer has for our society, and particularly for women.

### **Mastectomy versus conservation surgery**

Newly diagnosed, early-stage breast cancer confronts the woman concerned, and her clinician, with multiple treatment decisions (Nixon, Troyan & Harris, 1996). The primary goal of local, generally surgical treatment for early-stage breast cancer is to remove the primary tumour and minimise the risk of recurrence in the affected breast, chest wall and in the regional lymph nodes. Local treatment decisions are therefore directed towards the primary tumour, the remaining breast tissue and draining nodal areas. Currently, the standard means to achieve these goals are either mastectomy or wide excision plus radiation therapy (breast conservation surgery).

Although 'mastectomy' is used to describe a variety of more specific surgical procedures (for example, simple mastectomy, modified radical mastectomy) they all encompass complete excision of the breast (which includes skin and nipple), the underlying pectoral fascia, and a proportion of the axillary lymph nodes. Breast conservation surgery involves a wide local excision of the primary tumour with

histologically proven negative margins (it is desirable to have a margin of tissue around the tumour that is 'clear' or histologically negative for tumour invasion). An 'axillary dissection' (removal of a bloc of tissue from under the arm containing lymph nodes) is performed for all infiltrating tumours. Histological examination of the lymph nodes is a useful prognostic indicator and provides important information that influences the recommendation for additional treatment. There is ongoing research as to the level of lymph node dissection desirable. Axillary dissection can cause pain, tingling and lymphoedema of the affected arm in approximately 10% of women. Studies are currently investigating the technique of 'sentinel node biopsy'<sup>2</sup> in those women without clinical involvement of the axilla, as a means of avoiding complete axillary dissection, but its precise role is as yet unclear (Collins & Simpson, 1998; Veronesi, Paganelli & Galimberti, 1997). Local excision of the breast tumour will be followed with a course of radiation therapy to eradicate any residual, microscopic disease in the remaining breast, axilla or chest wall. In conservation surgery the goal is to retain a cosmetically acceptable breast. If this goal is unlikely to be achieved the surgeon will generally suggest that mastectomy be performed.

Historically the evolution of local treatment has reflected the prevailing theory of cancer dissemination (Fisher, 1996). As previously discussed, the Halstedian radical mastectomy involving an en bloc resection of the breast, overlying skin, underlying pectoral muscles and axillary contents, corresponded with the belief that tumour spread was primarily via local extension and lymphatic channels. The failure of this radical procedure to improve overall survival in the 1950s and 1960s invoked a shift towards the more conservative 'modified' radical mastectomy (Nixon, Troyan & Harris, 1996). It was becoming clear that systemic disease relapse was related to other criteria. However, because of the universal acceptance of the Halstedian dogma regarding breast cancer, a relatively large number of prospective randomised clinical trials have been conducted to compare outcome of breast conservation surgery to mastectomy. Results from six trials (including more than 4,300 women in total)

---

<sup>2</sup> The sentinel node is the first lymph node to receive lymphatic drainage from the primary cancer and can be identified by injection of a radioisotope tracer or a vital blue dye, or a combination of both around the tumour.



demonstrate similar survival when comparing breast-conserving treatment and mastectomy. No statistical difference in local recurrence or disease free survival can be demonstrated in either treatment arm when the prescribed treatment criteria are adhered to (Moore & Kinne, 1995; Nixon, Troyan & Harris, 1996).

#### **Scenario: A 'Lump in the breast'**

What then is the likely scenario if a woman finds a lump in her breast and presents herself to her doctor? Initially the doctor will take a clinical history including how the woman detected the change in her breast, questions regarding any discharge, pain in the breast, or other symptoms. The woman's age and family history will be noted. The incidence of breast cancer increases with age. A history of a first-degree relatives (mother, sisters, or daughters) with breast cancer, and age at which they developed cancer will be obtained (Cady, Steele, & Morrow et al., 1998). Women who have a pre-menopausal first-degree relative diagnosed with breast cancer have a three to fourfold greater risk of developing breast cancer than women with no family history. The practitioner may obtain information regarding parity and the age of delivery of the woman's first child. Women with no children, or those who's first full-term pregnancy occurred after the age of 35 have an increased risk to those who had children earlier in life. Other risk factors for breast cancer include early menarche (before the age of 12 years) and late menopause (older than 53 years). The use of hormone or contraceptive therapy may also be noted as there is a growing awareness that prolonged use may be a relevant factor in breast cancer risk (Chilvers & Deacon, 1990). A history of radiation exposure or treatment for malignant disease in childhood or adolescence may also alert the physician to higher risk of cancer. If, on examination, a solid or dominant mass is palpated, or if the woman is in a more 'at risk' age group (over 50 years) the physician will likely suggest the woman undergo mammography. If there is a suspicion of breast cancer, in today's world of increasing specialisation, the general practitioner may suggest to his or her patient that she be referred to a breast care specialist (general surgeon or physician specialising in breast conditions).

The 'lump' under expert medical hands is palpated, measured, x-rayed (mammogram, if not already performed, or an ultrasound may be requested) needed

(fine needle aspiration = FNA) and/or biopsied to determine its cellular/tissue composition. If fine needle aspiration (cytology) or open biopsy (histology) reveals malignancy, the surgeon is likely to suggest various treatment options. If the lesion is small, uni-focal (a single mass) and not tethered to other tissues (chest wall muscle/bone) then it may be possible to excise the lump, along with a (preferably 2 mm.) margin of adjacent flesh, leaving the breast per se intact. Variously this is referred to as segmental resection, wide local excision, or lumpectomy (and quadrantectomy when a whole  $\frac{1}{4}$  of the breast is excised) each with its varying surgical specifications; 'breast conservation surgery' is the generic term (Nixon, Troyan & Harris, 1996). Generally at this time, 'sampling', or removal, of the loco-regional lymph nodes is performed. This is referred to as axillary dissection and is generally regarded as a staging, diagnostic procedure as opposed to tumour clearance (although it may perform both functions). As discussed earlier, the regional lymph nodes are "indicators but not governors" of disease related survival (Cady, 1984).

Women choosing conservative surgery will generally be advised of the need to undergo a course of radiotherapy to the chest wall and axilla. Without this treatment there is a 30% risk of local recurrence in the treated breast (Nixon, Troyan & Harris, 1996). (There are occasions when radiotherapy may not be prescribed for specific other reasons.) Radiotherapy should reduce the risk of local recurrence to 10% which is on a par with the risk of (local) recurrence in the chest wall, after mastectomy. Mastectomy (amputation of the breast) may be indicated if the lesion is large (in relation to the volume of breast tissue), diffuse or multi-focal, or if there is extensive 'ductal carcinoma insitu' (Moore & Kinne, 1995). Ductal carcinoma insitu (DCIS) refers to pre-malignant changes in the cells lining the breast ducts, the natural history of which will be to develop into invasive carcinoma over time (Wood, 1996). Although less common with mastectomy, radiotherapy may be indicated if the tumour is close to resected margins or tethered to chest wall (Kinne, 1991). This is to prevent local recurrence.

Breast reconstruction is generally an option for women requiring or deciding on mastectomy as their treatment option. In New Zealand this may require the woman to travel to a tertiary centre to be seen by a plastic/re-constructive surgeon. There are



various options for reconstruction including breast implant's, or flap reconstruction, of which there are a variety (Bostwick, 1995). The timing of reconstruction is also variable; some women prefer immediate reconstruction, others deferred.

These are the complexities women must consider in deciding their surgical treatment options. For some histological sub-types of breast cancer, medical treatment (hormone, chemical or radiation) may be the first line therapy, although this is less common. More commonly women are required to decide whether they wish to have further adjuvant therapy once tumour resection and histological analysis have occurred.

### **Adjuvant therapy**

Histology of the breast tissue and axillary lymph nodes will determine the need for further treatment. Specifically this may involve decisions regarding the need for chemotherapy of some kind, either cytotoxic drugs, hormone therapy (generally an anti-oestrogen) or both (Hudis & Norton, 1996). This type of treatment is termed adjuvant therapy. Both therapies have a range of side-effects, chemotherapy generally the more severe. This is all aimed at preventing tumour recurrence at both local and distant sites. In other words, the goal of adjuvant treatment is to prevent distant disease spread and the related morbidity or death.

Systemic therapy only proportionally lengthens disease-free survival, or reduces mortality rate (Henderson & Mouridsen, 1988). For example, women with an expected mortality rate of 60% can be reduced to an expected rate of 40% with chemotherapy (a proportional 33% reduction). In women with a Stage 1<sup>3</sup> tumour and a 6% mortality expectation, adjuvant chemotherapy may reduce that risk to 4% (again, a 33% reduction). Cady and Stone (1990) reflect how patients may view the acceptability of 6 months chemotherapy quite differently when they have a 50% versus 5% risk rate of mortality. Six months of morbid chemotherapy may be seen as entirely reasonable and acceptable when the risk rate can be reduced from 60 to 40%.

---

<sup>3</sup> Earliest stage: tumour <2cm, no nodes involved, no known metastases. Stages range 1 – IV in the International Union Against Cancer (UICC) staging system (which includes the TNM [Tumour, Node, Metastases] classification system). (Ref: Dixon, 1995)

It may be considerably less attractive when only achieving a risk reduction from 6 to 4%.

These concepts are difficult to grasp. Generally clinicians leave discussion regarding these treatments until the post-operative phase when histology results are known. Occasionally, however, as mentioned above, these treatments may precede surgical intervention.

### **Summary**

The above information is a brief, simplified, medical overview of the nature and treatment of breast cancer. Current medical treatment is prescribed on the evidence from internationally orchestrated, prospective, controlled, randomised clinical trials, the 'gold standard' of clinical medicine. However, verification and falsification are admittedly a process of graduation (Kaplan, 1964) and the treatment of breast cancer remains evolutionary and progressive. Importantly, it is also constantly open to critique and refinement, as new knowledge is gained, and new treatments evolve.

## **(2) THE PSYCHO-SOCIAL PERSPECTIVE**

### **Introduction**

The diagnosis of breast cancer, even at an early stage is threatening on many levels. The patient's life is placed in jeopardy by the disease; the surgical intervention is, generally, disfiguring. Both of these realities have considerable implications for both social relations and emotional wellbeing. For example, the worry that the cancer has spread, fear of stigmatisation and rejection once other people learn of the diagnosis, psychological and physical effects of adjuvant treatment morbidity; all of these can have profound effects on a woman's life. Even more consuming is the on-going uncertainty of one's future. As well as concern for their own life, women are also concerned, should the cancer not respond to treatment, for their children and families. Women with daughters face the concern that they may have passed on a genetic predisposition for the disease. Younger women with breast cancer may still hope to have children and must weigh the risks of pregnancy. Could a pregnancy stir up distant, dormant metastases? Will they be alive to care for their child? What if they have a daughter and pass on the genetic risk to another generation? Single

women may feel their chances of ever finding a partner and having a family are foreshadowed. Financial issues may also be of major concern, especially if treatment is protracted. The issue of treatment choice is often an added burden.

This section will consider the published literature, progressively over the past three decades, related to women's psychosocial adjustment to breast cancer. Topics to be discussed are:

- Psychological adjustment.
- The benefits of choice and autonomy in decision making.
- Information needs.
- Fear of radiation.
- Other factors in decision making (including media and popular press).

### **Psychological adjustment**

In recent decades there has been a proliferation of psychosocial research into women's psychological adjustment to breast cancer and its treatment. Undoubtedly this research is generated by the attendant moral obligation to reduce the morbidity associated with the treatment of this disease. Now of almost historic interest, seminal papers by Bard and Sutherland (1955) and Bacon, Renneker and Cutler (1952), although largely anecdotal, revealed that anxiety and depression, along with impairments of physical and sexual function, were common sequelae of breast cancer and its treatment.

Estimates of depressive illness, anxiety neurosis, or both, are as high as 38 - 40% (Fallowfield, Baum, & Maquire, 1986; Farragher, 1998; Maquire, Tait, & Brook, 1980), even with the introduction of more conservative surgical approaches. Maquire (1980), among others (eg, Morris, Greer & White, 1977; Maguire, Lee, Bevington, Kuchemann, Crabtree & Cornell, 1978; Maguire, Tait, Brooke, Thomas & Sellwood, 1980; Wordmen & Wisemen, 1977) reported the effect of mastectomy on body image, and development of sexual problems, as well as general social morbidity including difficulty in performing household duties.

In 1987, Dean, however, refuted these findings. Her research estimated psychological symptoms were experienced in 26% of women at 12 months post operation, but only 5% were considered mentally ill by a psychiatrist. This statistic was no higher than that found in her control group (the general population). Irrespective of the debate as to how much psychological morbidity breast cancer measurably causes, it has been well established that breast cancer creates a major life challenge that touches on almost all aspects of a woman's life (Campbell, 1986; Nelson, 1996; Quint, 1964; Toombs, 1987).

During the mid to late 1970s, with conservative surgery (wide local excision and radiotherapy) becoming accepted as a safe alternative to mastectomy (if certain clinical parameters are met) researchers now had the opportunity to compare the psychosocial outcome between the two treatment groups. During the 1980s at least 13 studies were published. Some of these studies, such as those by Fallowfield, Baum, and Maguire (1986), Mausell, Brisson and Deschenes (1989) focused on measures of clinical anxiety and depression. Others were concerned with changes to quality of life measures such as body image, marital relationships, sexuality, and perceived social support (Kemeny, Wellisch, Schain, 1988; Bartelink, van Dam, & van Dongen., 1985). Owing to these differences in methodology and sampling procedures, comparison is difficult. However, some general points can be drawn. Studies that have sought to measure the effects of the type of surgery on psychological morbidity have shown little variation regardless of what treatment was given.

The fact that more conservative surgery has not 'measurably' reduced the psychological burden caused by this disease has been "a source of disappointment" (Fallowfield & Hall, 1992, p. 390). It was surmised that breast conservation surgery would surely protect women against psychological distress. Unfortunately, this hope has not been realised (at least not quantitatively). They ask why is there no difference in overall emotional adjustment between mastectomy and lumpectomy? What are the other factors? Seeking to answer these questions researchers have considered the 'other factors' that may be involved. For example, does having a

choice of treatment, and therein a degree of control over events, help women adjust to breast cancer? This is examined in the following section.

### **The benefits of choice and autonomy in decision making**

Critiquing this research in 1992, Fallowfield and Hall stated that research demonstrating the putative benefits of autonomy in decision making was limited and the current studies relatively small. Generally they had short follow-up assessments and a number provide conflicting data. For example, in a prospective study by Leinster, Ashcroft, Slade and Dewey (1989), 43 women were assessed pre-operatively and then at 3 and 12 months post-operatively. Of these women, 25 had their treatment determined by their clinician. The remaining 18 women were asked to choose which procedure they underwent, following an informal decision analysis procedure, performed by a psychologist. Four of these women requested the physician or surgeon make the final decision and therefore only 14 women eventually selected their own treatment. Six of these women chose mastectomy and eight chose wide local excision and radiotherapy. It appeared that the women with high concern for body image chose conservative surgery or requested reconstruction following mastectomy. Women with low concern regarding body image tended to choose mastectomy without reconstruction. The authors relate that the women, who chose conservative surgery, or re-constructive surgery, stated they would have been devastated to undergo mastectomy alone. Women who chose mastectomy stated they would have been unhappy with just lumpectomy.

In another small prospective, controlled study by Morris and Royle (1988), in which 30 patients were given the choice of simple mastectomy or wide excision plus radiotherapy, it was found that pre-operatively, and at two months post-operatively, patients who had not been given choice of surgery (control group) were more anxious and depressed (as rated on the Hospital and Anxiety and Depression Scale) than those who had been given choice of treatment. However, at six months, post-treatment anxiety and depression scores were high in both groups irrespective of surgery performed. A further prospective study by Pozo et al. published in 1992, examined the effects of procedure (mastectomy vs lumpectomy), and choice of procedure, as predictors of adjustment to breast cancer. This also demonstrated a



short-term advantage (higher life satisfaction ratings at 3 months post-surgery) for the patients who were able to exercise complete choice of treatment. However, at 6 months post-treatment, as with Morris and Royle's study, this difference had disappeared. Pozo and colleagues state that the overall impression gained from this study was much in line with the opinion expressed by Hall and Fallowfield (1989). Although women have concerns over body image (and some greater than others) their greatest concern is the fact they have a life threatening disease from which they may die.

In 1994, Fallowfield, Hall, Maguire, Baum and A'Hern published a 3-year follow up study, that sought to determine the impact of offering women choice in decision making about surgery in early breast cancer. Using a survey questionnaire tool, these researchers studied how women felt about choosing their treatment, which choices they made, and the effect choosing had on psychiatric morbidity over a 3-year follow-up period. Two hundred and sixty nine women with early breast cancer (stage I or II) were treated by three groups of surgeons, who either: (1) favoured mastectomy, (2) breast conserving surgery, or (3) offered patients a choice, when this was possible. Results identified that a significant minority of women experienced unremitting psychiatric morbidity, irrespective of treatment or surgeon group. At 3 years, 19% of women were clinically anxious and 15% symptomatic for depression. With 3-year follow-up, the relative risk for psychiatric morbidity was less in women treated by 'choice' surgeons, compared to women treated by surgeons favouring mastectomy ( $p < 0.05$ ). Sixty-two women were eligible to choose their surgery, and of these eight (13%) were unable to reach a decision. Difficulty was experienced by 23/62 (37%) of women. Nevertheless, 26/62 (42%) of the women was pleased that they had been asked to choose, although others had some reservations. Only five women expressed doubts about their original treatment decision. Fallowfield and colleagues concluded that there was no evidence that choice of itself prevents psychiatric morbidity in women treated with breast cancer.

In their report they discussed the need for woman to have the availability of a specialist breast nurse to help them through the difficult decision making time. Few women, either unable to choose or who expressed clear reservations about being

offered a choice, felt that they had received insufficient information. The women merely felt that it was the doctor who had the expertise and therefore should take the greater responsibility for either decision making or offering clear guidance. No matter how much information women received, they still felt that they simply did not have the depth of medical knowledge to assess the potential benefits and risks of the treatments offered them. A specialist nurse's counsel and support, at this time, was seen as extremely valuable and this has been verified in a prospective controlled clinical trial by McArdle et al. (1996).

Degner and colleagues (1997) performed a cross-sectional survey to investigate: (a) the degree of involvement women with breast cancer wanted in medical decision making (b) the extent to which they believed they had achieved their preferred level of involvement (c) and their information needs. A cross-sectional survey at two tertiary oncology referral clinics in Manitoba involving a sample of 1012 women was undertaken. Results indicated that 22% of women wanted to select their own cancer treatment, 44% wanted to select their treatment collaboratively with their physicians, and 34% wanted to delegate this responsibility to their physicians. Only 42% of women believed they had achieved their preferred level of involvement in decision making. They also identified a small group (15%), who believed they were pushed into more active roles than desired. Degner et al. believe that further research is needed to determine if systematic effort by health professionals to assess the woman's desired level of involvement would be effective in reducing the discrepancies between preferred and actual roles in decision making identified in their study. This correlated with previous studies by these researchers (Beaver, Luker, Owens, Leinster & Degner, 1996; Bilodeau & Degner, 1996; Hack, Degner & Dyck, 1994)

As can be seen from the above, research investigating the benefits or otherwise of choice have been conflicting. It appears to be an individual and multi-factorial matter requiring individual consideration between the treating clinicians involved and the women themselves.

### **Information needs**

In 1993, Hughes performed an exploratory study to determine the relationship between the information about breast cancer alternatives and patient's choices of treatments. The proposal was to recruit patients with breast cancer who were in the process of deciding between breast conservation (wide excision plus irradiation) or modified radical mastectomy (with or without reconstruction). A convenience sample of 71 female patients with early stage breast cancer was drawn from a breast clinic with a 1,000-bed tertiary medical centre. The amount of information, and the manner, in which it was given to each participant, was recorded using an observer checklist. The data collector also recorded the manner in which prognosis was framed; either positive, negative or mixed, and whether or not it was expressed in numeric terms or narrative language (probabilistic expressions were those made using numeric language – for example 90%). It was also recorded whether or not a specific treatment was explicitly recommended to the patient, and when a specific recommendation was made, whether it was in response to patient request. Recall of information and final treatment choice were ascertained during telephone interviews conducted six to eight weeks after surgery.

Results indicated that the subject's choice of treatment was unrelated to the amount of information received. Interestingly, however, it did appear to be related to the amount of information participants had obtained (from friends, relatives, media, popular press) prior to their clinic visit ( $p < 0.01$ ). No relationship was found between the manner in which information was presented, or the manner in which prognosis was expressed. Nor was it related to whether or not a specific recommendation was made, or whether the recommendation was requested by the patient or offered without request, even though some patients stated that their decisions were heavily influenced by clinician recommendation. In other words, the participant's 'perception' of clinician preference may influence treatment choice. Information recall was very poor. For example, 48% of subjects who selected lumpectomy could only recall one of thirteen possible information items presented during the clinic visit. Patients recalled even less information regarding the treatments they did not select. Neither treatment groups could re-iterate the treatment-related risks that had been previously enumerated to them.



Hughes study failed to support several assumptions often made concerning women's decisions about breast cancer treatment. Contrary to one popular notion, older women were not more likely than younger women to choose mastectomy. It also appeared that economics affected treatment choices. Women who were in lower income households tended to choose mastectomy. Many had an attitude that they just wanted to "get it over with ... get on with life" (Hughes, 1993, p. 627). Several participants said that they thought their decisions might be considered irrational because they could not quite explain them on the basis of information alone. Instead they attributed their decisions to a need to minimise both risk and post-decisional regret. Hughes concludes that more research is needed to better understand the nature of these factors and how they affect patients. Until then, Hughes advises, physicians and nurses need to consider that the amount of information presented, or the style in which it is presented, may not be the sole determinant of treatment selection "and that other factors may account for seemingly unexplainable behaviour by patients" (p.628). One of the goals of the present research was to identify some of these 'other factors'.

In 1993, Alderson, Madden, Oakley and Wilkins (1994) performed a pilot study concerned with women's views of breast cancer treatment and research.

The aims of their research was:

- To explore the needs for information and support among women affected by breast cancer screening, treatment and research.
- To investigate health professionals' views about women's knowledge and needs for information and support.
- To compare the views about breast cancer treatment and research held by the three groups of screened and treated women and health professionals.
- To provide evidence to assist practitioners and women affected by breast cancer when making decisions about treatment and research.

Alderson and colleagues (1994) found that for treatment, most women thought that all options should be explained to them, including the treatments long term implications, benefits, and risks. Most patients wanted detailed information about

their cancer; thought they should be told about the uncertainties in breast cancer, and wanted to share decision making with their doctors. Both screened and treated women wanted to take part in treatment or research that would fit with their moral values, their work and social circumstances, and their responsibilities towards themselves and their families.

Glaringly evident in this research were the differences in services in different localities and with different health professionals. For example, in larger teaching hospitals, lack of continuity of care meant that women rarely saw the same physician/surgeon/oncologist and often saw junior doctors who had limited expertise. Lack of time for consultations was a major barrier resulting in women feeling their questions were unimportant in the overall scheme of things, or often feeling 'fobbed off' because their wasn't time to give adequate explanations. Breast care nurses were viewed as an excellent resource of knowledge and support but it was acknowledged that some of them had huge workloads and this meant they often could not give individual women the support either desired or needed.

In 1994, Hack, Degner, and Dyck performed a study of 35 women with UICC Stage 1 and 11 (refer footnote 3, p. 16) breast cancer to investigate the relationship between women's preferences for decisional control and illness information. Quantitative and qualitative analysis was performed. This included a card sort measure of preference for information needs (quantitative) and semi-structured interviews to gain information on women's role preferences (qualitative). Results showed that patients who desired an active role in decision making also wanted detailed information. This relationship was not as clear for the passive 'decision makers'. There was a sub-group of 'passive' patients who, like active patients, wanted to receive detailed medical information.

In 1995, and a follow-up study in 1996, Luker, Beaver, Leinster and Owens examined the more specific information needs and sources of information for women with breast cancer. The aims of the study were to determine the preferences for the different types of information in women with breast cancer and to investigate whether the need for information changed over time. They also sought to examine

the sources of information for this group of women and how these sources were influenced by time since diagnosis. A sample of 105 women was chosen from one consultant's practice. Data were collected at two time points by means of a structured interview. The first interview took place at the time of diagnosis and the second 21 months from diagnosis. Findings identified that at diagnosis, priority information needs concerned survival issues. Further from diagnosis survival issues were still a concern, but information about risk to family members of getting breast cancer showed a significant increase in importance. At the time of diagnosis, information sources centred mainly around the specialist breast care service, while further from diagnosis, few professional or voluntary sectors sources were utilised, women receiving most of their information from media sources.

It was noted that the centre in which the study was undertaken had a high workload, and the breast care nurse, out of necessity due to limitations on her time, tended to focus her attention on women newly diagnosed with breast cancer. Once women were discharged from the hospital environment there was often limited opportunity to continue providing support and information unless the women themselves initiated the contact. Luker and colleagues (1996) state that the women in the study commented that they didn't feel it was appropriate to contact the breast care nurse just for information as other women with more urgent needs were priority. Women stated that nurses on the wards were seen to be too busy to provide information, but that information would be provided if asked for. Few women perceived that they had received any useful information from the voluntary support services. Anecdotal evidence from the study suggested that women perceived membership of a support group was a negative experience as membership involved reliving painful experiences and listening to others recalling painful experiences.

In 1997, Degner and colleagues identified that women have distinct information needs at different stages of their breast cancer journeys. Around diagnosis they want information about the likelihood of cure, treatment options and the stage of their disease. As time progresses, so too does their information needs. Around two-year's post-diagnosis, although they still want information concerning the likelihood of cure; they also want information regarding the risks to other family members of

getting cancer and information about self-care behaviours. Information needs are therefore not static but change over time.

As demonstrated above, considerable research has been undertaken to investigate the informational needs of women with breast cancer. It is a complex and diverse subject probably related to the fact that women who experience breast cancer are a diverse population and breast cancer itself is a complex and unpredictable disease.

### **Fear of radiation**

Ward, Hedrich and Wolberg (1989) found that many women who chose modified radical mastectomy did so because of concerns about the radiation therapy associated with conservative therapy. These women expressed concerns regarding side effects, claustrophobia in relation to the actual treatment, inconvenience and efficacy of radiation therapy. Ward and colleagues found that many women could not seem to believe the evidence that a combination of breast conserving surgery and radiation therapy had as good an outcome in terms of survival as mastectomy. These researchers report several other factor women considered when deciding between mastectomy and breast conservation including fear of recurrence, survival, concern for body integrity, and physician preference. The authors report that clinical expertise is essential in presenting options to support women in the decision making process, and, interaction with a nurse or other supportive health professional at this time may be crucial.

From the above it can be seen that fear, not only of radiation, but the risk of recurrent disease, is a major factor influencing women's choice of treatment when deciding the advantages of conservative surgery over mastectomy.

### **Other factors in decision making**

A study by Valanis and Rumpler (1985) reported four frequently mentioned influences in decision making. First is the media, especially television and magazines. Second were the physician's influences. Third: the effect of family and significant others and finally the coping style of different individuals. Fourth: the

woman's personal resources as defined by her previous coping mechanisms and her feminine identification.

Another factor influencing decision making is the affects of anxiety associated with a diagnosis of cancer. Scott's (1983) research identified that women are significantly cognitively impaired during the pre-diagnosis phase owing to the extreme stress associated with a diagnosis of breast cancer. Cimprich's (1992) study demonstrated that attention fatigue continues into the post-operative period, and others (Hughes, 1993, Northouse, 1989; Siminoff & Fetting, 1991; Siminoff, Fetting & Abeloff, 1989) have revealed that in fact women can recall very little information that they are given at this time often feel overwhelmed by the information provided.

These 'other factors' are all significant in the overall scheme of women deciding their treatment options. Cady and Stone (1990) relate that local medical customs and skills available (e.g., radiation and plastic surgery) will also influence their decisions.

### **Summary**

This section has attempted to provide a brief, loosely chronological overview, of the extensive research literature on breast cancer, and treatment thereof. It is only relatively recently (the last 10-15 years) that prospective, controlled clinical trials have, with confidence (replicate trials producing similar statistical results), confirmed that wide excision and radiotherapy can give equally effective local control as mastectomy. The general hope and assumption was that being able to offer women conservative therapy would reduce the psychological morbidity associated with the treatment of this disease. This has not been realised. Similarly, although breast reconstruction has been shown to have an important role in psychological rehabilitation, there is no 'objective evidence' of long-term benefits for psychological health and body image (O'Gorman & McCrum, 1988).



## **THEORIES ON DECISION MAKING**

### **Introduction**

This section will consider the more relevant psychological theories on decision making and choice particularly in relation to women deciding treatment options for breast cancer. It will also consider whether the framing of decisions, by the health professional, has an affect on the decisions women with breast cancer make. Venturing a turn to an alternative psychoanalytic theory, a brief review of the debate between moral development psychologist's Kohlberg (1981) and Gilligan (1982, 1987), and its possible relevance to women with breast cancer and decision-making, will be discussed. Topics in this section are:

- The psychology of decision making.
- Framing decisions and the psychology of choice.
- The 'Kohlberg-Gilligan debate': Does it have theoretical relevance to women's decision making in relation to breast cancer?

### **The psychology of decision making**

Much of the published literature on decision making has to date been based on retrospective survey research, or from presentation of hypothetical situations and scenarios to sick or non-sick populations. Few studies have been conducted on patients faced with making real decisions. An example of the former is the 'expected utility model' (Tversky & Kahneman, 1981) which is a major psychological theory of decision making and is based on the axiom of rationality. The surmise is that the choices an individual makes will be based on terms of predicted outcomes obtained by weighting the utility of each possible outcome by its probability. When faced with a choice, a rational decision-maker will prefer the prospect that offers the highest expected utility. This model implicitly assumes the decision-maker that carefully answers the question "What do I really want?" will eventually achieve coherent criterion. The common conception of rationality requires that preferences for utilities for particular outcomes should be predictive of experiences of satisfaction or displeasure associated with their occurrence. Prescriptive theories thus attribute decision-making to individual application of wholly 'rational' criteria (Pauker, 1982; Elstein, Rovener, & Holzman, 1982).

In contrast, behavioural decision theorists believe that real behaviour deviates from strict rationality and that these departures are due to the fact that people in real situations are often unaware of alternative frames of reference. Generally they do not have access to all the information; it is easy to relate this to the situation of women deciding treatment for breast cancer.

Siminoff and Fetting (1991) examined the decision making process of breast cancer patients and their physicians when deciding treatment options for adjuvant therapy (chemotherapeutic or hormone treatment) post surgical treatment. They relate how the discussion of treatment options between physicians and patients is by no means standardised. Much depends on the information transmittal style of the physician and the patient's information seeking behaviour. Some physicians will actively seek to involve the patient in the decision process; conversely, some may not.

The purpose of Siminoff and Fetting's (1991) study was to examine the decision making process of individuals actually facing a life-threatening illness, for example, breast cancer. Citing their previous study (Siminoff, Fetting & Abeloff, 1989) that found 80% of all patients accepted their physician's primary treatment recommendations, Siminoff and Fetting were anxious to determine the factors that influenced the remaining 20% of the non-accepting patients. They relate that their study findings support the 'behavioural decision theories' in that individuals in real situations use criteria other than rational utilities to make decisions. They found that patient's decisions are most strongly influenced by the physician's recommendations and that the pure rationality of this reliance is questionable appearing to be based more on an 'article of faith' than any in-depth understanding of how their physicians arrived at these treatment recommendations.

Siminoff and Fetting (1991) state that despite the notion that patients are playing a more proactive role in directing their own health care, their study demonstrated that they still relied heavily on their doctors to make treatment decisions for them. Characteristics of the non-acceptor patients indicated these patients tend to be better educated and were more likely to be risk takers (as identified on a Treatment Risk Index that participants underwent upon entering the study). These patients also



wanted more in-depth and specific information regarding treatment options. Often these patients interpreted side effects as more severe than the 'acceptor' patients did, however some chose more aggressive treatments with more severe side-effects, taking the 'risk' that this would accrue them greater long-term advantage. Siminoff and Fetting relate that the mitigating features attendant to this illness (breast cancer), such as the possibility of death, the technical difficulty of the treatment information, and patients feeling compelled to make their decisions quickly, may hamper efforts to draw patients into the decision process.

Sutherland, Llewellyn-Thomas, Lockwood, Trichter and Till (1989) relate that in recent times much attention has been focused on the need for health professionals to communicate with and provide information to patients in order that they may participate in informed decision making about their health care. This emphasis stems primarily from ethical, legal and social concerns. Ethically there has been a change from the paternalistic philosophy of care to one in which autonomy and patient self-determination are promoted and the provision of information is a central issue. Sutherland et al.'s research however revealed that although patients want to be given information regarding their health condition, their desire for either behavioural or decisional involvement in medical care are relatively independent. Their study of post-surgical cancer patients found that although patients wanted to receive, and actively sought information about their disease and its treatment, this did not necessarily mean they wished to participate in treatment decisions. They suggest that some patients prefer to 'express their autonomy' by authorising their physicians to make treatment decision; patients' anticipation of regret for a bad decision could lead them to ask to have decisions taken out of their hands. This is consistent with findings in other studies and is referred to as the 'competence gap' wherein patients have the view that they expect to take advice on trust and don't specifically envisage having to evaluate in great depth what they are told (Tuckett, Boulton, Olson & Williams, 1987; Waterworth & Luker, 1989).

Social scientists have described two patient response styles: (1) 'monitors', who want to know everything about their situations, and (2) 'blunters', who want to be protected from frightening or painful information (Schain, 1990). The study by

Pierce (1988; 1993) of women with breast cancer found some congruence with this. Pierce studied the decision process women with newly diagnosed breast cancer go through in deciding treatment options. A convenience sample of 48 women completed an open-ended interview whilst they were in the process of making a decision. Interviews were conducted both during the decision making time or within days or weeks of their treatment choice. Content analysis of these interviews identified five empirical indicators of decision behaviour: (a) perceived salience of alternatives, (b) decision conflict, (c) information seeking, (d) risk awareness, and (e) deliberation. Configurations of these indicators discriminated the decision-maker into one of three empirically derived groups. In order of complexity these were termed 'Deferrer, Delayer, and Deliberator'. Many (41%) participants used the 'deferrer' style. These women were influenced by the salience of a particular treatment option and were quick to choose that option with minimal conflict. Often it was the treatment that their physician recommended. The largest group of participants (44%) used the 'delayer' style. They considered two options but only superficially. The fewest participants (15%) demonstrated the 'deliberator' style. These women expressed a sense of responsibility for making their treatment decisions, and used explicit strategies to seek out information, weigh up the benefits and risks, and contrast the options. The empirical indicators put forward by Pierce appear to relate to normative models of decision-making found in psychology, business and economics. Pierce has extrapolated from these a more specific theory relating to how people decide important decisions consistent with their values in relation to health, body integrity and general wellbeing. Pierce states that a long-term evaluation of patient satisfaction with the outcomes of their choices would be useful in judging if there are potential hazards related to any of these decision styles.

Decision theory has its grounding in the psychological sciences. In looking for universals the topic is relatively abstract, but is extremely relevant to the topic of women deciding their treatment options for breast cancer. Pierce (1988; 1993) evidenced this in her research.

### **Framing of decisions and psychology of choice**

A number of studies have investigated whether the manner in which the clinician 'frames' treatment options will alter the decisions individuals make. Studies regarding deciding treatment options for breast cancer are discussed in this section.

Research by Tversky and Kahneman (1981) suggested that the framing of decisions often alter what choices people make; whether they are framed negatively or positively. In relation to breast cancer decisions, this may be the difference of whether the surgeon states that conservative surgery engenders a 10% risk of local recurrence or, framed differently, 'there will be no local recurrence in 90% of women who choose conservative surgery'. However, studies that have specifically investigated whether framing of outcomes (prognosis) either in descriptive or probabilistic terms, or in positive, negative or mixed frames, failed to demonstrate that this made any difference to the choices women made (Fallowfield, Hall, Maguire & Baum, 1990; Fallowfield, Hall, Maguire, Baum & Hern, 1994; Hughes, 1993).

Roberts, Cox, Reintgen, Baile and Gibertini' (1994) investigated the influence physician communication has on newly diagnosed breast cancer patient's psychological adjustment and decision-making. They relate the critical importance of the physician-patient communication when a breast cancer diagnosis is made relating how this is a time when the emotionally overwhelmed patient must be educated about her disease and available treatments so she can participate in treatment decisions. Their hypothesis was that patients whose surgeons used psychotherapeutic techniques during the cancer diagnostic interview would have better psychological adjustment to their cancer. Previous research indicated that three classes of physician behaviour tend to improve patient adjustment to cancer diagnosis:

- (1) providing information about cancer (Ganz, 1988).
- (2) using interpersonal skills such as empathy, listening, and conveying positive regard; and
- (3) instilling hope (Blum & Blum, 1988; Weisman, 1979).

One hundred women were surveyed six months after their surgery and asked to complete the Cancer Diagnostic Interview Scale (CDIS) and the SCL-90-R, a measure of psychological well being. Factor analysis of the CDIS revealed that physician's caring attitude was perceived as most important, with information giving as a much weaker point. They concluded from this study that provision of information needed for decision making appears to be valued largely within the context of a caring physician-patient relationship. Specific surgeon behaviours believed to facilitate patient adjustment included expressing empathy, allowing sufficient time for patients to absorb the cancer diagnosis, providing information in a way that was appropriate for individual women, and engaging the patient in treatment decision making. Thus, the development of a caring-trusting relationship was vital in assisting women to cope at this time.

Framing of decisions adds another dimension to women's decision-making behaviour and serves to emphasise the subtle complexity of this process. Feminist theory adds yet a further dimension.

### **The Kohlberg-Gilligan debate: Does it have theoretical relevance to women's decision making in relation to breast cancer?**

In Alderson et al.'s (1994) study which investigated women's views on breast cancer treatment and research, they stated that peoples' responses are "strongly influenced by public versions of philosophical traditions" (p. 14). They discuss how empirical research by the moral development psychologist Kohlberg (1981) and refutation of this research by Gilligan (1982; 1987) demonstrates that men tend to think in more abstract and general terms (Kohlberg) whereas women tend to think in more particular terms (Gilligan). Kohlberg, influenced by Kant, believed that certain men were capable of autonomy through pure reason that rises above emotion and bodily need. Therein this enabled them to make correct and moral judgements based on universal laws that were acceptable for all times and places (like laws of physics and maths). Kohlberg proposed six stages of moral development, through from accepting one's parents' values, to thinking in abstract general principles. This is a position he developed conducting empirical research using young, male adolescents in several countries and following their progress in moral thinking over time. This conclusion

fitted well with the traditional theories of moral development in philosophy and social sciences of the time. Kohlberg claimed that women tended to stop at stage three of the moral development; helping and pleasing others, loyalties and trust in relationships. When posed with a moral problem they tended to discuss concrete details, using a personal rather than a universal morality.

The comprehensiveness and reliability of Kohlberg's moral development theory became the subject of much criticism, however, when his former collaborator, Carol Gilligan, revealed a major design fault in his research. This was namely the use of all-male samples as the empirical basis for theory construction (Gilligan, 1982). Gilligan argued that Kohlberg had therein eliminated a 'care focus' in moral reasoning, a principle ingredient in women's moral thinking (Gilligan, 1982; 1987).

Alderson et al. (1994, p. 141) relate that there is a long (Kantian) tradition among philosophers of aspiring to rise above concrete details; to clear away the "household rubbish" so as to get to the detail. In relation to women's decision making (in this case related to the decision as to whether to enter controlled clinical trials for breast cancer treatment) Alderson relates how women resisted clearing away the contextual elements of their lives so as to consider the more universal concepts related to the value of clinical trials. Women were concerned (if they participated in research) about things such as the inconvenience they would be causing others, for example, having to make extra visits to attend time consuming outpatient appointments. They were also concerned how it would affect their families and work. Women considered the affect having treatment and being ill and more dependent (because of an arduous chemotherapy regime) would have on significant others. They also weighed this against the risk of no treatment and possibly an increased risk of death. How would this affect their loved others?

It is interesting to relate the Kohlberg-Gilligan debate to women's perspective on deciding treatment options for breast cancer. Alderson et al. (1994) relate how issues, which are swept away as private, subjective, emotional and physical, are the ones of greatest concern to women with breast cancer. For example, in relation to the choice between mastectomy or wide local excision with radiotherapy, an informed,



moral choice may take into account the woman's hopes of survival and 'getting rid' of the cancer, her hope of preserving the breast, weighed against her need to return to full-time employment quickly. She may worry that having to travel to the hospital daily for an extended period of time for radiotherapy (if she chose conservative therapy) may be a burden upon others if she is dependent upon them to provide her transport. Alderson et al. state: "the individuals hope and fears, her feelings about mortality and mutilation, her income and work are not 'clutter'; they are issues to be attended to if the morality of respect for autonomy, and non-maleficence is to have meaning" (p. 142).

Gilligan (1982, p. 19) states that in a morality of responsibility "the moral problem arises from conflicting responsibilities rather than from competing rights and requires for its resolution a mode of thinking that is contextual and narrative rather than formal and abstract".

From the above it would appear that women's decision making is often based on principles of care. Women's decisions are inclined to be based in the personal and subjective and are often context dependent. This does not mean women are not interested in facts and statistics (relating probability and prognosis) but they may also find the 'actual' and the 'particular' more relevant when making personal choices regarding treatment options. Literature providing 'the women's perspective' on breast cancer appears to support this argument.

### **THE WOMEN'S PERSPECTIVE**

For a woman the reality of breast cancer may start as a simple fact; a lump or thickening in the breast. More commonly, today, it may reveal itself as a shadow or calcification on routine (or screening) mammography. Therein a journey of many meanings begins. The knowledge of a lump or lesion becomes an awesome focus of attention; if medical attention is sought, a central focus, upon which warfare begins.

Wear (1993) relates that no other disease summons the kind of dread in women than that evoked by breast cancer. In western culture breasts are a strong symbol of femininity and sexuality (Kasper, 1995). A diagnosis of breast cancer can therefore

be a terrifying double edge; not only does she have to face a potentially fatal disease, she is also faced with the prospect of losing a precious part of her body that is deeply tangled with her sexuality, femininity and known self. Weir reflects how these deep and significant feelings cannot be medicalized into neat stage theories, treatment plans and reassurances. Breast cancer evokes extreme angst.

Rosser (1981) is critical that the research literature on breast cancer has often failed to explicate the essential meaning this illness has for women and the affect it has on their lives. Rosser stressed the need for research into the *meaning* of breast cancer from the women's perspective, as opposed to studies based on the logical-empiricist tradition seeking to identify the type of women at risk of maladjustment. She states that these are largely based on 'typifications' of women, often in the context of the 'other-orientation' and the affect mastectomy will have on her marital relations, sexuality, or ability to bear children, as opposed to 'self-orientation'.

Medical Consultant Wendy Schain (1988, p. 154) concurs with Rosser. Researching the sexual and intimate consequences of breast cancer, she states that it is not possible to "distinguish the psychological distress caused by the fear of the loss of one's life, from that caused by the fear of the loss of a cherished part of the body."

There are a number of qualitative studies (notably descriptive, phenomenological and feminist) considering women's experience of breast cancer. There is also considerable popular literature and autobiographies describing women's experience. This research/literature is necessarily of a more personal nature identifying what is individual and unique. As the focus of this study is the women's perspective on deciding treatment options, and these studies are more general (the 'lived experience' of breast cancer) they have not been included in this review.

An encounter with breast cancer has a huge impact on a woman's life. How women decide treatment options for breast cancer is just one aspect of that experience. In the present study, women talked about making their decisions within the wider context of how breast cancer affected their lives. This study is therefore unique in



that it offers the 'women's perspective' (as opposed to the medical or social scientists) view on deciding treatment options.

## **SUMMARY**

This literature review has provided a general background to the current study by taking a journey through medical, psychosocial (including theories on decision-making) and psycho-analytic (the 'Kohlberg-Gilligan' debate) theory. It has signalled the literature providing the 'women's perspective' on the breast cancer experience. Necessarily, this review has been selective, owing to the vast quantity of research literature on breast cancer.

Changes in treatment and societal attitudes over the past 30 years have made coping with breast cancer a very different experience in the year 2000. Patients now have more treatment and rehabilitation options, greater participation in decision making, better societal acceptance, and can expect less disfigurement. Clinicians will generally give full information about treatment options. Women are informed that no options offer complete assurance of cure and that their doctors are still uncertain as to which treatments are ultimately best (Wainstock, 1991). The greater use of adjuvant therapies adds to the complexity of this decision making.

This literature review has suggested that factors contributing to pre-surgery distress centre around uncertainty; lack of, or difficulty assimilating information in a crisis time, and often the added burden of being required to make decisions regarding their preferred treatment options. It was discussed how, in fact, women can recall only very little of the information they are given or read at this stressful time (Cimprich, 1992; Hughes, 1993, Northouse, 1989 & Scott, 1983). It is hoped that the present study will add further understanding of how women decide treatment options at this critical time. It will, at the least, provide the women's perspective on this process.

## **CHAPTER THREE**

### **Research Methodology**

*Nothing is so practical as a good theory*

Kurt Lewin (1951).

#### **INTRODUCTION**

Chapter three will begin with a brief review of the evolution of nursing, and nursing research, over the past few decades. It will consider how nursing has increasingly adopted qualitative research methods. Because grounded theory method was chosen for the present study, the reason for this choice, the method itself, and its applicability to the present study will then be discussed. This will be followed by a discussion of the philosophical schism that exists between the founders of this method (Barney Glaser and Anselm Strauss) regarding the correct 'method' of grounded theory.

The aim of this study is then outlined followed by an overview of how the research was carried out. Participant selection, the process of obtaining informed consent, the ongoing management of ethical considerations, and the interconnected phases of data collection and analysis will be described. Chapter three is organized in the following sequence:

- The evolution of nursing and nursing research.
- Qualitative research.
- Grounded theory.
- Objectives of the present research.
- Procedures adopted for recruiting participants and obtaining informed consent.
- Eligibility.
- Participants, demographics and ethical considerations.
- Ethical issues.
- Summary.

## **THE EVOLUTION OF NURSING AND NURSING RESEARCH**

Nursing continues to evolve as a profession as does its research tradition. This evolution has been a process closely associated with women's traditional place in society (Shaw, 1993). Since early centuries women have fulfilled the role of nurturer, caregiver, protector of the young, the frail and the elderly. Storlie (1970, p. 2) asserts that nursing is the "professional embodiment" of women's dedication to the relief of human suffering and that as a profession it must actively participate to improve the lot of human kind.

Florence Nightingale (1860), nursing's first 'nurse researcher', expressed her firm conviction that nursing required knowledge distinct from medical knowledge. She defined the discipline in terms of its responsibility to promote human health based on systematic inquiry into nature's "laws of health" (p. 4). Her astute observation of the sick lead her to proclaim that: "Of the suffering of disease, disease not always the cause" (p. 2). She observed that it was often the want of knowledge, care and attention, when a patient was ill, that led to suffering. She proclaimed: "What nursing ought to do ... Nursing ought to assist the reparative process" (p. 2) and that the job of nursing was to put the patient in the best possible condition for nature to institute the healing process. She believed that the nurse could do this by the "proper use of fresh air, light, warmth, cleanliness, quiet, and the proper selection and administration of diet – all at the least expense of vital power to the patient" (p. 2).

What Nightingale failed to appreciate, however, was that much of her ability and accomplishments were a function of her educational preparation. If nurses were to contribute in similar ways, then they too required a sound educational preparation. Instead she instigated an apprenticeship training system wherein the knowledge gained was largely instilled by authority, habit, and tradition. This type of nursing ritualized nursing to tasks and procedures rather than a profession that was questioning, innovative and autonomous (Walsh & Ford, 1994).

Walsh and Ford (1994) believe that nursing was also hindered by the fact it was a 'women's profession' dominated by the male medical model within a patriarchal society. Generally, it was doctors, who decided what nurses should learn, lectured them, wrote the textbooks (which was usually watered down medical knowledge)

and taught them just enough so that they could be good medical assistants. They say that because of this socialization of nurses into subordinate roles, it is not surprising that ritualistic practice, based on authority, as opposed to research, was the dominant mode of care.

Slowly, however, in the shadow of medical science, nursing research began to evolve. Initially it was a-theoretical and mainly concerned with improving the quality of nursing education and administration (LoBiondi-Wood & Haber, 1997). There were few studies that looked specifically at nursing practice per se. During the 1950s, however, an awareness of the importance of scientific inquiry and research based practice, began to surface. In 1952 the first nursing journal dedicated to research ('Nursing Research') was established and questions such as: "What was the nursing professions unique body of knowledge?" and "what was its realm of practice?" began to direct research inquiry. Out of this a concern arose the awareness of the need for theory development and a scientific base for nursing practice that would establish nursing as a unique profession.

Despite this progress, nursing education remained largely apprenticeship training until the late 1950s- 1960s when the transition from hospitals to tertiary institutions began (at this time, namely in America). Even then it was often at the diploma level and this hindered nursing's progress in undertaking the research that was necessary to make professional advancement. In New Zealand this transition didn't take place until the late 1960s early 1970s. In these beginning years, nursing associated itself with medicine and the positivistic sciences leading to its grounding in the natural as opposed to human sciences (Parse, Coyne & Smith, 1985). This was reflected in the work of the early nurse theorists, for example, Orem (1985) and Roy (1984) who's research was primarily concerned with developing concepts and propositions based on systematic observation of recordable events which would provide conceptual frameworks for nursing care (Silva & Rothbert, 1983). Then, in the 1970s and 80s, research from the humanities perspective began to appear in the work of nurse theorist's such as Paterson and Zderad (1974), Watson (1979; 1981; 1985), Benner (1984) and Benner and Wrubel (1989). These theorists were to incorporate ideas that were subjective, intuitive, humanistic, and integrative which had the affect of widening the domains of nursing inquiry. They also emphasized the ethical and

moral values inherent in clinical practice. As well as valuing nursing as a humanitarian service, they also fostered the belief that the goal of nursing is to promote self-respect and self-determination of its clients. Donaldson and Crowley (1978) state that whereas previously nursing research had focussed on gaining knowledge of interventions that could control and manipulate the person (to achieve a largely socially pre-determined health state) this new value orientation, "sought knowledge of the basis of human choices along with methods for fostering individual independence" (p. 17).

With this growing acceptance and wider definition of science, nurses have gone on to research practice issues using both qualitative and quantitative methods. Ultimately this has resulted in an expansion in nursing's research endeavours and knowledge base. Meleis (1991) believes that while nursing has adopted both competing and complementary theories (regarding the nature of nursing) the debate on the worthiness of these theories will continue to contribute to the scholarly development of nursing as a discipline over time.

During the past decade (1990-2000), nurse researchers and scholars have increasingly adopted qualitative research methodologies. This has not so much been a rejection of traditional science, but a growing awareness that certain boundaries are imposed by such a method and therein restrict the type of knowledge that can be gained. It has also coincided with a greater acceptance of qualitative research in the wider research community. The following section discusses the nursing profession's contemporary approach towards nursing research and theory development using qualitative research methods.

## **QUALITATIVE RESEARCH**

Qualitative research involves an interpretive, naturalistic approach to its participants (Denzin & Lincoln, 1994). Whilst the term covers a variety of research methodologies, originating in various scientific disciplines, each differs in terms of its philosophical, theoretical, ontological and epistemological orientation (Koch, 1996). Wherein quantitative research is based on the rational-empirical scientific method, qualitative research is largely interpretive. These are not so much opposing or competing methodologies as different ends of a scientific continuum, each

analyzing a different aspect of reality, the world, and life within the world. Each seeks to speak 'truths' based on 'evidence' as currently known, or able to be conceptualised. Each has a common goal, 'to know' what is, or could be. The quest is to further knowledge that will, in turn, lead to a greater understanding of the world, humankind, or both. Knowledge and understanding lead to prediction; prediction can lead to advancement and growth. To that end, the very nature of knowledge and "what is reality?" is called into question. Is theoretical knowledge reality? Who decides what is reality? Who decides what knowledge is valid or invalid? These questions remain open to debate.

Schumacher and Gortner (1992) state that there are no theory-neutral facts; no absolute sources of knowledge. The belief that science is theory neutral has long been discredited (Kuhn, 1979). Perhaps a more contemporary understanding of science is that articulated by Popper (1963). Popper proposed a fallibilistic conception of knowledge that is non-foundational. Popper believed that science merely progresses through the elimination of error as successive theories are found to be false and are replaced with better theories. Science therein remains a rational endeavour by virtue of its critical stance.

Research using inductive reasoning, based on naturalistic observations and field notes, is beginning to gain a more respected place in modern science (Schmacher & Gortner, 1992). This type of research does not depart from the canons of traditional science, but merely introduces a more human form. What does matter is the evidence produced. This in turn depends on the phenomena under investigation and whether the evidence produced is sound, credible and relevant. Often only the community of practitioners, or scholars of that discipline or professional group can be the judge of this.

Morse (1989) relates that various qualitative methods were introduced to nursing during the 1960s as nurses undertook post-graduate study in other scientific fields (notably anthropology, psychology, philosophy and sociology) and whose knowledge and methods were highly applicable to nursing. Grounded theory, developed by two sociologists (Barney Glaser and Anselm Strauss) was one of these. Grounded theory method asks the question "What is happening here?" This alone,



however, would result in merely a descriptive study. Through 'the tool', who is the researcher, grounded theory also seeks to ask, and hopefully answer, the 'how' and 'why' questions. In doing this, a theoretical model, or conceptual framework, can emerge from the data itself (Glaser & Stauss, 1965).

## **GROUNDING THEORY**

Sociologists' Barney Glaser and Anselm Strauss developed the grounded theory method at the University of California in the 1960s. They developed their method from their own experiences doing fieldwork among the hospitalised dying. It is a highly systematic research approach for the collection and analysis of qualitative data, and is aimed at generating theory that furthers the understanding of social and psychological phenomena. Grounded theory has its roots in the social sciences and specifically the symbolic interaction tradition, founded by Herbert Mead (1934) and later refined by Herbert Blumer (1969). Grounded theory is an interpretive method and continues to evolve as a research method. Indeed its 'founders' (Glaser and Strauss) appear to have evolved it in slightly different directions. This will also be discussed. This section is arranged under the following sub-headings:

- Symbolic interaction.
- Grounded theory method.
- Concept modification and integration.
- Literature in grounded theory.
- Philosophical conflict: Glaser versus Strauss.

### **Symbolic interaction**

Symbolic interaction is both a theory of human behaviour and an approach through which human conduct and human group life can be studied. This tradition holds that all theories regarding the world, both physical and human, are necessarily symbolic or abstract theories of reality. In other words, they are an interpreted reality. Kaplan (1964) relates that theories regarding human thought and actions are realised through some kind of interaction between the 'self' and others. Each of us comes to know about the world through a process of 'symbolic interaction'. Because human beings are 'subjects' as opposed to 'objects' in the world, and behave in relatively individualistic ways, this process can be extremely diverse and unpredictable.



Whereas the empiricist tradition produces theory from observable human behaviour, qualitative inquiry takes the view that human action is related to the meaning that things have for people. Symbolic interactionism believes that meanings are derived from social interaction with our fellow human beings. It is then modified through an interpretative process as the person deals with things encountered (Blumer, 1969). The reality, or meaning of situations, is created by people and leads both to actions and the consequences of that action. The individual becomes aware of her or him in relationship with others in meaningful ways. This view (cited by Blumer, 1969, p. 2) is summarised in the following statement:

Human beings act towards things based on meanings that the things have for them; the meanings of such things are derived from the social interaction that the individual has with his fellows; and meanings are handled in, and modified through an interpretive process and by the person dealing with the things they encounter.

This theoretical perspective forms the foundation for grounded theory.

### **Grounded Theory Method**

Grounded theory is a research method 'grounded' in the individual's interpretation of given meanings and perceptions. It is concerned with the 'particulars' of people's experience rather than generalisations and abstractions. The particulars of each participant's experience is analysed and examined in conjunction with the particulars of others (Glaser, 1992). Grounded theory is an inductive approach meaning that the researcher generates theory from the data. Generally there are no pre-conceived hypotheses, or theoretical structures to be investigated, although differences of opinion exist over this issue (Corbin & Strauss, 1990; Glaser, 1992). Constant comparative analysis of the data, right from the beginning of the research, emerges into theory development as reflection and continuous analysis of the data progresses. This encourages an open mindedness, creativity and flexibility in the research approach (Glaser & Strauss, 1967; Holloway & Wheeler, 1996). It is achieved by exploring and uncovering the relationships between the various themes, concepts or codes that the data generates. In a discovery method of research the researcher continually poses the question "What is happening here?" and therein the grounded theory method strives to be both descriptive and predictive.

### **Concept modification and integration**

A key concept of the grounded theory method is the interrelationship between collection, coding and analysis of data. This process is assigned the label 'theoretical sampling' and guides the data collection. To do this the researcher "jointly collects, codes, and analyses data and decides what data to collect next and where to find them, in order to develop theory as it emerges" (Glaser and Stauss, 1967, p. 45). This process is referred to as 'constant comparative analysis' (Glaser, 1992).

The two key activities in theoretical sampling are coding and memoing, both commencing as soon as data collection begins. Data is closely analysed in an attempt to understand "what is happening here?" and therein define the various codes and categories. Two different types of coding are used, substantive and theoretical (Glaser, 1978). Substantive coding attempts to capture conceptually the substance of the data gathered from the field. As data is analysed the researcher attempts to view it from a variety of angles. The data is then broken down into meaningful units, as intuited by the analyst. The labels used often arise from words in the data itself. Theoretical coding refers to the development of conceptual relationships between substantive codes that form a theoretical representation of the data. As data collection and analyses progress, further categories will be developed. As these categories become saturated (that is, no new data and no additions are being added to the category) the researcher will seek to identify one overriding core category which can explain the relationship between all of the others. In one sense, the core category best explains how a problem is processed.

Writing the theory, or performing a conceptual analysis, is an integral part of the research process and is stored as 'memos' (Glaser & Strauss, 1967; Glaser, 1992). Memos serve to store the ideas generated as the research and data analysis progresses. Through memo sorting and resorting, the researcher begins to develop an awareness of core codes and categories. This assists the researcher to clarify, refine and verify emerging concepts and therein leads to further data collection.

The present study sought to uncover the meaning particular treatment options had for individual woman, the factors that influenced their decisions and the process the women go through to reach these decisions. Although it was necessary to interpret,

'make sense of' the information given, the grounded theory method dictated that this interpretation remained true to the data. The final outcome of this study is therefore a conceptual analysis (or theoretical model), emerging from the data, giving the women's perspective of deciding treatment options for the treatment of breast cancer, and the contextual determinants related to this.

### **Literature in grounded theory**

Literature has a more limited or unique place, in the grounded theory approach, than other qualitative methods. Glaser and Strauss (1967) warn that the researcher must be cautious that the literature does not bias interpretation of the data under study. They state:

When someone stands in the library stacks, he is, metaphorically, surrounded by voices begging to be heard ... people converse, announce positions, argue with a range of eloquence, and describe events or scenes in ways entirely comparable to what is seen and heard during field work (p. 163).

They argue that an in-depth literature review of the problem may lead to an intrusion of concepts and a biased perspective on the collection and analysis of field data. This in itself may create a barrier to discovery. Emergent themes may be misconstrued or fail to be developed. This is particularly true of literature which is in the substantive area under study (Glaser, 1992). This literature should be reviewed later in the research process, after data analysis and identification of emergent theoretical concepts has been performed. It can then be utilised for its merit as comparative analysis and to stimulate theoretical sensitivity. It must not be used to create the theory itself; this must be grounded in the data. Glaser and Strauss suggest that at first the researcher actually ignore the literature in order to assure the emergence of categories will not be contaminated by concepts more suited to different areas.

In support of the grounded theory method, Charmaz (1983, p. 117) contends that researchers use relevant research to "expand and clarify the codes and to sensitize themselves to ways of exploring the emerging analysis". It should perhaps be noted that Glaser and Strauss were principally advocating their research method to fellow sociologists who may have been investigating unknown territory. As suggested by

Christensen (1990, p. 234) this “tabula rasa ideal cannot be applied to researchers examining their own arena of professional practice”. A nurse will necessarily have background experiential and theoretical knowledge of the subject area. However, this may not be a disadvantage in that the researcher will also be more aware of the ‘common place’ as well as the ‘unusual’ and also bring a richer knowledge base to the study.

### **Philosophical conflict: Glaser versus Strauss**

Glaser and Strauss developed grounded theory from combined research efforts and ongoing theory development. However, in later years they developed differing viewpoints on how data gathered for grounded theory should be examined (Glaser, 1992; Strauss & Corbin, 1990). Glaser’s (1992) central contention with the method as described by Strauss and Corbin (1990) was that they prescribed a method which literally ‘forced’ theory development rather than allowing it to ‘emerge’ from the data. Glaser (1992, p. 85) believed avidly that the whole of grounded theory is based on “emergent patterns”. He claimed that Strauss’ methodology of description sees emergence as only one of several ways to get patterns and that this was inconsistent with the whole basis of grounded theory as they had originally intended it to be.

Glaser and Strauss developed the method while they were both at the School of Nursing of the University of California, San Francisco (Stern, 1994). It was during this time they wrote their book ‘The discovery of grounded theory’ (1967). Apparently they both thought they were using the method the same way. Students of Glaser and Strauss (in the 1960s and 1970s), however, knew that the two had quite different *modus operandi*. According to Stern, Glaser only found this out when Corbin and Strauss wrote their book ‘Basics of Qualitative Research’ (1990).

Stern (1994, p. 220) argues that there is a key difference in the questions each author asks of the data. She states that as Strauss examines the data, he stops at each word and asks “What if?” whereas Glaser keeps his attention on the data and asks, “What do we have here?” According to Stern (1994, p. 220): “Strauss brings to bear every possible contingency that could relate to the data, whether it appears in the data or not. Glaser focuses his attention on the data to allow the data to tell their own story”.

Having considered the two viewpoints, it was decided to adopt the use of Glaser's (1992, p. 4) approach because it appeared the more authentic method. The three major questions that must be asked of the data when using this method are:

1. What is the specific concern or problem to be studied in this group of people?
2. What is the most significant variation in processing this specific area of concern?
3. To what category, or property of that category, does this incident indicate?

## **OBJECTIVES OF THE PRESENT RESEARCH**

The aim of this study was to better understand the process women go through and the factors that influence their choice(s), when confronted with a diagnosis of breast cancer.

Specific aims were therefore to:

- Identify the woman's perspective on defining and selecting treatment priorities for breast cancer.
- Describe how women choose treatment options for breast cancer.
- Develop a conceptual model of the processes involved when women decide their personal treatment choices.

A description of the application of the methods of grounded theory follows. Preparation for the study, performance and data gathering methods are discussed as well as the ethical issues related to the research project.

## **PROCEDURES ADOPTED FOR RECRUITING PARTICIPANTS AND OBTAINING INFORMED CONSENT.**

This section will discuss how participants were recruited to the study, criteria for inclusion, and the procedure for obtaining informed consent. A brief demographic overview of the participants is provided. Sub-headings are:

- Recruitment.
- Eligibility and invitation to participate in the study.



## **Recruitment**

The principal avenues used for participant recruitment were the local hospital's specialist Breast Clinic and the local division of the Breast Cancer Support Service. The hospital's Maori Health Unit was also approached in the hope that this would provide an avenue through which Maori women could be invited to participate.

### ***Breast Clinic***

Women were invited to participate in the study by the Breast Care Nurse who attends this clinic. If women indicated they were interested she gave them the Letter of Introduction and Information Sheet (appendix A) which also contained the written Consent Form (appendix B) and a reference list of the questions that would be asked in the interview if they agreed to take part (appendix C). This meant that the researcher did not directly approach women, which ensured they did not feel pressured to participate in the study in any way.

### ***Breast Cancer Support Service (BCSS)***

The Coordinator of the BCSS was approached for assistance in recruiting participants to the study. This is a support group organised for and by women who have had breast cancer. It has both national and international affiliations. One of the functions of the group is to offer women support during the pre and post-operative phase of their treatment for breast cancer. The coordinator of this group kindly offered to invite women who meet the study criteria to participate. She discussed the study at the groups bi-monthly meeting and mailed the introduction and information sheet to eligible members.

### ***Maori Health Unit***

Hoping to include Maori women in the study if possible, the local hospital's Maori Health Unit was approached. An overview of the study was presented at the monthly board meeting and the Letter of Introduction provided to them. Although support was demonstrated for the study, unfortunately, no Maori women were forthcoming.

### **Eligibility and invitation to participate in the study**

Criteria for participation in the study included the following. Women who:

- a) have had a diagnosis of breast cancer and were required to decide their preferred treatment options.
- b) were six months to five years post-treatment.
- c) did not have recurrent disease for which they were undergoing treatment at the present time.

As stated, women who indicated an interest in being involved in the study were given the 'Letter of Introduction and Information Sheet'. If they proceeded to contact the researcher (either by telephone or mail) the researcher then contacted them by phone to determine whether they were still interested to participate. If this was affirmative, it was then ascertained, in a sensitive manner, that they meet the selection criteria for entry into the study. An interview date, time and place, that was convenient for the participant, was then arranged. Informed, signed consent was obtained before the initial interview and after it had been ascertained that the participant had read and understood the information sheet and what her participation in the study would involve.

### **PARTICIPANTS, DEMOGRAPHICS AND ETHICAL CONSIDERATIONS**

This section will summarize the:

- (a) Participants (age, marital status, employment - full-time or part-time).
- (b) Treatments they underwent.
- (c) Procedure in which they were involved.
- (d) Procedures followed to protect participant confidentiality and the process of obtaining informed consent.

#### **Participants**

Fourteen participants were recruited to the study, six via the specialist Breast Clinic and eight from the BCSS. Of the fourteen women, 11 had stage I-II disease and three had stage III (refer footnote 3, Chapter 2). Ages ranged from 33 yr.'s to 65 yr.'s with a median age of 50 yr.'s and an average of 54 yr.'s. Eight of these women were married and living with their partner, four were divorced (two had new partner's), one was single, and one was widowed. Thirteen of the women had children. One of



the participants was a full-time wife and mother (pre-school child), three worked full-time, five worked part-time and five had retired from active employment.

### **Treatments**

Five of these women had undergone mastectomy alone and one of these women had undergone bi-lateral mastectomy for breast cancer in both breasts (1 year apart). Five women had undergone mastectomy with reconstruction, two of these women had also had bilateral mastectomy. One of these women chose to have bilateral mastectomy owing to the nature of her tumour and the risk it could occur in the remaining breast. The other participant who had undergone bilateral mastectomy with reconstruction had a five-year interval between her first and second breast cancer. She had undergone delayed reconstruction after her first mastectomy and immediate reconstruction after her second mastectomy. Of the remaining women who underwent reconstruction, three had immediate reconstruction, and two underwent delayed. Four women had reconstruction using the tissue expander method, two of these women having bilateral reconstruction. One woman had undergone 'TRAM' (transverse rectus-abdominal muscle) flap reconstruction. Five women had undergone conservative surgery (wide local excision and axillary dissection) followed by radiotherapy. One participant had initially chosen conservative surgery but owing to inadequate tumour clearance went on to mastectomy. One woman had required radiotherapy post mastectomy. Three had post-operative chemotherapy (one women twice after each mastectomy), eight had received hormone therapy (Tamoxifen), one of these women also having had chemotherapy. Table One (p. 53) provides an overview of relevant information.

### **Procedure in which participants were involved**

An informal, loosely structured (conversational) interview format was adopted. As mentioned above, participants received a reference list of questions (appendix C) prior to the interview so that they had an indication of the format the interview would take. Participants were requested to start from the beginning and talk about how they became aware of their breast cancer and how they went on to decide their preferred treatment options. Interviews lasted approximately 1- 1½ hours. As is the procedure with grounded theory, the initial interviews were quite open; women talked generally about their experience of breast cancer and then brought this back to how this related

to their specific treatment choices (or restricted choices). After the initial five to six interviews, and data analysis having begun, interviews became increasingly more focused.

All interviews were tape recorded and transcribed, in private, by the researcher. Pseudonyms were given to all participants. Any names mentioned in citations in the text were replaced with a lower case "xx" for first names and upper and lower case "Xx" for surnames. Generally these relate to surgeons or other health professionals. Otherwise, the relationship of this person to the participant is included in brackets, for example, xx (son).

**TABLE ONE: DEMOGRAPHICS OF PARTICIPANTS**

Interview number, pseudonym, surgical treatment, adjuvant therapy, age at diagnosis and time since.

<i>Interview Number</i>	<i>Pseudonym</i>	<i>Surgical treatment</i>	<i>Adjuvant therapy</i>	<i>Age at diagnosis (yr. 's)</i>	<i>Time since Diagnosis (yr. 's)</i>
1	Cathy	Conservative	Chemo/Rx	33	4
2	Julie	Mastectomy	Tamoxifen	50	2 <sup>1</sup> / <sub>2</sub>
3	Alaina	Mastectomy	Chemo	48	5
4	Gwen	Mastectomy	Nil	60	3 <sup>1</sup> / <sub>2</sub>
5	Joanne	Bilat. Mast. & Reconstruction	Tamoxifen	Early 50's	5
6	Sonya	Mast. & recon.	Tamoxifen	57	4
7	Louise	Mastectomy	Nil	38	5
8	Pam	Mast. & recon (bi-lateral)	Tamoxifen	45/53	8 & 2
9	Margaret	Conservative	Tam/Rx	55	5
10	Denise	Conservative	Rx	46	4
11	Mary	Conservative	Rx.	47	3
12	Catherine	Conservative	Tam/Rx	65	6 months
13	Richelle	Conservative	Tamoxifen	65	6 months
14	Gill	Bi-lat. Mast.	Chemo/Rx Chemo/Tam	54/55	1 <sup>1</sup> / <sub>2</sub> & 6 months

**KEY:**

Conservative surgery: Wide local excision and axillary dissection

Mast. & Recon: Mastectomy and reconstruction

Chemo: Chemotherapy

Rx: Radiotherapy

Tam. Tamoxifen (anti-oestrogenic = endocrine therapy)

## **ETHICAL ISSUES**

### **Informed consent**

The appendices contain the Introduction and Information Sheet (appendix A) and the Consent Form (appendix B) used for this study. As stated, the consent form was signed prior to, but at the time of the initial interview, and after the researcher was confident that participants had read and understood the information contained in it and what their participation involved.

### **Anonymity and Confidentiality**

Pseudonyms and/or codes relating to the origin of the data have been used throughout the study. Every effort was made to promote privacy during the interviews, and all interviews were performed in the participant's home, except for one, which was carried out at the researcher's home, as this was more convenient for the participant. Transcribing was performed in the privacy of the researcher's home. All hard copies, discs and tapes were kept in a safe storage area.

All participants were advised of their right to:

- withdraw from the study at any time.
- request the researcher to delete any data they do not wish to have included in the report.
- end the interview at any time.
- have the audiotape turned off at any time during the interview process.

A professional counsellor was arranged to assist if any participant was found to be emotionally distressed, either before, or because of the interview process. This service was not required.

Participants were requested to talk about their experience of discovering they had breast cancer and deciding their treatment preferences. Topics such as their personal fears, concerns regarding their self-confidence, their relationships and the like, were treated in a sensitive, caring and ethical manner. Every effort was made to develop a supportive-trusting relationship.

## **CHAPTER FOUR**

### **The historical-social perspective on 'autonomy of choice' in health care decision-making**

*Social action, since it has a career, is recognized as having a historical dimension which has to be taken into account in order to be adequately understood.*

Herbert Blumer (1969, p. 77).

#### **INTRODUCTION**

The right to autonomous choice and informed consent has its roots in multiple disciplines and social contexts including those of health professions, moral philosophy, law, the social and behavioural sciences (Faden & Beauchamp, 1986). This chapter will briefly consider the historical development of the doctor-patient relationship with regard to patient choice and decision making. It will begin by looking at the traditional concept of this relationship followed by a reflection on its changing nature over the past two to three decades. The more recent influences of consumerism will then be considered along with consideration of the demographic and epidemiological influences on healthcare. Finally the ethical perspective on patient involvement in decision making are considered in relation to the evolution of 'informed consent'. This overview is to situate the present study within the wider historical-social context of the doctor-patient relationship, decision making and personal choice which is central to women's decision making regarding treatment alternatives for breast cancer. This chapter is arranged in the three following sections:

- The history of patient participation in health-care decisions.
- Patient decision-making: The ethical perspective.
- A brief history of the evolution of informed choice and informed consent.

## **THE HISTORY OF PATIENT PARTICIPATION IN HEALTH CARE DECISIONS**

### **Introduction**

This section will discuss the history and evolution of patient participation in health care decisions, and the changes in society that have affected this relationship over the years. Discussion is arranged under the following topics:

- The traditional approach.
- Changing professional and patient relationships.
- Consumerism and information technology.
- Demographic and epidemiological factors.

### **The traditional approach**

The traditional concept of the doctor-patient relationship places the patient in a passive, compliant role. The patient's primary obligation is to seek competent help and then cooperate with the physician's treatment plan in order to get well. The doctor's role is to diagnose the illness, confer the sick status on the patient, and establish treatment priorities and initiate ongoing evaluation of its effectiveness. Parsons introduced this model of 'sick role' patient behaviour in 1951. He believed that along with obligations, certain privileges were granted to people when they were sick. As well as relinquishing their normal social roles, they were also entitled (or obliged) to relinquish the responsibility for making health decisions. This 'sick role' however, also had its incumbent responsibilities including the motivation to get well, seek technically competent help, trust the doctor, and comply with the medical regimen. The traditional concept of the doctor-patient relationship has therefore been one of the 'passive' patient and the 'active' doctor.

Brody (1980) relates that there are many factors that have maintained this imbalance of power between the doctor and the patient. First, the doctor possesses an esoteric body of knowledge acquired through years of study and post-graduate training. This information gap is often difficult to close owing to theoretical constraints. Often the information is extremely complex and patients may lack the intellectual capability to receive and process this information so as to make rational medical decisions. As the

patient carries the emotional and psychological burden of the disease, they are often in a state of relative shock and unable to process information as effectively as normal. Physicians have often taken a paternalistic approach, owing to the concern that patients will become over anxious if presented with too much information about their conditions. There has been the assumption in most professions that those who consult a professional do so because they feel they are not capable of making a decision (because they are not professionals). Exceptions have included patients whom themselves are professionals or are highly educated (Gadow, 1989a).

In more recent times, the role of the patient and the imbalance of power that has favoured health professionals have changed. As part of the consumer movement, consumers are now more actively involved in health care and health care choices. Biley (1992) relates that a greater knowledge of health care issues and the development of bodies to protect the interests of consumers have contributed to patients having a more active role in their healthcare. In the year 2000, with readily available information at the touch of a key (for example, via Internet), this is becoming increasingly the case.

### **Changing professional and patient relationships**

Starr (1982) traces the origins of the active patient concept from the move towards increased personal freedom in the mid-eighteenth century. This call for more freedom in health coincided with the decline in religious practice. Medicine, which guarded its knowledge as sacrosanct, had fostered a degree of mysticism, which served to distance doctors from their patients. Woodward and Richards (1977) describe nineteenth-century England as a time when traditional folk medicine and mutual self-help flourished. Schön (1992) called this the 'crisis of confidence in professional knowledge' stating that the public was becoming increasingly disposed to external regulation of professional practice to protect them against professional incompetence or venality. Hughes (1959) stated that the professional's tradition of claiming autonomy of practice, along with a privileged social position came into question as the public began to have doubts about professional ethics and expertise.



Starr (1982) refers to the 'retreat of private judgement' which accelerated in the early twentieth century as the medical profession increased its knowledge base and power as vaccines and drugs were discovered. Also broad social changes since the Second World War, for instance, the rise of existential philosophy and vociferous calls for self-determination from groups such as ethnic minority and women's groups, encouraged distrust of authority and doubt about the benefits to be derived from technological advances (Thomasma, 1983). In the last twenty years or so, particularly in the USA, there has also been the growing influence of the user-pay philosophy and self-responsibility.

Powles (1973) refers to the 'crisis of contemporary professionalism' as consumers criticised the bureaucracy, inflexibility and impersonal nature of the health services. The concept of 'iatrogenesis' was introduced by Illich (1974) and others, and the argument put forward was that the only answer for medical 'mistakes' was for the patient to be fully informed and involved in the decision making process. Martini (1981, p.197-198) writes: "The principle impetus for the steady growth of the self-care movement has been not so much the demonstrated efficacy of self-care as the crisis of confidence in professional medicine."

Brearley (1990) relates that the emphasis for change in patient-provider relationships also came from the allied professions such as nurses and psychologists. Engaged in this struggle against hegemony, they championed the ideas of patient autonomy and have developed educational programmes and behavioural treatments designed to facilitate greater patient involvement.

These changes were also influenced by such moments as the women's liberation movement and, in the later 1960s (originating in the USA) the women's health movement. Two influential publications in the field during this decade were "Our Bodies, Ourselves" (Boston Women's Health Collective, 1971; Rakusen and Phillips, 1978 [revised British version]) and "For her own good: 150 years of the experts' advice to women" (Ehrenreich & English, 1979). The former publication encouraged women to become more aware of their own bodies and issues pertaining

to women's health (pregnancy, childbirth, contraception and other gynaecological matters). The later publication documented the history of the movement linking it to the important position of women as health-care providers. A lot of their work was related to consciousness-raising about the wider issues of women's health. Both of these publications encouraged women to be pro-active and involved in health-care decision-making. Since these early publications there has been a proliferation of literature on women's health and related issues.

It was during the 1970s, and no doubt influenced by this changing social environment, that women protested against the so-called 'one-stage biopsy-radical mastectomy procedure'. Kushner (1988, p. xv) a non-fiction medical writer relates:

During those barbaric, not-so-long-ago years, the manuscripts  
that filled my mailbox usually aimed bile and venom at the surgeons  
who had promised a Band-Aid after a twenty-minute little operation  
... but who cut a precious breast off while a women lay unconscious  
on the operating table.

By 1982, the 'one-stage' procedure was no longer routine in the United States and by 1988, fifteen states had enacted laws requiring doctors to tell women diagnosed with breast cancer about alternatives to mastectomy (Kushner, 1988).

There are now a number of self-help and support (also activist) groups for women with breast cancer. For example the New Zealand Breast Cancer Support Service that is both a national and internationally affiliated, forms a support network for women with breast cancer. Working collaboratively with the New Zealand Cancer Society they have set up training programmes for their members to become volunteer visitors, support people, or both, to women newly diagnosed with breast cancer. They are often involved with helping women through the pre-treatment phase and coping with the aftermath. The Breast Cancer Network (NZ), whose role is mainly one of information networking, both nationally and internationally, casts a 'watchdog' eye in relation to how breast cancer is being managed both 'personally and politically'. Other smaller groups are evolving and it is hoped that soon a Maori women's breast cancer group will be formed (Holt, 1998).

It can be seen from the above that an accumulation of factors have added to the changing relationships between patients and practitioners over the years. Another 'cultural shift' was the growth in consumerism.

### **Consumerism**

Richardson (1983) states that consumer participation in publicly provided services became popular in the late 1960s and has been so ever since. The reason for this becoming 'fashionable' when it did is possibly related to the wider phenomenon of 'consumerism'. Participatory mechanisms in health have evolved alongside this societal trend.

In addition to participation, consumerism also calls for a degree of protection for consumers (Brearley, 1990). Kennedy (1981) considers that consumerism is best understood as being concerned with protecting the legitimate concerns of the consumer in the face of the greater power of others to harm (injure or exploit), or undermine the power of self-determination and responsibility for the individual's own destiny. Consumerism's aim was for "a better balance of power, in the light of prevailing values" (Brearley, 1990, p. 6). Brearley states that a consumerist stance can be seen as a challenge to professional authority, since it focuses on consumer's rights and provider's obligations rather than on the professional right to direct and the patient obligation to comply.

Together, the women's movement, and consumerism, has both had an affect on the level of women's involvement in their health-care decisions.

### **Demographic and epidemiological factors**

The reduced burden of communicable disease through improved sanitation, nutrition, housing and living standards (at least in western society) has led to both increased and longer survival. This, however, has made more apparent the existence of a variety of chronic health conditions, for example, ischaemic heart disease, diabetes, stroke, cancer (including breast), trauma and others. Sophisticated technology has

also increased the pool of chronic ill health survivors. Brearley (1990) relates that this has become a factor in the rise of patient participation for the following reasons:

- The present state of medical knowledge cannot offer cure.
- Continuing care is needed.
- Self-help has the potential to create a bond between sufferers and relatives reducing the need for professional support.
- Group activities with fellow sufferers can provide the most appropriate practical and emotional help.

The marked increase in elderly in our population who suffer from chronic degenerative disease processes is having a marked impact on our health and public support systems. The weakening of traditional social structures (the extended family) has led to increasing alienation and loneliness, which can manifest itself in impaired physical and mental health. There is increasing emphasis on community as opposed to hospital care in an effort to reduce public spending on health. This requires considerable consumer involvement, and particularly the help of women as the main care givers.

The technology and the information explosion (wherein anyone with access to, and knowledge how to use, a computer can access information through the 'world-wide Web') has had a major impact on lay involvement in health care decisions. This technology provides access to the latest scientific medical knowledge as well as what are often described as naturalistic or alternative health-care methods. This in itself, however, creates its own problems in relation to the potential for 'misinterpretation' of information, as well as information overload.

### **Summary**

Society's history and culture contribute to the doctrines and beliefs of the present day. This section has considered the changing nature of patient-participation in decision making over the past three decades. These have been influenced by factors such as the growing sophistication of society, an emphasis on 'self-care' (more so in the USA) and growing consumerism.

Brownlea (1987) describes participation in health-care as being 'tidal' in its behaviour; sometimes there is a strong ideological pull (often the direct result of structural breakdown) and sometimes because certain groups in the population are particularly hurt. This may be economic or in terms of the level or nature of their healthcare. The next section will discuss the ethical and legal foundations of patient involvement in health-care decisions and the rise of informed choice and consent.

## **PATIENT DECISION MAKING: AN ETHICAL PERSPECTIVE**

### **Introduction**

The main ethical principles generally raised in discussions of patient participation are those of paternalism and autonomy. This section will discuss the varying nature of those principles in relation to the doctor-patient relationship and patient participation in decision making.

### **Paternalism, autonomy, and patient participation**

Childress (1979) defines paternalism as an action taken by one person in the best interests of another without that person's consent. Thomasma (1983) distinguishes between 'strong' paternalism and 'weak' paternalism. Strong paternalism is action exercised against the wishes of another whereas weak paternalism is an action taken by the physician in the best interests of a patient on presumed wishes, or in absence of consent, for those who cannot give consent due to age or mental status. Owing to the power relations in the patient-professional relationship, and a feature of professionalism being autonomy, invariably the patient may find him or herself in a dependent position when health decisions are required. Thus a medically dominated health-care system tends to be characterized by professional autonomy and paternalism, albeit beneficent (Thomasma, 1983).

Gadow (1989a, p. 99) takes a wider perspective stating that paternalism is "when decisions are made without sufficient ascertainment of and respect of the patient's wishes" and the failure to obtain full and free consent from the patient, based upon full understanding by the patient. Gadow (1989a) states that there are two domains

that patients must explore in making treatment decisions and these are personal values and clinical options. Only the patient can provide subjective information regarding his or her personal values, whereas objective information is provided by the health professional. It would appear that a counterbalance must be reached between expert advice on the physician's behalf and the unique value system of the individual patient. Only the patient can provide subjective information regarding his or her personal values, whereas the health professional provides objective information. Gadow coins the phrase 'advocacy partnership'. Advocacy is a moral commitment to enhance the patients' autonomy (Gadow, 1989b, p. 535). Partnership advocacy implies that the patient be assisted to reach decisions that reflect their complex totality as individuals. Gadow (1989a, p. 101) states:

The objective portrayal of a patient's clinical condition through information about statistical probabilities or laboratory findings is insufficient information for a patient to make a decision regarding treatment. The unique subjective situation of the person is highly relevant to that decision. The advocate must promote the inclusion of patient wishes in the decision.

An associate professor for the Institute of Medical Humanities, Texas, Sally Gadow is a strong advocate of patient self-determination, and is perhaps best known in nursing for her concept of 'existential advocacy'. This is a concept of professional involvement that behooves both unifying and directing of one's entire self in relation to another's need. Advocacy implies that patients can be assisted in reaching decisions that express their complex totality as individuals. Gadow believes, in the nurse-patient relationship, this can only be achieved by nurses "who themselves act out of the same explicit self-unity, allowing no dimension of themselves to be exempt from the professional relation" (Gadow, 1980, p. 91).

There is an on-going tension between professional and patient autonomy. The physician's focus is to advocate in the patient's best interest whereas the patient must advocate for his or her own personal value system. Inevitably these issues are complex and sometimes incompatible.



## **A BRIEF HISTORY OF THE EVOLUTION OF INFORMED CHOICE AND CONSENT**

### **Introduction**

Informed choice and consent is both an ethical and legal commitment and patient right. Legislation to this effect was passed in New Zealand in 1996 (Code of Health and Disability Services Consumers' Rights, 1996). However, the history of informed consent dates back well before this and will be discussed in the following section. This is followed by a brief discussion of informed consent in the New Zealand context.

### **The history of informed choice and consent**

Brody (1980) relates that the first mention of 'informed consent' seems to have been in 1914 in relation to surgery, and since then it has developed as a legal mechanism for extending the liability of surgeons in the event of injury to the patient (Kaufmann, 1983). Kaufman charted the cumulative growth over the two previous decades in medical, legal and social science research literature on informed consent and patient decision-making. He states that supporters of the doctrine have promoted it as a vehicle for establishing patients' rights and a basis for challenging the autonomy of doctors in administering medical care. Contrarily, doctors have related the conflict between the principle of autonomy as a legal concept and the realities of clinical practice that often make involvement of patients in medical decisions difficult, particularly in relation to emergency situations.

Ingelfinger (1980) relates that informed consent has been regarded as undermining the fiduciary relationship between the doctor and his patient. He suggests that the legal requirements of disclosure may be regarded as a sign of bad faith in the doctor's ability to recommend the best treatment. The physician is concerned that fear generated by the knowledge of potential risks of the procedure will unduly worry the patient and causes him to reject the treatment essential for his or her health.

Faden and Beauchamp (1986) relate that up until the late 1950s the justification of practices for disclosure and consent seeking were related to what they called the 'beneficence model' rather than an 'autonomy model'. The 'beneficence model' depicts the physicians responsibilities of disclosure and consent-seeking as established by the principle of beneficence and the physicians primary obligation (surpassing the obligation of respect for autonomy) to provide medical benefit. Thus the physicians primary obligation in relation to information and decision making is to do it in such a way that it promotes or maximises the patient's medical benefit. They describe the 'autonomy model' as the view that the physician has a primary responsibility to disclose information and seek consent for treatment. Thus these two models, or principles, have the potential to conflict.

Faden and Beauchamp (1986) relate that it took time for clinicians to become 'informed' about informed consent and this was namely through legal action taken against them in relation to consent issues. These authors state that although most physicians recognised both a moral and a legal duty to obtain patient consent, and offer a degree of disclosure, this was not universally embraced. For example, they report a study in which 379 physicians evaluated 26 cases (some hypothetical and some based on the facts of actual malpractice cases) in terms of the question: "Was the resolution of the case proper as a matter of good medical practice - as a matter of ethics? As a matter of law?" (Faden & Beauchamp, 1986, p. 89). A question was posed as to whether a surgeon needed the patient's consent to proceed to mastectomy when a breast lump was found to be malignant when the only authorisation from the patient was her signature on the blanket consent form required for hospital admission. Fifty percent of the physicians thought it medically proper for the surgeon to proceed with mastectomy. Thirty percent of physicians regarded this procedure as ethically proper and only 38% viewed it as legally proper. Until the 1970s it was common for women to submit themselves for the surgical removal of a breast lump unsure whether they would wake with or without their breast. Women's political action (discussed earlier) and changes in medical science have now stopped this once common medical practice.

### **Informed consent and the New Zealand context**

In New Zealand the issue of informed consent was brought abruptly to public attention in 1988 with release of the Cartwright Enquiry. This was the result of an investigation into practices at Auckland National Women's Hospital after an article published in Metro magazine in June 1987 written by Phillida Bunkle and Sandra Coney. Their investigation revealed that a professor of gynaecology (and colleagues) had carried out a disastrous research programme at the hospital over a number of years. The professor (Professor Green) had a personal hypothesis that cervical carcinoma insitu (a pre-malignant abnormality in the cells at the neck of the womb) would not progress to an occult malignancy, which was against international evidence at the time. His subsequent non-treatment of this condition put women at risk of developing invasive cervical cancer. Furthermore women were unaware that (a) they were part of a research study and (b) they were receiving unconventional treatment. The outcome was that women entered in the study developed potentially fatal invasive cervical cancer at an appalling twenty-five times the rate of women treated in the conventional (Coney, 1990). Of the various recommendations in the Cartwright report, one was that a working party be set up on informed consent, which would include standards for patient care services. Despite this, Coney (1990) related that, even after the enquiry, there was still huge medical resistance to informed consent. She relates: "The aftermath of the cancer inquiry was the demonstration of the resilience and the resistance, and therefore the power of the medical institutions. If change was going to occur it would take place on their terms and in a way that did not threaten the medical monopoly" (p. 242).

This tension between patient autonomy and professional autonomy (or benevolent paternalism) continues. Weiss (1985) states that the concept of patient autonomy emphasises procedure and the right of patients to decide for themselves, whereas modern paternalism emphasises health outcomes and the principles of the patient's best interests. This tension continues as the modern physician tries to attend to and respect the need to inform the patient adequately, to remain a compassionate voice, and to steer them away from making decisions that could result in negative health outcomes. Bias is inherent in the physician's personal beliefs and comprehension of

medical evidence in relation to the particular patient in question. The manner in which the physician relates information and the patient's ability to assimilate and interpret information, ultimately affects treatment decisions.

In the year 2000 informed consent is both an ethical and legal obligation on the part of the treating health professional and a patient right. This then directs responsibility to the patient for making decisions regarding his or her health care. Informed choice and informed consent, as well as changing knowledge and treatment protocols have made the patient-doctor relationship in relation to the women with breast cancer a very different experience in the year 2000 than it was three decades ago.

## **SUMMMARY**

This chapter has reviewed the history of patient participation in relation to health-care decisions and how this has changed over the past-three decade's result of changing societal attitudes and the influences of consumerism and increasing technology. It has briefly discussed the evolving history, legal and ethical perspectives, or debates, on patient involvement in decision-making, including the obligation of informed choice and informed consent. The aim of this chapter was to provide a background to the present study.

Brearley (1990) argues that one of the most consistent findings in relation to research on patient participation in decision making, and preference for, varies with social, educational and demographic factors. She relates that people who have not always been encouraged to think and choose for themselves become 'used' to solutions being imposed by experts. Brearley is critical that not enough effort and imagination has been devoted to structuring health services so that people can participate in more than just token ways. She believes that to be really effective, partnerships need to be between those with some fundamental basis of equality. Perhaps this will be the new contemporary focus of patient involvement in health-care decision making for the future.

## INTRODUCTION TO DATA

### KEY TO THE INTERVIEW ABBREVIATIONS

The following conventions have been adopted within the data chapters and are presented here to assist the reader.

xx/Xx	Any names mentioned in citations in the text were replaced with a lower case “xx” for first names and upper case “Xx” for surnames. Generally these relate to surgeons or other health professionals. Otherwise, the relationship of this person to the participant is included in brackets: for example - xx (son).
Name (4-5)	Participants are identified by a pseudonym (refer chapter 3: Table 1, p. 53). The number in brackets after the name indicates the lines in the typed transcripts where the citation can be located.
...	Indicates that material has been edited
[ ]	Insertion of information by researcher to clarify meaning
The women	Refers to women in the present study

## **CHAPTER FIVE**

### **Detecting a cancer – the crisis evolves**

#### *Cancer in the breast*

*Is hard as the pit of a ripe peach.*

*Those who have it know it*

Pat Gray (1988, p. 36).

#### **INTRODUCTION**

To discover the women's perspective on deciding treatment options it was necessary to start at the beginning; to hear their stories of 'finding a lump', or for some women, how they had been recalled to their doctor because of a suspicious lesion found on screening mammography. From this point forward their journey of breast cancer began.

The diagnosis of breast cancer is a catastrophic experience. Colyer (1996, p.1999) states: "It hurls a woman into a painful, existential crisis". Yet this is also a time when women are required to make major decisions regarding their choice of treatment; decisions that will irrevocably affect their bodies and their lives. This chapter explores the various ways women became aware of their breast cancer, and their initial reactions. It describes their experience of having breast cancer confirmed and hearing their treatment options.

There are three central categories in this chapter relating to the women's initial encounter with breast cancer:

- Emerging the problem.
- The 'bad news' consultation.
- Developing knowledge of clinical options.

The various codes inherent in these categories will be listed in the introduction to each section. As each interview was in itself potentially a 'case study', it has been a challenge to split events into isolated segments. However, it was not the goal of this study to present individual woman's stories (which would have been a different type of study); the goal was rather to identify commonalities in that experience.



## **EMERGING THE PROBLEM**

### **Introduction**

For some women breast cancer presents itself as “a palpable fact – the lump, the lump in the breast belonging to me” (Lifshitz, 1988, p.xvii). For others it may present as an abnormality on routine or screening mammography. Mammography can be an equally threatening experience; Kennedy (in Lifshitz, p. 5) describes it as looking for that “pea-sized death”. This first section will explore that event. How women in the present study encountered their breast cancer. Three codes pertain to this category:

- Finding a lump.
- Screening detected mammography.
- “Feeling devastated”.

### **Finding a lump**

Of the fourteen women interviewed (two of whom developed bilateral breast cancer within five years) seven women found their own lumps, two found them in combination with the GP and mammography, and one woman’s husband found her lump. Of these ten women, four had previously had fibrocystic changes in their breasts. Four of the women had their cancer detected on routine or screening mammography and one of these was via the Aotearoa Breast Screening Programme<sup>4</sup>.

It is not uncommon that it is a woman’s partner who detects the lump or thickening in the breast. Cathy recalled how her husband had found her lump:

Well my husband found my lump initially, and I raced down to the doctors as soon as I could get there. I went so fast I didn’t care if I didn’t see my own GP I was happy to see whatever doctor was there (4-6).

The four women who had a prior history of fibrocystic changes in the breast hoped that ‘this’ lump would prove to be fibrocystic too. Three of the women stated however that they had an underlying suspicion that this one was different. Sonya

---

<sup>4</sup> ‘Breastscreen Aotearoa’ is a national programme (launched on 10/12/98) offering women between the ages 55-65 free screening mammography on a biannual basis.

said "I knew I was going to get that prognosis because, um, I don't know, you just sense it, and the way she [the GP] actually reacted ..." (14-15).

The women related different incidents that provoked them to examine their breasts, either the news that a friend had breast cancer, or a media message about mammography screening. For example, Sonya reported:

It happened to be breast cancer month, October. I was at a friend's place, and she'd just had breast cancer so I thought I must go home and do it [breast self-examination], and I still didn't do it. I went to a wedding the next day, and I felt some peculiar things going on in my breast... so I tested and found quite a big lump, and I thought, well I wonder if that's breast cancer?" (10-14).

One woman's altered health status, as opposed to her 'lumpy breast', took her to her doctor. Alaina said that she had always been aware of having lumpy breasts, and as part of her health assessment requested a screening mammography, which her GP declined saying she was not in an 'at risk' age group. She described herself as a fit, healthy 48 year old, "A tomboy mother who loved tramping, camping, yachting, the lot" (274-5) and that her body had always "worked like clockwork" (34). Then suddenly things had changed. She described herself as feeling "in a state of complete panic and confusion" (35). Her symptoms were quite non-specific and her GP said that they were most likely related to impending menopause. Alaina, however, did not go along with this explanation: "My periods were still very regular—I didn't have hot flushes or any menopausal symptoms what-so-ever but my body, I felt this panicky-as though my blood was racing" (30-38). Retrospectively, Alaina was convinced that these symptoms were a result of her body fighting the undetected cancer in her breast. She had read up about menopausal symptoms and these were not they! Her doctor remained convinced that her symptoms were pre-menopausal and offered her counseling and anti-anxiety medication. She stated: "He humoured me and said, look, I don't think you've got anything to worry about. You're very fit and healthy" (96). (Later on, after her treatment for breast cancer, Alaina was found to be hyperthyroid. It was unclear whether her GP had done thyroid function tests at this time.)

Dissatisfied with her treatment, she decided to change her doctor. Her new GP, also unconvinced, somewhat reluctantly granted her wish and ordered a mammogram. The radiographer/radiologist performing this mammogram expressed her immediate concern that there was a very dense lump in her left breast, which she couldn't visualize the centre of. She cautioned Alaina; "If you were my mother or my daughter, I would not be happy. I'm telling you not to leave it but to go and have a needle biopsy" (104-105). Alaina's new GP remained unconcerned but agreed to arrange for a needle biopsy, reassuring her all the time that he had felt lumps like this before and they were just calcifications. Unfortunately this was not to be. It was a cancer, and had probably been there "for several years" (118). Her GP was "quite upset and devastated" (119). Alaina said that she was just plain angry, angry that her first GP had not listened to her concerns. In her own words, "Why can't doctors listen. I was really furious with the previous one who had refused me a mammogram...when he told me the result I said: 'Well, I knew there was something wrong. I'm not surprised at all'" (123).

Therefore the women found their lumps in a variety of ways. Cathy, Sonya and Alaina's story are three examples. Seven of the women in the present study came across their lump 'accidentally' either in the shower, or happened upon it when getting dressed or lying in bed. Two women said they 'occasionally' performed breast self-examination. Three of the women's doctors requested screening mammography owing to their now being in an at risk age group, which revealed an abnormality.

### **Screening detected breast cancer**

Although the reality of breast cancer is met with disbelief by most women who encounter this condition, it is perhaps another kind of fate when it is revealed through a pro-active measure such as screening mammography. This was the case for four women in the present study. They too related how devastated they were when an abnormality was detected.

Joanne joined her friends in going to a menopause clinic, which included mammography and bone density screening, and was called back for a repeat mammogram. This was the first sign all was not well. After the second mammogram

she was called by the clinic's nurse and advised that they would like her to see a breast surgeon asking whom would she like to see? On attending this appointment, she knew as soon as the surgeon asked if she had someone with her, that the news was bad. She had been so positive that her result was going to be negative, when her husband had asked if she wanted him to come with her to the appointment she had said no. She said when she told him the news: "He was absolutely devastated - we were both crying" (74).

Richelle also had her breast cancer diagnosed via screening mammography. She had responded to the Aotearoa National Screening Programme. Owing to a suspicious mammogram she was requested to have an ultrasound which revealed a mass and she was asked to have a biopsy as an in-patient day case. She then had a follow-up appointment with the consultant, an appointment where she waited for four hours to be seen and was finally seen at 7 p.m:

And that was really interesting, in the light of your inquiry's,  
because he didn't beat about the bush. I have to admire it really.  
But it was a bit of a shock – because he almost said, good evening,  
you can either have a mastectomy or we can do this other thing (52-56).

So from believing themselves to be healthy women moving into an age group more at risk for age related conditions (breast cancer being just one of these) these women were suddenly faced with the fact of cancer and having to consider their treatment options.

### **"Feeling devastated"**

Women related that they were "devastated" to find a lump in their breast. They described a sense of shock and bewilderment. Most of the women in the present study made an appointment to see their GP almost immediately, although one waited until after her period, and another about a month because at the time her sister had just been diagnosed with breast cancer.

A positive fine needle aspiration (FNA) was often the first diagnostic proof of breast cancer. For example, Louise described how devastated she was hearing the news that hers was positive. When she found the lump in her breast she had gone straight to

her GP who had advised her to wait until after her period and if it was still there to come back. It was – so she did. She was then referred to a specialist breast surgeon who performed an FNA. Louise states: “I was called back in five minutes by the private nurse and she just had to tell me over the phone that it was a full blown cancer ... I was thirty eight, so I was pretty devastated” (19-21).

All of the ten women who detected a lump (which was later proven to be a cancer) expressed their shock and fear at its detection. Underwood (1990, p. 199) describes her experience of finding a lump: “Touching a lump in the breast at first dazes and numbs all other senses, pushes all cold numbers and odds from consciousness, then centers all feeling and thought on one question: what does this mean?” This vivid description would be a fairly universal response for a woman finding a lump in her breast wherein her journey of breast cancer began.

### **Summary**

This section discussed ‘emerging the problem’; discovering a lump, thickening, an altered contour in the breast, or an abnormality detected on screening mammography. Universally, women were devastated to find they had a breast lump which they rightly identified as a potentially life threatening problem. Confirmation of cancer by their clinician was generally followed (immediately) by a discussion of treatment alternatives.

## **THE ‘BAD NEWS’ CONSULTATION**

### **Introduction**

This section will discuss how along with confirmation of breast cancer, the women in the present study almost instantaneously received information regarding their treatment options. Although in a relative state of shock at the news they had cancer, the women still had to try and absorb the information they received from their clinician regarding possible treatment alternatives. The women variously described the process after confirmation that they had breast cancer as like being ‘on a roller coaster’ or ‘conveyor belt’. Events carried them along. Women often described it as seemingly a bad dream from which they were certain they would soon wake up and

it wouldn't be true. They often had 'flashbulb'<sup>5</sup> memory of hearing they had cancer, then events after that became a little blurred. Concentrating on the details of what they were being told was very difficult. Codes identified in this section were:

- Receiving the 'bad news'.
- Facing a breast cancer diagnosis – hearing treatment alternatives.
- 'Flash-bulb' recall.
- Receiving and telling 'bad news' is difficult.
- Concentrating on detail 'difficult'.
- Feeling "out of control" – on a "roller-coaster".
- Grieving potential losses and asking the questions: "Why me?"  
"Why this?"

### **Receiving the 'bad news'**

Generally it was the surgeon who confirmed the women's fear that they had breast cancer, although in some instances it was the surgeon's nurse (when phoning women requesting them to come in for a consultation with their specialist). Up until this time most of the women still maintained the hope that their lump might be benign, fibrocystic, nothing to worry about. Confirmation however, catapulted them into a world of having cancer. Generally it appeared surgeons confirmed the diagnosis, discussed the treatment options, and then told the women to take time to think it all over. They then made a further appointment with each woman so as to go over the treatment options, and confirm a treatment plan. If a woman chose conservative surgery (wide local excision, axillary dissection and radiotherapy) she was generally required to see the radiation oncologist prior to planned surgery. If she chose mastectomy and wished to consider immediate reconstruction, an appointment was arranged with a plastic surgeon to discuss re-constructive options. No women in the present study required pre-operative chemotherapy or radiotherapy which is occasionally required if the tumour is advanced, or inflammatory (a histological variant).

Women in the present study were relatively charitable regarding their physician's communication styles relating that it must be an extremely stressful task having to

---

<sup>5</sup> Memory for an unexpected, biologically significant event (Brown & Kulik, 1982).



repeatedly inform women that they have breast cancer. Most surgeons were 'up-front' with the news, then spent time going through the details with each woman. All surgeons encouraged their patients to take time in making their decisions, although, as will be discussed in subsequent chapters, time can be a relative phenomenon and women preferred different lengths of time. Sometimes 'circumstances' (surgeon availability) imposed certain timeframes. All of the women appeared to have absolute faith in their surgeon's competence and held no grudge if communication was initially a little constrained. Most stated that over time they developed a more relaxed and friendly relationship with their specialist(s).

### **Facing a breast cancer diagnosis – hearing treatment alternatives**

Although the shock of a breast cancer diagnosis generally had an immobilizing effect on the women, this was just the beginning. Within minutes of hearing they had breast cancer, women were confronted with information regarding the possible treatment options available to them. They were not expected to make a decision at this time, but it generally meant they left the appointment with options to consider, or on-going staging procedures to undergo.

The women related hearing their treatment options in a relatively objective and factual manner. For example, Gwen, who had a screening detected cancer, described her briefing on her treatment options:

Mr Xx is fairly matter-of-fact about it, and that is good, because I'm sure he deals with a lot of emotional women. He said:  
"These are your options. You can have partial mastectomy or mastectomy. If you do that, that and that will follow. Well you can decide and come back next week ..." (30-33).

Gwen said that after the appointment she went home and thought about things:

You feel a bit sorry for yourself, and then I thought, oh well, this is where we are, what is the next step. Within a day I really had made my decision what my choice would be (34-35).

Gwen felt very positive about the fact that her cancer had been detected early: "In my case it was very small, it was nothing it was just a 1 cm cancerous growth" (30). She chose mastectomy. She didn't want to live with the fear of recurrence.

It appeared that the women in the study were given relatively little time to digest the fact that indeed they had a cancer before their clinician discussed treatment options. Obviously this was important as having learned that they had a breast cancer they needed to be given their treatment options so as they could go away and think these over, prior to their next appointment. Denise described the initial consultation with her surgeon. He already had the results of an FNA performed by her GP, and her mammogram:

He said, "yes it is cancer –what do you want? Do you want me to take the lump out? You have three choices. Your breast off, the lump out, and radiotherapy". And I said, "well I definitely don't want my breast off", and I said "I would just like the lump out with no radiotherapy" (48-51).

The surgeon said he would not recommend this but that he was not going to dictate one way or the other, and that it would be best she go home and think it over. Denise said that she didn't want to go home and think it over, she wanted the lump out tomorrow: "So then he said, 'Alright', and he got me into hospital the next day" (59). Denise's reaction stemmed from her devastation and shock at having a cancer and just 'wanting rid' of it as soon as possible. She related how this all happened amidst the turmoil of her marriage breakup. She also stated that it was fairly typical of the way she made decisions, but that she believed it would have been a whole different ball game for her if she had been required to consider mastectomy.

It has already been related in the previous section on 'screening detected breast cancer' how Richelle received the news of her cancer and her treatment options. Although it appeared Richelle received her news in a very blunt manner, she was unperturbed stating that the surgeon needed to get the facts out so they could go on from there. She said she hadn't found this consultant unkind in any way, "it was just a bit of a shock" (54). He had been unhurried and talked with her at length about her options.

Consultations are generally scheduled to a certain timeframe. Physicians often have to give women considerable information within a short period advising them to go away and take their time to think over their options. The women in the present study

were generally advised that they could either ring the surgeon's nurse or contact their GP's if they wanted information clarified or needed help or support.

### **'Flashbulb' recall**

Although women were interviewed retrospectively, most women had a 'flashbulb' memory of being informed they had breast cancer. However, events after this, often became a bit blurred.

Cathy related that she had had to wait six weeks for an appointment with a breast care specialist after finding her lump. The specialist performed an FNA of the lump and asked her to return the following day. Although her husband and son had gone with her to her first appointment, because the clinic had been running late and they had had a very long wait, she suggested her husband come in later for the following days appointment. She related how he had arrived about quarter of an hour after she had been given the 'bad news'. She could only vaguely recall this consultation:

Ah, he said they [the cells] were cancerous. I can't remember half the emotions I felt at the time. Probably your biggest concern was xx (son) – Well I mean he was only – he wasn't even two. I thought, 'excuse me, I'm this child's mother – I can't be sick' (38-42).

She vaguely recalled the conversation that followed about treatment options:

I know we did obviously talk about it and he did say that if I had to have a mastectomy he would tell me that obviously, and I guess its just the pro's of con's as to whether I would want to have my breast cut off and what would follow ... (59-62).

Cathy related that she found it hard to think past the words 'cancer'. Her mother had died when Cathy was 20 years old. All she could think of was that she had to survive. She couldn't leave her child, like her mother had left her.

Women appeared to recall the highly significant information they were given in their 'bad news' interview, but were often vague on detail. Salient points to them were getting rid of the cancer and their long-term survival; questions that couldn't be answered at that time.

### **Receiving and telling 'bad news' difficult**

As may be expected, the receiving and telling of 'bad news' is a difficult event. It would be unusual if it was remembered as a positive experience and indeed it wasn't by women in the present study.

Louise described her surgeon as being "a bit on the negative" (336) but that "he probably has to be like that because you don't want to give people false hope" (337). Louise was also sympathetic to the surgeon's predicament having to constantly deal with women with cancer and 'telling bad news'. She related:

I mean he's very down to earth and says, "you've just got to get on with it", and so you do. I'm sure its terrible: "Yes, you've got cancer – your breast has to come off. No, I don't know whether you're going to die or not". I mean, it must be terrible (345-348).

Knowing that it was likely to be a very stressful consultation, women often took someone with them. As well as her partner, Mary took a tape recorder to her 'bad news' interview. She said that the surgeon gave her a number of options to consider:

He gave me all the options as far as I could have the breast removed, I could have, so many things I could have. I actually had a tape with me; I had my partner with me. We're not married yet (30-31) ... He left it for me to decide basically what treatment I wanted (40).

Mary related that as a practice nurse she was relatively well informed about breast cancer and the possible options. She had also done a lot of reading around the subject having attended a special course for practice nurses offered by the local Cancer Society. She said: "He never gave me any false ideas that everything would be fine - that I wouldn't have to have anything else done. So I just opted for the lumpectomy" (76-77). Asking Mary how long it took her to decide she replied: "Not long really, it was probably only about two weeks" (81).

Most women received 'the bad news' from their clinician or in two instances, the surgeon's nurse specialist. Pam relates: "xx [nurse] rang me. I was actually told over the phone, which was a hideous experience" (38). She then went to the clinic for an appointment saying 'they' wanted her in hospital the following week. She asked: "Why not tomorrow?" (40). The surgeon responded: "Well we want you to have

time to think about it. We always leave it a couple of days so you have time for it all to sink in" (42). So she went back to see him in about three days, accompanied by her husband. She said that by this time she had reached the decision to have a "deep wide excision and my nodes removed" (44). Pam related hearing her treatment options:

Like I mean he sort of said to me "what would you like?" and I said to him "well I'm in your hands". I haven't got big breasts, so the fact that I would lose a breast, I suppose. I mean even though it's not a big breast, it's still my breast (44-46).

The surgeon said he believed he could conserve Pam's breast so she proceeded to have a wide local excision and axillary dissection. Unfortunately the tissue margins around the tumour weren't clear (free of tumour). She related her distress at hearing this news: "Then the results came back from my operation and he walked into my room at (Hospital) and he said he would have to do further surgery because they didn't get all the cancer" (49-50). Pam said she was devastated: "That really really knocked me" (57). Although the surgeon had advised her pre-operatively that sometimes it is necessary to proceed to either further resection, or mastectomy (if tumour cells are present in tissue margins on histological examination) she felt it had sounded a very remote possibility and hadn't really taken it on board. Her surgeon then explained that 25% of women have to go on and have mastectomy. She said how she had responded "But that's a huge amount" (76) and he had turned it around saying, "well, it's not really, that means 75%, or 75 out of 100 will be okay, only 25 will have to have mastectomy" (77-78). Pam said that she 'supposed' she had been advised of these statistics pre-operatively but "when you're told you have breast cancer, your mind goes a total blank, and, I couldn't make the decision myself. I mean I was in a state of shock. It's terribly difficult" (79-80). She continued:

I mean you want the cancer gone. I mean if I ever had it again, which I did, [Pam developed another primary in her remaining breast 5 years later] there would be no question, I was going to have a mastectomy. I was never going to go through two operations again (81-83).

Considering these statements, which are reflective of how most women felt or reacted when they were first told they had breast cancer, it can be seen how difficult it is for women when they are required to make decisions within relatively tight time frames. Yet they are also desperate to get on and get rid of the cancer 'as soon as possible'.

### **Concentrating on detail 'difficult'**

All women described their struggle to take in the information their specialist gave them owing to the shock of a cancer diagnosis.

Julie described how she found it extremely difficult to concentrate; neither could she quite recall the sequence of events. She could remember the surgeon confirming the fact the lump (she had undergone open biopsy as a day patient) was cancer, and then things became a bit blurred. She knew that she was going to need further surgery, and that the options were re-excision or mastectomy. If she chose mastectomy, then she could also opt to have re-construction. Women said the more complex details of these options were rarely absorbed at the time and had to be gone over, or read about, later.

One participant was perturbed by the fact that she felt her surgeon had been discriminating in relation to her age when he had put the options to her. She relates:

I didn't feel that he was in anyway unfeeling about it - I had xx with me, one of my daughters, and what I didn't like was that he said, "if you were your daughter's age then perhaps you might go for a lumpectomy but at your age it doesn't matter" (62-65).

She said how she had told the clinic nurse about this at her next visit, but that really she wished she'd had the courage to tell the surgeon herself. She continued: "I mean I could see what he meant, but I was quite fond of my breasts. Ah yeah, they'd given me a lot of fun ... I didn't want to loose them" (68-70)

As stated above, women all vividly recalled the moment of being told they had breast cancer but from this point on, events were sometimes less clearly remembered. All of the women interviewed for this study related that their concentration was impaired



by the shock of it all; their daily existence became a bit robotic. Surely it was all just a bad dream from which they would surely soon awake?

The receiving or telling of 'bad news' is a difficult communication. Generally the surgeon or physician will have a central and on-going relationship with a woman with breast cancer. It was important to the women that they developed a supportive and trusting relationship with their clinician. Generally they were sympathetic to the surgeons dilemma of having to repeatedly give 'bad news' to 'emotional women'. Universally the women expressed their trust and confidence in their specialist clinicians'. Universally they found it an extremely stressful period and making decisions was rarely easy.

#### **Feeling "out of control" – "on a roller coaster"**

After the initial consultation with the surgeon, things seemed to happen at relentless pace. Often women underwent a number of staging procedures such as chest x-ray, bone scan, and further blood tests. Although timing of surgery was generally not regarded as urgent (that is, today-tomorrow sort of thing as it was in the past when less was known about cell growth and tumour spread), there was still a sense of urgency to get on with things. The women described this themselves. They just 'wanted rid' of the cancer and it was generally their surgeon saying, 'no, I want you to have time to think it through and come to terms with it all'.

A number of women expressed that they felt as if they were on a roller coaster or conveyor belt as events happened one after the other, their normal routines shattered.

Joanne related her feelings of being out-of-control:

So you suddenly feel like you've just been thrown on this conveyor belt, and I've always felt this is a period when you feel you are no longer in control, and I've always liked to be in control of what I do and make my own decisions (38-40).

Others described similar emotions. Louise said:

It was a real "roller coaster", it was awful. I couldn't sleep. I cried and cried and cried. I was so absolutely scared ... I felt like, like, I had rocks on my shoulders – I thought this was going to be it for me (66-69).

The phenomena of 'shock' has been related a number of times and indeed it appeared that most women entered a cycle of grief, disbelief or both, in relation to the fact that they had breast cancer. But events continued on, and they struggled to keep pace.

**Grieving potential losses and asking the questions: "Why me?" "Why this?"**

As stated, in trying to come to terms with a diagnosis of breast cancer, women appeared to experience reactions commonly associated with shock and grief. Women variously described a state of disbelief, disorientation, and of feeling out of control. This section discusses how many women reacted with questions such as "why me" "what have I done wrong" or perhaps 'how might this have been prevented'?

Questions such as "Why me?" are commonly associated with grief reactions (Kubler- Ross, 1972). Women appeared to enter a preparatory grieving process in relation to the potential losses that lay before them. This included the threat to their bodies and their lives as known; their life itself.

Denise related how she questioned "Why?": "There is just so much going on in your mind and I think the main thing going on in your mind is that you can't believe it is happening to you. Why me? What have I done?" (300-301). Denise had 'requested' the surgeon operate on her the day after she was told she had cancer. Although this was extremely unusual, the surgeon respected her wish (if she had chosen mastectomy this may have been different). Denise related that it was some time (months) after that it really hit her that she had had cancer (to be discussed in chapter 6).

Conversely, other women reported that they came to an acceptance of the fact of their cancer without too great anguish. For example, Margaret related that she had about "two tears for about two minutes" (109) when she read her x-ray report: "You know how you sort of think 'why me?' Then I sort of felt well this is a bit ridiculous so, I thought, well you've just got to get on with life, um, so I did" (109-111). She added: "Maybe I suffered without knowing it. I probably did, but I didn't perform about it" (108-109). Gwen was reported earlier as saying: "I think the first day you

feel a bit sorry for yourself" (34), and then you ask, "Oh well, what is the next step?" (35).

Another participant related having to deal with the 'why me' question but said how this soon led on to the more practical question: 'What do I have to change in my life to prevent me getting it again?' Julie said that the questions she was asked at her pre-operative assessment inferred that there may be suspected pre-cursors to the disease which left her questioning her own lifestyle and whether she could she have put herself at risk:

So, I suppose it does affect you deep down and things like that.

... I mean the first thing they say to you is do you drink?

And I said, why, can't I even have a wine? And they [the junior doctor] said to me, "well apparently" (270 – 273).

This went on to other questions about food and diet leaving Julie thinking over her lifestyle and eating habits (it was unclear as to whether this was a medical school research study or cancer research data).

Women automatically assumed breast-feeding would be protective against breast cancer, after all it was the main functional aspect of the breasts; what they were really there for in the first place? Joanne related: "It's interesting because cancer is not in our family, all these things. I've breast fed four children; doesn't mean a thing" (65-66).

Women appeared to feel better about what had happened to them if they had done all within their power to have their breast cancer diagnosed early. Conversely, Richelle, whose cancer was diagnosed on screening mammography, related that she was sorry she had delayed having a mammogram because of the cost: "I should have had a mammogram sooner. But I was on a transition to retirement benefit and ninety dollars was too much. I knew it [screening] would be coming. But that was foolish on my part" (242-246).

In conclusion, there was anticipated grief in relation to loss of 'the self' as known and then there was grief in relation to a pervasive sense of vulnerability and uncertainty. The women questioned why this disease had touched them. It appeared

that all of the women had to search for an explanation as to why breast cancer had happened to them.

## **Summary**

Liftshitz (1988, p. xvii) described the diagnosis of breast cancer as “the cataclysmic change that drops like a death sentence and forces us into being who we are not”. This section has explored the beginning of that journey, from the suggestion of a problem through to its clinical confirmation and the discussion of treatment alternatives. Women in this study variously used the term devastating, terrible, being shocked, and numbed. They describe reactions common to people experiencing severe grief and loss. Women talked about denial, ‘this is not really happening’, to feeling ‘out of control’. They asked questions such as ‘why me?’ and ‘what have I done to cause this?’ Just one woman described herself as angry (Alaina) and this was related to the fact that her GP had refused to arrange a mammogram for her when she had requested it and therein her diagnosis was delayed. Universally the women experienced a sense of powerlessness as they were swept along by events. Although the women were still reeling from the news that they had cancer (a life threatening condition) they still had to concentrate on deciding, collaboratively with their clinicians, and often their partners, families, or both, their preferred treatment plan. The section to follow will explore the next step in that process; developing knowledge of treatment options.

## **DEVELOPING KNOWLEDGE OF CLINICAL OPTIONS**

### **Introduction**

In the present study women were generally guided by their surgeons with regard to their most appropriate treatment choice. When there was no clear advantage of one treatment over another (this was namely with regard to surgical options and conservative surgery versus mastectomy), or only a minimal gain (chemotherapy for women in low risk groups), the decision largely became a value judgement by the woman herself. The question of reconstruction was very much the woman’s personal choice. So how does a woman faced with the diagnosis of breast cancer get from ‘A’ to ‘B’, that is, diagnosis to treatment choice. This section will discuss how women in

this study struggled to sort out information, seek advice, and 'get in touch' with how they felt about the different options they had been given.

Codes identified under this category, and to be discussed in this section are:

- Seeking information – gaining expertise.
- Researching the literature.
- Talking with others who had encountered breast cancer.
- Discussing options with family and friends.
- 'Statistics unhelpful?'
- 'Statistics helpful?'
- Choosing not to seek out information.
- Deciphering the jargon; getting it all together.

### **Seeking information – gaining expertise**

With the diagnosis of cancer, women sought information to help them gain a wider understanding and therein develop a greater sense of control. The women appeared to have learned the 'medical jargon' regarding types of cancer, surgical procedures, and chemotherapy. Women in this study used various avenues for increasing their knowledge base. Many accessed the local public library, the local Cancer Society's in house reference library, and also Internet literature searches for specific information. GPs were often helpful as they not only had a grasp on the medical aspects of breast cancer but also had the advantage of 'knowing' their patients. Knowledge 'by authority' from other women who themselves had experienced cancer was also a very important source of information. Some women chose not to do any research preferring to listen to their clinicians and then either make their own decision, or perhaps make their decision collaboratively with their specialist.

### **Researching the literature**

Most women appeared to receive the written information provided by the Cancer Society. These were distributed to them by their surgeon, the breast cancer nurse specialist (private), the clinic nurse, or were obtained from the Cancer Society itself. A number of women went to both the Cancer Society and their local public library for further information.

Cathy was typical of a number of women who searched their local library and the Internet for more in-depth information on breast cancer:

I did get books from the library. I think I got a couple from the library and just started reading because I want information.

I'm the sort of person who likes to have information. Plus I also had a search on the Internet ... that just raised a whole lot of questions that I could ask, which was good (50-52).

A number of the women sorted out in-depth medical information. Joanne, whose husband was a health professional, related that her husband "overnight became a breast cancer specialist" (131). He had searched the Internet (notably MEDLINE, an international electronic medical database) and sent off for all current and relevant medical reports (of which there are many). As he read these he highlighted important points and gave them to Joanne ('bedtime reading'). She related how they had found that Tamoxifen was being used preventively in USA, even in node negative (lymph nodes free of any tumour cells) pre-menopausal women, which is generally not the case in New Zealand at this time owing to lack of supporting evidence. They discussed this with the medical oncologist. As Joanne was node negative he said there was no need for chemotherapy, and as she was pre-menopausal, it was not routine to use Tamoxifen as it was unlikely to offer much advantage. However, if she felt strongly about this, he would prescribe it, as there were still a lot of 'unknowns' and research was still in progress to answer such questions. Joanne related that she took it for 3 years. In the end she took herself off it, as she didn't like the side affects. She had put on weight and felt it was draining. She stated: "I actually stayed on it for 3 years. In the end I took myself off, mainly because I didn't like it ... I felt in my opinion, no medical opinion at all [laughs], I had done my bit with it" (125-127).

Most of the women appeared satisfied with the information resources available to them. The women (or their partner's) who delved into some of the more complex medical literature (readily accessed through the Internet) were challenged to interpret the often difficult issues surrounding current treatment protocols. As well as literature, women also sought information from 'first hand experts', namely women who themselves had experienced breast cancer.



### **Talking with others who had encountered breast cancer**

Talking with other women who had experienced cancer was generally regarded as another important source of 'information' and support. Often the surgeon's nurse asked women if they would like one of the Breast Cancer Support Service volunteers to contact them or women themselves knew about the service and rang the Cancer Society.

A number of women received a pre-operative visit or phone call from a Breast Cancer Support Service volunteer. Pam found her visitor excellent: "She invited my husband and I to go round and have drink with her husband and her – which I thought was lovely because here was these two men, you know" (100-102). What Pam meant was that she thought this had been wonderful support for her husband, having a male to talk to, who had been through the same thing with his wife.

Finding someone to talk with, however, was not always straightforward. Being just 33 years old, Cathy was in a minority age group for women with breast cancer. It was not so easy to meet other women of a similar age with whom she could discuss her treatment choices or concerns. Cathy said:

Well, I haven't spoken to a lot of women my age, in fact I have spoken to a women my age with children - I don't know what surgery option she chose, who had children when she was diagnosed, but I don't know what she took (118-119).

She did however meet older women with whom she talked and developed a better feel for what it was all about, the 'inside' story, as it were. Cathy's major concern was with survival and continuing to be a mother to her young child. Concern to minimize the assault on her body (and her life) however, was also an integral factor in her decision making. Later in her breast cancer 'career' Cathy had other information needs. These were in relation to the risks of pregnancy having had breast cancer. She was very grateful for the help she received from the nurse employed at the Cancer Society who did a literature search for her. Her surgeon also made arrangements for her to see an oncology gynaecologist at the hospital to discuss the 'pros and cons' of a further pregnancy.

### **Discussing options with family and friends**

Family and friends were also people with whom women discussed their treatment options as a way of helping them come to a decision. For example, Gill said that her search for knowledge and sorting out what to do came from discussing it with a number of different people:

I discussed it with, I've got four daughters, and I discussed it with friends, I've got two friends who are nurses. One of them works in oncology, and my son-in-law is an anaesthetist, so he has seen quite a bit of stuff going past him (103-108).

Depending on each woman's individual circumstances, various resources were used to help with making decisions regarding treatment. As well as their clinician's, friends, family and Breast Cancer Support Service volunteers were all avenues women accessed, and generally found helpful.

### **'Statistics unhelpful?'**

It appeared that surgeons (and oncologists) often quoted women statistical probabilities in relation to the risk of recurrence when giving them information regarding treatment options. A number of women found it hard to grasp the concept that conservative therapy can offer the same prognosis as mastectomy, with regard to the risk of local recurrence. They realistically feared that cancer cells could be left in the remaining breast, and generally (it appeared) the women found statistical information relatively unhelpful; a risk was a risk. The women feared that retaining their breast could put them at risk for metastatic disease. For example, Julie's expression was that "she didn't want any time bombs ticking away" (50). In this study, fear of recurrent disease and metastatic spread was the major reason women chose mastectomy over lumpectomy, irrespective of the statistics they were quoted either by their surgeon or oncologist, or read in the various literature.

It appeared the women struggled to relate information regarding 'statistical probability' to their own personal situation. For example, Joanne talked about the fact that her surgeon used statistics from international studies in relating information about her cancer and the surgical options from which she could choose. She said how she told him:

Look xx, all these percentages are a load of rubbish. I've already fallen into the first hole. There's always a chance you're going to be the one that falls in the next hole. These percentages are immaterial (293-299).

Louise also stated that she "didn't want to know statistics" (122). She continued:

I really didn't want to know. I wanted to know what was going to happen to me and what the results would be ex cetera. You know, some people seem to want to know everything, but I was the opposite. I preferred not to know" (123-125).

So, for some of the women, statistics seemed relatively meaningless. Basically, they assumed that they were already the 1 in 11 who had got breast cancer, so how could they hope to be the lucky in any other statistical probability? Some women, however, appeared more receptive, and found statistics helpful.

#### **'Statistics helpful?'**

Whilst obviously women struggled to interpret the 'statistical advantages' they were often either quoted or found in their research, some women impressed with their interpretation. For example Gill related her medical oncologist's explanation regarding the advantage for her of having adjuvant chemotherapy, and how she interpreted this for her own situation.

I had to make a decision but I could also have refused it [chemo] ...it would only improve my chances by 5%. The 5% percent was something like 80-85%, because I didn't understand quite what it meant... For instance, they may say, well you have a 60% chance that it doesn't spread anywhere and if you have chemo that makes it 65. ...Oh 5% isn't very much ...but I came back from that idea because the story then was, if it spreads anywhere else then its not curable anymore (139-145).

So, although difficult, statistics helped Gill come to a decision regarding adjuvant therapy; she accepted chemotherapy as she wanted that 5% advantage. Other women

couldn't recall exact statistics but had grasped that adjuvant therapy offered some survival advantage and therefore they were willing to accept it.

### **Choosing not to seek out information**

Three women (21%) spoke of actively not seeking information although they all still appeared to be well informed having acquired information in a variety of ways. The reason given for not seeking information was that it could all be quite burdensome, particularly statistical information regarding survival.

Sonya explained how the literature her GP had given her was quite distressing:

In the books, you're going to be dead in a year. So I stopped reading about it because all of these books told me I was going to die ... I'm not going to be one of these statistics. I'm going to see my grandchildren get married, and I haven't got any yet [laughs] (294-300).

Pam stated that she didn't seek out written information (although she relates that she went to the library) but sought information in other ways. She explains:

I mean I'd done lots of reading and I'm a nurse so I sort of knew – it doesn't make any difference being a nurse because when it's yourself it's a whole different story, when it's your own body ... (89-92).

One participant insisted that she was in total denial about her breast cancer and therefore had no reason to seek out information. Richelle stated that she was surrounded by quite a highly achieving academic family and left the research side to them. She related that she tried not to bother with too much information. Richelle was talking about the advantages and disadvantages of taking Tamoxifen: "Well, I haven't taken too much notice because I'm so firmly convinced if that if I don't think about these things they won't happen ... I'm mentally lazy in relation to these things" (135-140). Richelle related that denial was also her main ally in dealing with her breast cancer. She stated: "Yes, I think I was, and still am, in complete denial, really. I'm not ill – I didn't have anything happen to me. I'm fine. Just a bit different here and there" (16-18). Having had a very small tumour (detected on screening mammography) and conservative surgery, denial seemed quite a good coping mechanism to Richelle, and she was getting on with her life.

So, whilst some women were extremely active in seeking out in-depth information there were three or four women who were content with the information they received from their clinicians, and Cancer Society brochures, and didn't actively 'seek' information. The cancer diagnosis in itself was enough to deal with. However, all of the women in the present study appeared relatively well informed.

### **Deciphering the jargon; getting it all together**

In this study it was obvious from the narratives heard that the women had been explained things in a combination of lay and technical terms. It was obvious that both parties had struggled – the woman trying to grasp what it all meant for her, the physician trying to relate very difficult information and concepts about treatment in an easily understood manner. This section looks at how different women interpreted the information they received (or researched).

The women freely related the histology of their tumours, their nodal status and the reasons for the treatments they had received, or in the case of Tamoxifen, were still receiving. For example, Julie stated:

First of all they said it was a lobular carcinoma and it was just starting to move, and they wanted to take a larger piece out, and get a margin. And he said we are going to have to take a look at your lymph nodes (307-309).

Contrarily, although the women tried desperately to get a handle on all the information, often there were misunderstandings in relation to relatively key issues. For example Gill stated:

I decided to have the whole breast removed because I decided if I had my lymph nodes removed then I mightn't need radiotherapy but apparently that is not quite correct? I seem to have later on heard that is not always the case? (11-14).

Although not directly related to deciding clinical options, the following is an example of how the women could misinterpret information. Richelle appeared to believe that owing to axillary lymph node dissection her whole body had reduced

infection defense. She related how she had a rash on her leg and because of her lymph node dissection had to be careful: "Um, in fact it was only just in recent months; I had a rash on my foot, and I thought, help, I'm more exposed to infection, but I hadn't really realized that" (73-74).

The science of cancer, and the ever-evolving science related to the treatment of breast cancer contain complex knowledge and concepts. The women in this study struggled with these in trying to relate their understanding of their cancer and their treatment options. The emotional burden such a diagnosis brings was immense and ever present in their stories.

## **SUMMARY**

This chapter began by exploring how the women in this study first became aware that they had a breast cancer. Women then became involved with health professionals, notably a breast surgeon, generally a radiation or medical oncologist, or both. These specialists actively diagnosed their cancers, performed staging investigations, and presented their treatment options. Without exception, this was a period of crisis for all the women interviewed.

All women in this study had read some information on breast cancer and the possible treatment options. Most women had actively sort information, either from the local Cancer Society, the local library, or both. A number had used the Internet to gain a wider information base including MEDLINE. As well as receiving specific information from their specialists, women received information from friends and family. Other women who encountered breast cancer were important sources of 'inside information' on breast cancer and the different treatment modalities. It was interesting that some women found statistical information helpful in relation to the various options whereas others did not. Women appeared to develop a working knowledge of medical terminology, which soon became part of their own vocabulary. As they gained information from a variety of sources, women then had to decide their own personal value priorities regarding the different treatment options. This is the focus of the next chapter.



## CHAPTER SIX

### Discerning value priorities

*Personal decisions are subjective, involving a response based upon personal values, goals and desires.*

Sally Gadow (1989, p. 101).

#### INTRODUCTION

In listening to the women's narratives regarding how they came to decide their treatment options, especially when there was no clear evidence to suggest that one particular option had any clear survival advantage over another, it became obvious that it largely comes down to a matter of women deciding their personal value priorities. As well as deciding surgical options (conservative surgery versus mastectomy with or without reconstruction) women also had to decide what value they placed on gaining an often relatively small 'statistical', and only probable, survival advantage from further treatment modalities such as adjuvant chemical or hormone therapy. They therefore had to do a 'cost-benefit' analysis weighing advantages over disadvantages. With information being relatively esoteric, this was often a difficult equation. Thus, owing to the complexity of these concepts, it was also extremely important to the women in the present study that they felt they could trust that their physicians would guide them in making 'the right' (medically sound) decisions. Other helping-trusting relationships were also formed. Women talked about the support they received from the breast care nurses, and the support they received from Breast Cancer Support Service volunteer visitors.

'Discerning value priorities' is the central category that will be discussed in this chapter. The following sub-categories relating to this were identified:

- Maximizing survival – containing the crisis.
- Situating breast cancer within the context of ones life.
- Soliciting expert guidance.

## **MAXIMIZING THE CHANCE OF SURVIVAL - CONTAINING THE CRISIS**

### **Introduction**

In the present study it appeared that survival ranked as the women's highest value priority. Alongside this decision was the wish to avoid disfigurement, and, if possible, protracted treatment therapies. Of the six women who chose mastectomy in preference to conservative surgery, three underwent reconstruction. Conservative surgery was regarded as less invasive, and preferable to mastectomy, if survival was deemed equal. Two of the five women in this study who were offered the choice of conservative surgery or mastectomy, and chose the former, stated that for them mastectomy would have been a totally unacceptable option. For some, reconstruction after mastectomy was not regarded as an immediate priority but most women preferred to keep their options open. Others were grateful to be offered immediate reconstruction stating that this helped reduce the grief associated with losing their breast(s). Women generally viewed chemical, hormone or radiation therapy as necessary rather than optional and all women accepted treatment if offered.

Three codes relating to this category were identified:

- Surviving the disease priority: preserving 'body wholeness' integral.
- Defying disembodiment.
- Accepting adjuvant therapy.

### **Surviving the disease priority: preserving 'body wholeness' integral**

Although initially women related their shock in hearing their cancer diagnosis and their fears regarding what this might mean for them, they then went on to talk about what the different treatment options meant to them personally. This section will discuss how although long term survival was priority, preserving 'body wholeness', or protecting 'the self' was also integral to women's decision making.

It is not too difficult to understand why survival might be priority when one is just 33 years old, and has an eighteen-month-old son. However, it is equally understandable that preserving one's body image might also be extremely important. Cathy (who was this person) stated:

Well obviously cancer creates a lot of fear and also knowing some people that have been very sick and have died ... probably my biggest concern was I want to be here to see my son grow up, thank you very much (44-46).

Although body image was important to Cathy, she said if conservative surgery had put her more at risk of recurrent disease, then she would have gone with mastectomy. However, her surgeon was confident that a wide local excision would give her adequate local clearance. Although Cathy didn't have nodal involvement she was advised that her tumour was 'aggressive', and so agreed to undergo both radiotherapy and chemotherapy after her breast resection. She related that what she really wanted was minimum treatment for maximum gain. She stated: "One thing that I considered with mastectomy was that I probably would want reconstruction but that would mean two lots of surgery which had no appeal to me at all." (72-74). Being a full-time mother to their young child, one of Cathy's major concerns was not to let the cancer disrupt their lives more than was necessary, whilst still not compromising her treatment. As they lived close to the hospital, visits for radiotherapy and chemotherapy were not such a major problem as it would have been if they had lived further away. Cathy related: "I wanted to get on with other things – that was my forward focus" (72).

In an effort to reduce the risk of recurrence, and related to the histology of her tumour, Joanne chose bilateral mastectomy. The histology of her tumour (multi-focal lobular) meant that there she was at increased risk of recurrence in both the remaining breast tissue if she chose to have conservative surgery, and her contra-lateral breast. Joanne stated:

I forget what the percentages were, I actually decided to have a bilateral, I just wanted to get everything out of the way, just get rid of everything. So I made the decision to have a bilateral ... and if I'm having bilateral, I said, I want reconstruction (83-86).

Reconstruction was chosen in the quest to 'preserve body wholeness'. Joanne stated: "I just wanted to put myself back to where I was. I didn't ever want to feel that I was not as I was." (152-153). Thus a compromise was reached. She related that in her 'breast cancer support network' (a personal group of her friends who had all

encountered breast cancer), although a couple of them had undergone reconstruction, others were happy with their external prosthesis: "It is, it's a very personal thing. They're quite happy with their prosthesis, which really are revolting things" (321-327).

The desire to maximize survival was universal. Comments such as follow were the norm. Louise stated:

At that stage I would have done anything just to get rid of it [the cancer] (30). It's not the fear of the treatment or losing your breast, it's finding out that instead of death being so many years down there, ... it's suddenly here – right in front of you (408-411).

'Getting rid of the cancer' and 'being done with it'; these were common statements from the women who chose mastectomy over conservative surgery. Reconstruction was viewed as a way of reducing the impact or loss. Having undergone mastectomy and reconstruction Julie said:

I think the fact of the matter is you don't feel, you don't have that sense of loss, even when you wake up with a tissue expander, for goodness sake ... it does give you a much better, sought of a feeling about what's going on (60-62).

Julie said her decision to have reconstruction was not so much about keeping her breast as retaining her symmetry and balance. She said that having reconstruction meant she didn't have the constant reminder of her disease every time she looked in the mirror. She didn't have to look at a flat chest wall or concern herself about wearing a prosthesis:

I've spoken to woman who have had full mastectomy's, and you know, had the mastectomy and no reconstruction, and their comment to me is that every time they get dressed they are reminded of it (184-186).

As well as trying to preserve a sense of 'body wholeness' reconstruction was viewed as desirable for other reasons. Although Pam rejected the idea of reconstruction initially saying "I had a husband who loved me for what I was, and, it didn't bother him" (145-147) she still found the mastectomy wound distressing, and the prosthesis extremely uncomfortable:

I actually couldn't cope with getting undressed or anything in front of him, well forever, even now. I turn my back towards him (146- 147).

She continued:

You know it's a dreadful thing to lose a breast. It's a threat to your femininity, and after three years I decided, mainly because of this prosthesis that I was wearing, it was just so uncomfortable and sweaty ... I just wasn't coping with it so I had a saline implant put in (147-153).

The underlying message was repeatedly that the women were primarily concerned to maximize survival; coping with altered body image was secondary but still very important, and more so for some than others. For example, Alaina stated how she only ever wanted a mastectomy; "I wanted it gone" (138). The surgeon suggested she go home and talk about it with her husband and she said that her husband would support whatever decision she made. Alaina related this to the fact she had such a prolonged period leading up to a diagnosis (this was discussed in chapter 5). Survival was Alaina's primary concern.

From the above, which were fairly typical of most women's responses, it can be seen that survival, at least initially, was the women's main concern. Concern for retaining body wholeness and protecting body image, were, however, integral determinants in this equation. Women talked about this more in the latter parts of the interviews.

### **Defying disembodiment**

Women also feared the threat of disfigurement, or more than that, the threat of disembodiment. It was not only the threat of losing a body part, losing a breast was a threat to their symmetry and their feeling of 'womanly' wholeness, or, in existentialist terms: "To have a body is to be a body" (Macquarrie, 1972, p.75). Again, some women gave this more priority than others (or at least admitted to it).

Describing how she defied 'disembodiment' Richelle related that her value priority was "not to be chopped about" (83). This rather terse expression (which she repeated a number of times) related deeply felt emotions. She explained: "You see I have had a hysterectomy, and I did lose an ovary when I was in my thirties, late twenties. And, you know we're given the skin to contain us and I'd rather it wasn't

interfered with" (89-91). When asked what her image was of mastectomy Richelle replied:

I suppose a deforming thing. But it's the idea of being chopped about I don't like, partly because having had *more* of a problem, but then it's mine. You know, and feeding the children and all that sought of thing. Yes, intact (147-152).

From this it may be seen that breasts embody womanliness and nurturance. Richelle related how she was always viewed as a motherly sought of person. Over the years she had been very involved in the Arts. She explained:

I've played so many mothers (in the theatre) and people say I am this sought of 'earth mother', and people would always, even when I was nineteen - they'd come and tell me all their troubles. So large bosoms is part of that [laughs] (207-209).

She also related that she hoped not to live alone forever and the importance of her breasts in relation to confidence about her womanliness and sexuality.

I suppose too, to be as normal as possible because I don't expect to always live alone, and as far as intimacy with the opposite sex goes, I would rather be entire (213-215).

The fear of mutilation associated with mastectomy, was more fearsome to some than others. Denise feared mutilation: "I would have been a totally different person if I had had to have a breast removed. There's no way. That would have made a whole different ball game" (245-7).

Women repeatedly related that surviving was their major concern, however, retaining their sense of wholeness was also priority, although often sacrificed to advantage the former. The interplay of these two factors continues in the next section and throughout this thesis.



### **Accepting adjuvant therapies**

The women participants saw adjuvant therapy as a means of decreasing their risk of recurrent disease and increasing their chance of survival. The concept of 'statistical advantage' to be gained by chemical or hormone therapy is quite complex (as discussed in chapter two). Women were inclined to trust their physicians. All women interviewed appeared relatively resigned to putting up with side-effects of adjuvant treatment if it increased their chance of survival. There are three predominant forms of adjuvant therapy: hormone (primarily Tamoxifen), chemical (chemotherapy) and radiation (radiotherapy). Details of these were discussed in chapter two. The women related how they felt about the choice of adjuvant therapy. The sub-codes depicting these are 'understanding it', 'getting on with it', and 'putting up with it'. These will be discussed in relation to each form of adjuvant treatment:

- Hormone therapy.
- Chemotherapy.
- Radiotherapy.

### ***Hormone therapy***

Most of the women didn't consider they had a choice in relation to hormone therapy. If their consultant had advised it, then they took it. Women described a variety of symptoms related to Tamoxifen. 'Hot flushes' were universal and for some women these were severe. Others reported problems were general itchiness, weight gain and mood changes, depression or both. Although women varied in the severity of side-effects they reported they still felt this was a relatively small price to pay if it offered them some protection from disease recurrence. They talked about 'putting up with it', and they did.

'Putting up with it' was the price one paid to gain a small insurance against the risk of recurrence. Margaret related it this way:

Yes, I have [had a choice] but I haven't really had a choice in lot's of ways because I think well, Mr Xx said I should take it and I'm prepared to listen to that. I also had to weigh it up, should I not take it and I get breast cancer in the other breast, and then I've got to face my family and say, it was all because I wouldn't put up with

a few night sweats, well, this is the thing. This is what I personally have to weigh up (300-304).

As stated, Tamoxifen caused most women to have hot-flushes, either recurrent if they were post-menopausal, or as part of an induced menopause if they were pre-menopausal. These were often quite severe and caused considerable discomfort. 'Putting up with it' could be tiresome. All women had looked at other medicinals that might help, for example, herbal remedies. A number of women had been prescribed Dixarit, a drug that can reduce symptoms such as flushing and sweating. Most women, however, were prepared to take Tamoxifen for the 3-5 years or as their physician had advised. There was a reluctance to complain.

### *Chemotherapy*

Chapter two related how the advantage to be gained from chemotherapy is based on large cohort international trials (prospective, double-blind controlled clinical trials). Advantages to be gained from chemotherapy are thus generally related in percentages and degrees of statistical probability. This can be a difficult concept to grasp. Generally women accepted their oncologists recommendation.

Chapter five related two women's reactions to hearing statistical probabilities in relation to their various treatments options. It was related how Gill had struggled with the concept of a five percent advantage to be gained if she accepted chemotherapy. She appeared to rationalize that 'a stitch in time saves nine', and therefore accepted chemotherapy to achieve that five percent advantage. Gill's narrative highlighted the complexity of the subject and the difficulties for both the physician and patient. The physician must endeavour to give an honest overview of the advantages and disadvantages whilst the women, who will have to endure the treatment (and hopefully gain the advantage), has to make sense of it all.

Women more at risk for metastatic disease, proportionally, are set to gain a greater 'statistical advantage' from having chemotherapy. The oncologist will therefore encourage these women to accept treatment. Women 'more at risk' will also often receive a harsher chemotherapy regime. Alaina was one of these:

*Did xx Xx – did he give you the option of chemotherapy?* [Researcher]

No. Well, he did. He [laughs], very slight. He said, almost daringly “Don’t turn this down”. He said “you must have chemotherapy to follow this up, because of the lymph glands. You’ve got to follow it up – you must have chemotherapy”, and I said, “fine, yes, when do we start?” (234-239).

Chemotherapy was not an easy choice. Accepting it was one thing, surviving it another. Alaina talked about her chemotherapy.

I lost my hair. I was very very sick. I was just so sick. They gave me lot’s of anti-nausea and it did help. I think it was because the dose was quite strong (255) ... Ooh, it’s a wretched thing (261).

Alaina related that “You’re feeling so ill, and you actually feel as though you’re dying” (410). She said how she had to keep reminding herself it was the chemotherapy and not the cancer that was making her feel this way.

Others had to consider the information they were given and decide their value priorities. Cathy accepted a course of chemotherapy, as advised. Her lymph nodes were negative but she was told that she had an aggressiveness tumour. “I didn’t want to have chemotherapy but of course you don’t know that [whether you require it] until you’ve had surgery but as it was I guess I coped.” (64-65). She talked about why she made the decision to accept the chemotherapy:

It was a very aggressive tumour ... I guess it was the cautious approach. It was a bit hard to sell me on that one ... I had in my mind, the surgery, and all. I would have to have was six weeks of radiotherapy. So I guess when they said we’re recommending chemo it came as quite a shock ... So I had to go away and think about the chemo really. Probably only for a day though (160-169).

Cathy talked about the fact that she would never have forgiven herself if she had refused chemotherapy and the tumour had recurred.

The risk of something coming later because I didn’t have the chemo – I’d be kicking myself ... I want to be around for as long as possible this is something I have to do, a chance that I will take. Because I mean my understanding was they couldn’t be certain whether or not the chemo

was going to make any difference or not (188-193).

Chemotherapy took its toll. Cathy related that it took her a year to really get over the chemo:

I didn't feel really good until about a year later. But I mean I was chasing around after a two to three year old all the time and while he was a very settled child, he slept in the afternoons and at night, I didn't sit back and do nothing (310-312) ... I was exhausted (318).

As related above, women were prepared to pay the price, put up with side affects, struggle to survive the ordeal – anything to gain a survival advantage, be it a modest one.

### *Radiotherapy*

The women choosing conservative surgery readily accepted that radiotherapy was 'the price you paid' to for this option, or in the case of mastectomy, was the added protection against local recurrence. They appeared to tolerate radiotherapy without too much difficulty. Most reported tiredness and soreness of their chest wall by the time the treatment ended.

The women talked about their radiation therapy relatively matter-of-factly. It was a matter of 'putting up with it', and, 'getting on with it' along with trying to keep life as normal as possible. Most continued to work taking time out to go in for their treatment. Denise talked about her treatment:

I started radiotherapy about three or four weeks later, and that was a drag. The people were lovely. I didn't have to wait, but it was a drag going up to the hospital everyday. I was working. I kept working (106-108).

Mary also continued working throughout her treatment:

I just travelled from work and then went back to work. They said if I didn't feel well after it just to let them know. But, I never had too much of a hassle with that ... work were really supportive ... You don't feel guilty. I probably went back to work a bit early (457-461).

As participants reported their treatment decisions retrospectively, it often got caught up with memories of the treatment itself. It was a lot to juggle; coping with the fact of cancer and its treatment whilst struggling to continue with life's routines and daily demands. Once they understood what it was all about, it was a matter of 'putting up with it' and 'getting on with it'.

### **Summary**

Although maximizing survival appeared to be the women's greatest concern, protecting one's sense of self and body wholeness was an integral and inseparable determinant in women's decision making. It appeared, however, that most women were prepared to sacrifice body image to achieve a survival advantage. For some, reconstruction offered a compromise, a chance to maintain a breast form. Others were not quite so sure about reconstruction and needed more time to decide, perhaps to grieve their loss, and come to terms with their situation and their altered bodies. Reconstruction could never replace the breast loss; the self as known.

The women demonstrated similar values in relation to accepting adjuvant therapy. These treatments often meant protracted courses of radiation, hormone, chemotherapy, or all three. If accepting these modalities offered even a small survival advantage (often at considerable cost to quality of life) then the participants accepted these treatments. They 'got on with it'. Treatments were accepted with a view to the future.

It is somewhat artificial to separate out the different factors that affected the women's treatment decisions. As well as trying to cope with a cancer diagnosis and treatment decisions, they were also trying to keep their lives together – to 'contain the crisis'. The next section will discuss how women's life situations affected their choices.

## **SITUATING BREAST CANCER WITHIN THE CONTEXT OF ONE'S LIFE**

### **Introduction**

Women in the present study invariably related their personal life situation, their relationships with others, along with aspects of their past (or their families) life history as they retrospectively considered how they came to decide their treatment options. The concept of 'timing' was also important. Time is a relative and temporal phenomenon. Individual women felt they needed more or less time to come to terms with the fact of cancer and to make their treatment decisions.

This section serves to relate the uniqueness of individual women and the various contextual determinants that influenced their decisions. It also demonstrates how clinicians or health professionals can only know the surface of other people's lives, and the depth of issues and concerns which affect their personal choices. Many factors co-existed as women struggled with their decisions. Importantly they made decisions that they felt they could live with. These were connected with their past, present and their hopes for the future.

The contextual determinants to be discussed in this section are:

- Reflecting on one's personal life situation: past, present and projected future.
- Living in the community with others.
- Timing: Too little – too much – rarely right.

These determinants formed the background of women's decision making.

### **Reflecting on one's personal life situation: past, present and projected future**

Women encounter breast cancer across a wide age range. The youngest participant in this study was 33 years. The upper age group was 65 years. The younger participants generally had a different life situation to older women. However, this did not alter the crisis. Whatever age the women were, breast cancer was a nasty intrusion into their lives.

At times of crisis past events regain their significance; the present is re-defined and the future re-assessed. For example, Cathy's past included losing her mother 13 years earlier when she was 20 years old. In 'the present' she was a full-time wife



and mother. In her 'future before cancer' she had hoped to have another child but this was now less tangible. She related that because of her son, she had to survive, and whatever treatment she chose, it had to (a) maximize her chance of survival and (b) be minimally disruptive to her busy life. These were her central value priorities. She talked about how having a toddler helped her cope with it all; the fact of cancer, the threat to her mortality, and the treatment:

I think if I hadn't had xx (son) it would have been much more difficult. Like, you know, you can't lie in bed and wallow in self pity when you've got a toddler going: "Breakfast, breakfast, TV, take me out, where are my clothes" [Laughing] It was a blessing really – full on (140–147).

Cathy and her husband were trying for another child when she found she had breast cancer. Because of her experience of her own mother dying, along with the fear that a further pregnancy could stimulate latent cancer cells, a further pregnancy required careful weighing. So in many ways Cathy was grieving for the child she might never be able to have. Cancer left her with a sense of uncertainty and vulnerability in the present and had robbed her of her future as planned.

Family history was also significant to Cathy. It would appear her grandmother might have died of metastatic breast cancer when she was about 50 years old, although the family history was a little unclear (cancer was not much spoken of in those days). Cathy stated that she worried about the affect her having cancer had had on her father as they had endured a number of deaths and illnesses in close family members in recent years (mother and brother). Not only was Cathy a wife and mother, she was also a daughter and had been a sister.

The women's past history and experiences had significant bearing on their decisions. Mastectomy being recommended to ensure tumour clearance, Sonya made an instant decision regarding whether or not to have reconstruction. Her father had been a double amputee and had to wear prosthetic limbs. She associated breast prosthesis with her fathers daily routine of having to apply his artificial limbs: "My father was a double amputee and he had to put his legs on every morning and I thought I would have to put my breast on every morning" (47-48). She also related her experience of

phantom pain in her nipples with her father's limb phantom pain: "I get these pains in my nipple, and it isn't there, and that's what my father used to have" (419-421).

Unsurprisingly, the women's present life situations had a major affect on their decisions. On a more humorous level, Sonya related how she explained her choice to have reconstruction to her work colleagues. They were all in Real Estate: "I said well it's no use having a vacant section, I may as well have a house on it. My breast, oh well, I won't have a vacant section, I'll have a house" (372-376).

Family history also affected Catherine's treatment choice. When Catherine was told she had cancer and asked, in the very next sentence what she would like, either the lump only removed or mastectomy, she immediately had her sister in mind, who had previously had a mastectomy:

My sister had had a breast off and I didn't really want to have my breast off so I thought, I suppose the vanity of it more than anything else, just all of a sudden having a breast and then having nothing (45-49).

Gill's fairly recent past (her husband dying five years earlier of cancer) became part of her experience. She related how, upon learning she had cancer, she had gone straight to the Cancer Society to obtain further information. She qualified this by saying:

I must add that I have lost my husband because of cancer ...  
I've been through it before and maybe that helps a little I don't know.  
I had seen the oncology people before ... My husband died 5 years ago so when I had my first breast removed that was three years.  
Yeah, you could say I had a pretty rough 5 years (117-123).

Women's experience of others that had encountered breast cancer was also influential in their decision making. For example, Aliana stated that although she had never been overly concerned with her body image, she knew some women were quite different. One of her very dear friends had developed breast cancer and was totally devastated at the prospect of losing a breast. She had readily accepted reconstruction. Alaina said that her friend would never have coped with the

disfiguration of a mastectomy scar. She then related that this woman was now dying of metastatic breast cancer, seven or eight years after her original surgery. It was because of this friend's experience that Alaina said she would never consider reconstruction. She believed that it was because of the reconstruction that the recurrence went undetected.

It can be seen from this section how women's past, present, and projected future all had bearing on the decisions they made. Women's life situations were also entwined with the relationships they had with other people. The following section discusses how this 'living in relationship' was a contextual determinant in women's decision making.

### **Living in the community with others**

This section considers how women's relationships or 'relatedness' with others affected their decisions and choices. As stated above, these were considered to have been contextual determinants as opposed to substantive codes in women's decision making.

It appeared that in deciding treatment options for breast cancer women either seek out 'others' advice, or try to avoid it altogether. There is always the concern as to how loved ones, especially husbands, children, and sometimes parents, will react to the news of cancer. Dealing with others emotions can be as difficult as dealing with one's own.

Women had to make decisions regarding whether to share the news of their breast cancer, or keep it to themselves. Julie decided it was best to be open about her cancer. She related the experience of telling her employee: "Ooh, my boss was more scared about it than I was. I mean she went into an absolute flap. She has a daughter who's a doctor, and, um, she really got quite upset about it all" (209-211). She also related: "You've got to be careful not to buy into everybody else's concerns and fears. You've got to really think, how can I give myself the best opportunity to survive and get the best out of life" (170-72).

Sometimes a conscious decision was made not to involve family in decision making. For example, Julie wanted her decisions to be just that, her own. She also didn't wish to burden others.

I don't know whether it's being single, and well I didn't involve my mother or my sister in my decision what have you. I made the decisions independently. I mean I discussed it with them and they were great. They sought of took the attitude, well, whatever is best for you (340-34).

Others related the anguish of the affect their breast cancer had on their families and loved ones. Joanne related: "I think it is really more your family and your loved ones that are the most. My parents were just devastated. My children were devastated. Xx (husband) was devastated" (166-167). Women with young families were terrified of dying and leaving their children motherless. Those who had daughters worried that they may have passed on an inherited trait for breast cancer. Hearing of someone they knew dying of breast cancer also had a huge impact.

Margaret related how the worst thing for her was telling her father about the breast cancer. Her father had insisted she have the mammogram which revealed her breast cancer because his (second) wife died of breast cancer:

The worst thing was going out and telling my father. Because at that stage you never know whether you're going to make it or not because I mean mum at fifty-five and now me at fifty-five. And also my husband's mother died years ago of breast cancer too (141-143).

Sadly Margaret's father died not long after her cancer was diagnosed. She said: "I often think he swapped his life for mine" (55).

Human beings are a gregarious species. We live in community with others. Women in particular experience a strong gender characterization towards an on-going relationship with others because of a care-orientated perspective in their gender related roles (Gilligan, 1982). With regard to women's decision making in breast cancer, this care-orientation could be identified. This section serves to illustrate (giving just a few examples) how the women's decision making, in this study, was

contingent on their personal life histories, situation, relationships with others and hopes for the future.

**Timing: too little – too much – rarely right**

Throughout the interviews there was the issue of timing. The women needed ‘time’ to adjust to the crisis, to deal with their own and others grief, and time to make decisions regarding their preferred treatment options. However, the length of desirable ‘time’ was quite variable. Time is a ‘relative’ phenomenon and hence the reason it has been included in this section as a ‘contextual determinant’ in the women’s decision making. It resided as a background phenomenon throughout the study. This section discusses the variance in ‘timing’ women found satisfactory or unsatisfactory. It also discusses the relativity of timing in relation to reconstruction.

It would appear that those who were given ‘more time’ from diagnosis to definitive treatment (for example, two to six weeks) in retrospect found this very difficult. Others, who had limited time (a week), felt in retrospect, they would have preferred more time. Surgeon availability influenced timing for Sonya who was deciding between mastectomy alone and mastectomy with reconstruction. Her surgeon was going overseas to a conference for three weeks. He was prepared to do a mastectomy prior to leaving, but if she wanted to have reconstruction, then he would defer the operation until his return so that he would be able to supervise the post-operative period. Alternatively, she could have mastectomy and delayed reconstruction. Sonya decided to wait so as to have the one stage procedure. Although the surgeon reassured her this would not put her at risk of tumour spread (3 weeks was insignificant in relation to cell growth and so forth) she found this an extremely stressful waiting time:

So I waited but it did make a difference in relation to the agony and fear and worry that you had and until they operate they don’t know how far its spread. So you have all these things in your mind (93-98).

Contrarily, other women felt rushed, overwhelmed with the speed with which events happened. Joanne related:

I sought of had this pressure that I had to have the operation straight away ... I’m sure I could have had another week or two weeks to think

about it...I would have liked that little bit more space (91-95).

*Timing relative to undergoing reconstruction*

Timing was also an important factor when considering the option of reconstruction. For some women it was an option they definitely wanted, and therefore decided to have it done straight away, either to save another operation, because that was what they wanted, or both. Others wanted to deal with one thing at a time. They would wait and see how they coped with their mastectomy and may or may not decide to have reconstruction at a later date. Things, however, were not always straightforward.

Timing was complicated for Pam owing to the fact that she had elected to have conservative surgery and was then advised she needed a mastectomy. Pam stated:

I was totally disinterested in it [reconstruction] because I said I just wanted to get rid of the cancer and I didn't really mind what I look like. I just could not cope with anymore surgery (31-133).

Pam said at first she wouldn't even consider reconstruction but how, after a time, and finding that she "hated the prosthesis" (461) and thought her mastectomy wound "hideous ... devastating, and ghastly" (582, 585) she decided to have reconstruction. Although this relieved the need to wear an external prosthesis, Pam was not overly impressed with her reconstructed breasts which she described as "these great big things sticking out as hard as" (449-450).

Margaret related that she didn't have much time to think about the fact that she had a cancer or about the eminent surgery: "I never really had a lot of time to think about it – I think sometimes people do but, you know, just that short time and I was busy up and down to the hospital every day for these tests" (148-150). She related: "I don't think I had time to, time to grieve" (74). Three years after her initial operation, Margaret underwent reconstruction. She commented somewhat humorously:

I probably would have [undergone reconstruction] if I'd had more time to think about it ... I guess it's very individual. Like some people have their teeth out and they want them back in the same day. But I do think if I'd had more time to think about it [reconstruction] (607-614).



Time is a relative phenomenon. Different women required different amounts of time to make their decisions. Time is also relative to other variables. For example, the amount of time women spent in discussion with their physicians relative to the significance of the decisions they were being asked to make.

### **Summary**

The women's life stories and present life situations, as well as their goals and aspirations for the future (and their fear of not having a future) were all entwined with their personal value priorities regarding their treatment decisions. They not only considered how their decisions would affect them personally, but also how their partners and or families would be affected by their decisions. The following section relates the importance women placed in the communication and relationship they had with their various clinicians.

## **SOLICITING EXPERT GUIDANCE**

### **Introduction**

This section will relate how it was of critical importance to all participants in this study that they felt they could trust their clinicians to advocate in their best interests. They needed to be able to trust in their competence and skill, and also see them as a "trusting ally" (Schain, 1990, p. 919) to share in their fight against cancer. Initially women solicited assessment from their primary physician or GP who then referred them on to a general or specialist breast surgeon. From this point on the women often met with radiation and medical oncologists and if reconstruction was a consideration, a plastic (reconstructive) surgeon. Along the way they sometimes received help and guidance from breast care and oncology nurses. Other 'experts' were the women who had gone before them, women who themselves had experienced breast cancer. These women were often encountered informally or formally via the Breast Cancer Support Service network. Codes to be discussed in this section are:

- Seeking expert advice.
- Developing helping-trusting relationships with other 'experts'.

### **Seeking expert advice**

This section will discuss how women solicited advice from their doctors (GPs), their specialist surgeons and oncology physicians. As well as GPs referring women to specialist surgeons, surgeons often suggested to women to make an appointment with their GP to discuss their treatment options. This appeared to be based on an awareness that (a) GPs 'know' their patients because of a longer association with them and (b) they are often in a position to spend more time with women, and in an on-going way. Also, GPs generally have a good understanding of the issues involved.

Julie related that she made an appointment with her GP so as to discuss her treatment options. She said he advised her to 'go with her gut feeling'. He also related the view, that owing to the size of her tumour, her breast could end up quite distorted by the time she had undergone surgery and radiation, if she chose conservative surgery. She found it helpful to discuss her options with someone informed, someone with knowledge and wisdom that she could trust. Her GP recommended a specific book that Julie found very informative and which helped her reach her decision. She decided to have mastectomy and tissue expander reconstruction. She remained very positive and pleased with her decision. Julie said: "I think that basically I was being guided but nobody actually told me that I had to do this or that, which is good" (153-154). She joked about the relationship she developed with her surgeon:

He asked me, on one or two occasions, "how did you find that out?" And I said, "I read it", it was sought of one of those funny sought of situations where it's like, "I've read this book" (312-317).

Other participants also talked about discussing their treatment options with their GPs and they too found this to be helpful.

The women were confident that their clinicians would advocate in their best interest. Julie related: "You got the sense, if you made a silly decision, they would give you guidance" (325). She trusted that her breast specialist would tell her if any decisions she made were medically unsound: "The surgeon was basically open. And like, I know he would have given me guidance, had he thought it was inappropriate" (408-410).

The women also talked about 'intuiting' what they believed their surgeon thought was the best option by the way they phrased the choices. Louise related:

They don't say you've got to have it done but as far as I was concerned I didn't really think I had a whole lot of choices ... either you went the whole way and relied on their expertise ... you're feeling so vulnerable (57-60).

As stated in chapter five, women were quite sympathetic to their clinician's predicament, and were forgiving if at times they were not quite as perceptive to individual women's emotional needs. This trust is reflected in the following two statements. Pam stated; "Like he sought of said to me – what would you like and I said to him, well I'm in your hands" (45). And Mary related; "I think you sought of leave it in the specialist hands, so you probably have extreme sought of faith in specialists" (421-422).

Although the women found decision making difficult, they believed it was important that they participate in their treatment decisions. They also appreciated guidance in these decisions, when it got too tough. For example, Mary related: "I just went along with him really because ... I think, you develop that faith in a person that they understand what they're talking about" (124-125). She concluded: "His advice in the end probably just made me go ahead. I felt confident that he was right in what he said" (545-46). Some choices they wanted to be actively involved with, others less so. As well as making choices, women then had to work at committing themselves to those choices.

Humour often appeared to remove the distance between the 'expert physician' and 'dependent patient'. For instance, although this example was post-operatively, and unrelated to decision making, it does illustrate the importance women placed on developing a congenial relationship with their clinicians. Margaret related a particular incident:

And that's what I liked about him. He told you that if you sat there and felt sorry for yourself you were going to make it worse. And he said I want you to keep doing this [demonstrating the exercises

he wanted her to do – hands on shoulder moving arms up and down] and I burst out laughing because he looked so ridiculous, like a blimin' chicken. But I did, I did the exercises every day and I had no problem (384-388).

In summary, the doctor-patient relationship in the context of the breast cancer experience is extremely important, and probably never an easy one. Surgeons meeting women often for the first time, are faced with telling these women that they have cancer and that there are no assurances of cure. Whereas once it was the physician who was responsible for making all the decisions, it is now (or should be, and was in this study) a collaborative process. The clinician has the responsibility for being informed about the most up-to-date information on breast cancer; the training, clinical skill and competence to treat the disease. The woman must be the expert on how she wishes to deal with the disease and what treatment option is most congruent with her person, and personal life situation. Hopefully the two can come together.

#### **Developing helping-trusting relationships with other 'experts'**

The role of breast care nurse is relatively new in the public sector. Only one participant meet this nurse pre-operatively, but a number of the women received support from the private sector nurse. Most women also had contact with a Breast Cancer Support Service volunteer, but this was generally in the post-operative period.

The 'public sector' breast care nurse had visited Catherine at home pre and post-operatively. Catherine related that she didn't know how she would have coped without her gentle low-key support. She said how she visited the day after her initial consultation with the surgeon and went over everything the consultant had discussed clarifying things she had not quite grasped. She found this to be most helpful. This nurse then visited every week. Catherine said that one of the most important things was that "She gave me encouragement" (84). Women in the private sector said the surgeon's nurse had spent time explaining and organising things for them and this was greatly appreciated.

A number of participants stated that they found the Breast Cancer Support Service visitor helpful. Just one woman was displeased with her visitor. Generally these women offered support and encouragement and resisted being drawn into helping women decide their treatment options.

Trust and confidence in their clinicians' knowledge and competence was extremely important to all women in the present study. Concepts relating to breast cancer can be (or are) complex and it was important to women that they felt their physicians would guide them in making these decisions. Women also appreciated the support and 'experiential knowledge' from others who themselves had encountered breast cancer, although this was not universal.

## **SUMMARY**

This chapter has sought to expose the more complex aspects of human existence including women's personal value priorities which are related to their life situations (past, present and projected future) along with their inter-relationships and dependencies. It also discussed the temporal, or relative, nature of time. The codes identified were deeply woven into the narratives women related in describing their experiences and how they reached their treatment decisions. In making their decisions, women considered how these choices would affect both themselves and others, particularly those near and dear to them. With regard to surgical options, they also considered how treatment would alter 'the self' as known. To do this they had to project how they would be in the future; how they would live with the choices they had made.

## **CHAPTER SEVEN**

### **Reaching a point of salience and commitment to choice**

*The very project of a freedom in general is a choice which implies  
the anticipation and acceptance of some kind of resistance...*

Jean Paul Sartre (1969, p. 507).

#### **INTRODUCTION**

Chapter six identified the influencing factors and contextual determinants that affected women's decision making with regard to deciding treatment options in the present study. This chapter will look more specifically at the salience of those decisions, and the women's commitment to their choices. It will discuss the question of choice itself. Did the women want to participate in deciding their treatment plan? What about when things didn't go to plan?

This chapter also relates how inevitably there is always paradox inherent in choice; for every option there are both positives and negatives. For some of the women deciding treatment options for breast cancer it appeared that even though they were given a choice, one option appeared more salient, especially if they wished to avoid the need for further surgery, or the risk of recurrent disease. For example, it was often tentative whether conservative surgery would be successful; further surgery may be required if excision was incomplete on histiological examination. In the case of mastectomy, reconstruction was not always considered a feasible option clinically. Achieving a satisfactory cosmetic outcome, or wound healing (particularly if the women required radiotherapy to the chest wall) could present a problem. Women were not necessarily told that they couldn't have either of these options but advised that they may not get a very satisfactory result, and may require further surgery.

The main categories to be discussed in this chapter are:

- Making decisions – taking the plunge.
- Revealing the paradoxical nature of choice.

Codes related to these categories will be introduced at the beginning of each section.



## **MAKING DECISIONS – TAKING THE PLUNGE**

Chapters five and six related that a number of the women interviewed appeared to decide the surgical treatment they wanted almost instantaneously. They were desperate to get rid of the cancer, even if their clinicians reassured them that there was no great urgency about this. However, on deeper analysis, it was found that the ‘instant deciders’ had engaged in a considerable degree of ‘pre-reflective’ thought regarding which treatment they might prefer. All women found the pre-treatment period extremely stressful. The knowledge that their breast harboured a life threatening disease, and the uncertainty regarding their prognosis, was a considerable burden. A number of women said they ‘just wanted rid’ of the cancer.

As discussed in chapter six, it is obvious that past events in one’s life, our family history, and our interactions with others (how and where we are socialised) all invariably influence how new situations are approached. This ‘life fabric’ appears to pre-ordain how people react to new situations. For example, some participants related that they made up their minds regarding what surgical option they wanted instantaneously. It was as if they had already considered the options, or were quite clear about their value priorities. The following sections will look at the women who appeared, on the surface to be relatively instant deciders. It will consider how ‘pre-reflective’ thinking supported their decisions. It also considers the situation ‘when things don’t go as hoped’ (‘fielding the knocks’) and further decisions have to be made – values re-prioritized. The codes depicting these concepts are:

- Just ‘wanting rid’.
- Instantly deciding.
- Subconscious decision making.
- Protecting body image.
- Fielding the knocks.

### **Just 'wanting rid'**

The thought of having a cancer in their breast, a life threatening disease, was almost intolerable for some of the women. Universally they just 'wanted rid' of the cancer or at least a definitive treatment plan. Unfortunately, this did not necessarily mean they had come to terms with their disease, or would escape the grieving process.

Owing to a prolonged pre-diagnostic phase, Alaina was relieved to finally have a diagnosis and now just wanted "to get rid of it" (411). It appeared she had done considerable thinking about "What if?" her lump was a cancer. She appeared to already know her priorities regarding the surgical option she would prefer should cancer be confirmed. Alaina related:

I went to see Doctor Xx in his rooms and he said, you know, the lump was reasonably big - I could have a lumpectomy but ... It was reasonably big and sort of centre ... or I could have a mastectomy. It was up to me to make up my mind and I said "I'll have a mastectomy" right then and there (128-133).

It was almost a year since Alaina's first concerns something was not right with her health. She now just wanted rid of the cancer, and rid as soon as possible. It would almost be a relief.

Other women stated that they just 'wanted rid' of the cancer; this was their main priority. Louise made the following statement:

Personally, the women I've spoken to, some just want to be cured and just want to get rid of this thing that could kill you, and at the time, you know, having the mastectomy doesn't seem so bad, but later on you do go through, I don't know whether it's grieving, but, you know, you do go through thinking, gosh ... (387-392).

Inevitably women appeared to go through a period of grieving. In the first case it was grief that their body could harbour a cancer that was a threat to their lives. Then, in the case of mastectomy, it was also grief at losing a breast. A number of women related that this was possibly more so if you were big breasted – it then seemed even

'more' of a loss. So there was always this double threat; the threat to their lives and the threat of losing part of their body, the body that was 'the self' as known.

### **Deciding instantly**

As stated, it was difficult to know how much 'pre-reflective' thinking affected the women's decision making. Some women appeared to make their decision(s) instantly and then spend the time between their initial consultation and surgery rationalizing that decision. Plus there was the time between finding a lump and cancer being verified; a time when women said their minds never stopped ticking over thinking 'what if?'

Gwen was one of the participants who reported 'deciding instantly' which option she preferred. She had a small lesion detected on screening mammography. She related how within a day she had made a decision regarding her treatment choice. She chose mastectomy explaining: "I didn't want the fear hanging in my mind, in the back of my mind, 'is it coming back?'" (37-8). She had also considered the fact that until excised breast tissue is examined histologically, the surgeon cannot be one hundred percent certain that he has achieved tumour clearance. Twenty five percent of women undergoing local excision will require further surgery. Gwen related: "That would mean I would have to have a double lot of surgery. I actually was quite happy with that resolution [to have mastectomy]" (39-40). She went on to explain that she thought it might be different for younger women (Gwen was 60 at the time). In relating her decision Gwen stated: "Within a day I really had made my decision what my choice would be and my choice was that although it was a very small cancer that I would have a mastectomy" (35-37).

In the present study, the women who had been given a choice of either conservative surgery or mastectomy, and who chose mastectomy, all stated that fear of recurrence in the same breast was the major reason they had chosen mastectomy. Often it appeared that the surgeon hadn't been very confident that conservative surgery would provide adequate local tumour clearance. This led on to the fact that for some women lumpectomy would have resulted in a very poor 'cosmetic' outcome (owing to the amount of tissue that would have to be removed) whereas at least with mastectomy they had the option of reconstruction.

As related in chapter five, Denise recalled 'instantly deciding' she wanted to have a wide local excision and axillary dissection and went on to have this the day after her initial consultation with her surgeon. Denise was adamant she didn't want to consider mastectomy and the surgeon was confident that he could perform a satisfactory local resection. He wasn't prepared to debate the radiotherapy option at that instant, which Denise apparently agreed to given time. Denise said that she never wavered from her decision to have conservative surgery; maintaining her body image was high priority for Denise and she was relieved that she didn't have to consider mastectomy. She related that it was sort of 'unreal' that she had cancer. She went through the routines of daily life doing what she had to do, but couldn't really believe breast cancer had happened to her. Even after her surgery, her breast looked much the same, she felt the same; had she really had cancer? Denise said that it wasn't until a certain incident brought it home to her, that she really took it in that she had (had) cancer. She was waiting in the hospital oncology outpatients to see the radiation oncologist. Her mother had accompanied her. The doctor came out of the consulting room and called her name. Both she and her mother acknowledged the call. The doctor immediately began to address Denise's mother, presuming she was the patient. Denise related that it was this incident (and another similar incident) that really 'hit home' to her, the unfairness almost, that it was her that had cancer. So although on the outside she appeared to have dealt with things very well, had made decisions with little conflict, inside she was struggling to believe it had really happened to her.

Sonya was another participant who reported deciding instantly which surgical option she preferred. She related that her decision was biased by the manner in which her surgeon 'presented the case'. Her lump was immediately under the nipple, and the surgeon didn't think that wide local excision was a very good option for her. The surgeon advised her that she would have a poor cosmetic result, and that really mastectomy was probably the most appropriate course of action. She could decide whether or not she wished to consider reconstruction. Sonya relates: "I more or less decided right there and then in the surgery that I would have breast reconstruction which he told me to go away and think about it" (41). Sonya stayed with this decision.

Margaret was also an instant decider. She had come to her own conclusion that her lump was too big for local excision to be successful. The surgeon said he could try for wide excision, but because of the size of the lump, he couldn't promise that her a good cosmetic outcome and he might still need to perform further surgery if the 'margins' weren't clear (of cancer): "He did give me the choice but I sort of put it back to him because I had already made up my mind" (53). She related that just feeling the size of the lump it was obvious to her mastectomy was the best option. Margaret believed that she had done a lot of work sub-consciously and this was possibly the reason why, on the surface, she seemed so calm about it all. She related: "I thought, well you've just got to get on with life, so I did" (111). Margaret said her instant decision to have a mastectomy, as opposed to wide local excision, was because she didn't want to face the possibility of further surgery. She explained: "I just decided that I wasn't even going to consider anything but the full mastectomy. I wasn't even going to consider two operations" (89-90).

It appeared that some women knew quite quickly which choices they found acceptable or unacceptable. However, on further exploration it could be deemed that these decisions had been preceded with a considerable degree of reflection, both reflective and pre-reflective. This relates to the next section: 'Subconscious decision making'.

### **Subconscious decision making**

Although some of the women appeared to decide their preferred surgical option almost instantly, it was obvious that between events (for example, finding a lump until seeing a specialist and having their cancer confirmed) they had indulged in considerable thought about their breast cancer, its treatment and possible outcomes. It appeared that the women also worked to 'suppress' many of their fears, namely about the possibility they could die from metastatic spread.

Fear of dying is probably a constant in the sub-conscious of women deciding treatment options for breast cancer. Margaret related how she had refused to consider reconstruction because 'sub-consciously' she believed that she was going to die, and therefore it wasn't worth going through all that extra surgery. A few years later,



when she found herself to still be very much alive, and with no evidence of disease recurrence, she decided to accept the option of reconstruction. For Margaret this was a sort of turning point, a reaffirmation towards life and living. She related how her decision to undergo reconstruction came about. Margaret and her husband had gone on a trip to England to visit her husband's family. She was getting ready to go out to dinner:

I never wore a prosthesis. Mr Xx gave me a script for it but for some reason I just didn't want to know, so I just used to full my bra with cotton wool ... For some reason I just didn't feel right. I was looking in the mirror and my husband said: "You're not happy are you. Don't you want to go out?" (205-218).

It was the first time Margaret had got 'dressed up' since her surgery; perhaps the first time she'd really looked at herself in the mirror since her mastectomy. Margaret said: "I had forgotten that side and also I think I didn't believe that I would be lucky enough to survive it" (227-228). She hadn't admitted to anyone that this was how she felt. It was this incident that decided her to go for reconstruction. It was a celebration of being alive and accepting her 'whole' body again.

### **Protecting body image**

Women who could 'accept' reassurances that conservative surgery was as effective in removing the cancer as mastectomy were able to find salience in this option, which also helped to retain their body image and sense of personal 'wholeness'. Although protecting body image was an important priority for most women, it was more important for some than others.

Mary was relatively young and had a new partner, and was keen to preserve her body image if possible. She therefore chose wide local excision over mastectomy. Mary said: "I think with me it was just hoping it wasn't anything worse, and I thought, well you've got to be practical and have it removed and then go from there." (153-154). Mary related how she really appreciated the support from her partner. She related that he came to all her appointments although "he found it hard to decide" (518):

He wasn't worried about the physical side, he just said "well you've got to do what you've got to do". But he was supportive of any decision



I made. He sort of left me to do what I wanted ... I think that's being a nurse though really, you tend to be more practical ... you just go along with what seems right at the time and you just do it (520-528).

Retaining body image and body wholeness (as related in chapter six) was also a priority for Richelle, as long as local resection was a medically safe alternative to mastectomy. She said she knew immediately that "no way" (56) did she want a mastectomy. She related, however, that if things had been different, she might not have made the choice so easily:

But, I got the impression that if it had been more severe, he did tell me it was very small, the lowest grade, caught early, slow growing, all those things that could possibly be fortunate in the circumstances. But had it been something more drastic, requiring more drastic treatment – well that would have been a different matter (79-83).

More 'drastic treatment' was often an option women had to re-visit. Whilst wide local excision was an option women were often given to decide, surgeons always qualified this by saying that this was only a satisfactory option if it could achieve tumour clearance. This had to be verified 'histologically' (tissue inspection under the microscope) that tissue 'margins' were 'clean' or free of cancer. This might not always prove to be the case and women may have to consider re-excision, or proceed to mastectomy.

### **Fielding the knocks**

As discussed above, it is not always possible to achieve the desired result. It then becomes a matter of 'fielding the knocks'. This may mean re-visiting having a further re-excision, but generally this meant proceeding to mastectomy.

Pam initially chose to undergo wide local excision (and axillary dissection) but unfortunately this did not provide adequate tumour clearance. Pam related that she was fairly open to mastectomy but that "If the breast can be saved why not save it" (581). So Pam had chosen to have "deep wide excision" (47). Unfortunately, her histology results revealed that there were tumour cells in the tissue margins and she would require either re-excision or mastectomy to ensure local clearance of the

disease. Pam recalled how the surgeon "Walked into my room at ... and said he would have to do further surgery because they didn't get all the cancer" (49-50). She describes herself being devastated: "That really really knocked me, because I thought I'd got rid of the cancer and it was going to be okay" (57-58). Pam said that the surgeon explained the possibility that 25% of women who have wide local excision have to go on to mastectomy. She relates:

I don't know initially whether he told me those statistics. I think when you're told you have breast cancer your mind just goes a total blank and, I couldn't make the decision myself. I mean I was in a state of shock ... you know to know what you want done – I mean you want the cancer gone (77-81).

Pam related her initial decision making: "I made the decision in his rooms. I'm quite good at making decisions, and it was clear. He said he could save the breast" (616). Pam stated that in retrospect she wished she had chosen mastectomy: "I would have had a mastectomy the first time, because I just think it's horrible to have to go back" (558-559). As discussed in previous chapters, Pam hated her prosthesis, and her mastectomy wound. Three years after her initial treatment she went on to have reconstruction. At five years she was found to have a new primary in the contralateral breast for which she underwent mastectomy with immediate reconstruction. Pam had a number of 'hard knocks' to field.

'Hard knocks' also came with the news that histology had revealed axillary lymph node involvement, or an aggressive tumour, which meant an increased risk of recurrence, and predicted the need for further therapy. For pre-menopausal women this generally meant chemotherapy; post-menopausal women were generally recommended hormone therapy. Few women experienced indecision about adjuvant therapy. Cathy related: "I didn't want to have chemotherapy but of course you don't know that until you've had surgery but as it was I guess I coped." (64-5). She continued:

I guess it was basically the aggressive nature of the tumour... it was a precaution ... not a particularly convincing one, the scenario that if I didn't have the chemo and something happened later, then it would have been worse (181-5) ... I'd be kicking myself (189).

So Cathy ended up having conservative surgery, radio and chemotherapy over a period of six months or so.

It is important to point out that none of the participants in this study had experienced recurrent disease. Although two women had undergone bilateral mastectomies, these were for new primary breast cancers. They were not due to tumour recurrence. Women may have felt differently about their choices if they had. For example, if they had chosen wide local excision, and had then had a local recurrence, they may have wished that they had undergone mastectomy initially. Conversely, if they had chosen mastectomy and then found they had distant metastases, they may have questioned losing their breast if this hadn't improved their prospects in relation to long-term survival.

### **Rejoinder**

On the outside it appeared women made their decisions in a relatively uncomplicated manner but in fact the reverse was true. The women all brought a life history to their decisions, and their personal value priorities. Initially 'maximizing survival' was a core factor, then as things progressed and women felt more secure about their prognosis and chances of survival, they were often ready to take 'another look' at the option of reconstruction. Although the women openly stated survival was the most important issue for them, they also wanted to preserve their bodies, their sense of self, if this was possible. It was interesting to note, for every choice there always appeared to have been a number of positives and negatives. The following section will relate this 'paradoxical' nature of choice.

## **REVEALING THE PARADOXICAL NATURE OF CHOICE**

### **Introduction**

For every choice it seems there are generally a number of possibilities, or contingencies, within that choice. In making decisions and choosing one thing, inevitably 'the other' is given up. There is always a positive and negative. In choosing one also comes to 'own' those choices. Therein freedom to choose has its own inherent anxiety. Choosing is rarely easy. This section discusses the issue of choice itself and the question: 'Do women want to be involved in deciding their

treatment plan?' It discusses how choices are often restricted. For example, although women were given a choice, it was obvious that one option appeared to offer a more reliable medical outcome, and therefore was more salient. In choosing one option, women necessarily rejected another. This section will discuss how women weighed the various 'pros and cons' associated with different options. Codes in this section are:

- Choosing (is never easy).
- Deciding (when choices are restricted).
- Weighing (the 'pros and cons').
- Wanting (a definitive answer).
- Accepting (that there are no perfect solutions).

### **Choosing (is never easy)**

The freedom to choose was generally viewed favourably but sometimes with a degree of scepticism. A number of the women related that they had been quite surprised when asked to choose between various options. Surely this was why they had come to a specialist? However, they rationalised that it was good that women were asked to choose if it was really down to what treatment they preferred, as opposed to what treatment was medically best.

Three women, all members of the Breast Cancer Support Service and who were occasionally requested to make visits to women pre-operatively, felt that some women just couldn't cope with the added burden of having to decide treatment options. Paradoxically, as can be seen in the following statement, they still thought it was important that those women made their own decisions. Joanne stated:

Well often I think the women would like the surgeon to say: "This is what we would like you to do", but they're actually given a choice and I think its very difficult to make a choice, and they sort of ask us and we're not in a position. Again, we can't make the decision – it's something you have to do yourself (8-12).

Although choice could be viewed as quite a liberating element (for example, in the 1960-70s the standard operating procedure was a so-called one-stage procedure: biopsy, if positive, proceed to mastectomy) choice was rarely easy, and for some

women it appeared choice was more 'illusion' than real. The nature of their cancer, or its proximity in their breast, or the size and shape of their breast, meant their options were really quite restricted if they wanted the best 'medical' outcome. However, they were still asked to make a choice. Consent was never presumed. They could always accept or refuse a particular course of action. None of the women in the present study rejected treatment or sought a second opinion.

### **Deciding (when choices are restricted)**

A number of women related that although they were offered a choice, often their clinician informed them what she or he thought was the better option medically. They therefore deferred to his or her expertise. For example, Margaret believed the size of her tumour made it obvious that wide local excision would be a difficult surgical quest. She related:

He said I probably did need a mastectomy, but if I wasn't happy with that he was happy to just remove the lump. He did give me that option. But the fact that it was there and I could feel the size of it, I thought, well, maybe if it had been a bit smaller I might have considered the lump [ectomy] but to me I couldn't really (100-103).

Louise also had restricted choices. She related:

I was thirty-eight, so I was pretty devastated and the process was that the next day we went to see Mr Xx and he talked about the options ... about surgery, because my breasts were so small, he really recommended me having a mastectomy rather than anything else because he felt that there actually wouldn't be much left by the time he'd finished (24-30).

Choices were also restricted for Louise as far as reconstruction. She said that she could have chosen reconstruction but would that it probably wouldn't have resulted in a very successful outcome. She explained:

I did think about it but because they took so much and they really had to stretch the skin; the skin there is so thin and also with radiation treatment it destroys the good stuff as well and so really it is very tender, even now, and the thought of going through another operation and also Mr Xx (Plastic Surgeon), when I

talked to him about it said he couldn't guarantee that it would even look that great. I could get scar tissue ... it wasn't worth it (45-53).

Thus choices for Louise were quite restricted. She was never told she had to have this or that done, but as far as she could make out, she didn't really have a whole lot of options, not really, not rationally.

Conversely, despite the 'appearance' of choice, surgeons did not willingly negotiate (on what they regarded) as medically unacceptable choices. Pam, who had already undergone mastectomy on one side, was distressed when a new lump appeared in her remaining breast and which proceeded to evade repeated attempts to obtain histological verification as to whether it was a benign or malignant lesion. Pam wanted to go ahead and have a mastectomy irrespective of a definitive diagnosis. She could no longer tolerate the anxiety of a 'possibly' malignant lump in her breast. If there was a suspicion of cancer, that was enough for her, she wanted it gone. She related:

I said "for goodness sake can you not just do a mastectomy!" Which is interesting because I would have thought the patient has the ultimate say. And he says, "no, I don't want to do a mastectomy until I know what type of tumour it is" (213-215).

Eventually pathologists (a tissue specimen had been sent overseas for a second opinion) reached a consensus that it probably was malignant and Pam went on to have a mastectomy and reconstruction. She related how the surgeon then said he was going to put her on Tamoxifen, but that he wanted to wait until they were sure the tumour was oestrogen sensitive. Pam said, "I knew it was because I felt it hurting every period, so of course it was sensitive to oestrogen – Tamoxifen" (241). She laughed and related somewhat wryly; "I thought this was the basics of the thing. You can't tell these surgeons. So I had to go away and have another little test and it came back oestrogen sensitive" (243-244).

Restrictions also exist for surgeons in the form of surgical knowledge, training and college (Royal Australasian College of Surgeons) guidelines and standards, which prescribe the state-of-the-art surgical management for breast cancer. This can



sometimes appear a restrictive element for women with regard to treatment options. For example, Gill felt her choices had been restricted in relation to removal of her axillary nodes. She related that it was a “bone of contention” (97) with her that women are not given the choice as to whether they have their axillary nodes removed, which increases the risk of lymphoedema and restricted shoulder movement in the affected arm (which she acquired). She said she understood that there was current research underway looking at removing just the sentinel node (as discussed in chapter two) which would mean much less invasive surgery. Gill stated: “That was really a bone of contention with me. They took my nodes and they were perfectly all right and it gave me a lot of discomfort. So I hope, that in time that will actually change.” (97-99). Again this emphasises the difficulty for women interpreting the medical (or popular) literature. Sentinel node biopsy is still in the very early research stages. Whether it is a safe or even satisfactory alternative to axillary dissection is still to be determined (Smith, 2000). It would therefore be inappropriate for a surgeon to offer this procedure to women outside of a clinical trial setting.

In summary: The management of breast cancer continues to evolve with new knowledge and techniques. It has certainly progressed from the so-called one-stage procedure common until the late 1970s even early 80s. Today (hopefully) the surgeon will advise a woman of her options and involve her in treatment decisions. However, often the nature, or position of the tumour, or both, will restrict these options. There is a complex knowledge and skill base attached to these choices which the specialist is challenged to translate in language her or his patient can understand. There will be both positives and negatives for all options. Women have to weigh the ‘pros and cons’ in relation to their personal value priorities.

### **Weighing (the ‘pros and cons’)**

Usually, for most choices in life, there are both positives and negatives, something to be gained, something to be lost. In choosing one course of action another is rejected. This was evident in the treatment choices the women made. It has already been discussed how because mastectomy has long been the ‘traditional’ surgical intervention for breast cancer and that some women felt less confident choosing conservative surgery. Conservative therapy required a six-week course of radiation

and this was another consideration when deciding this option. Reconstruction meant more extensive surgery and for some women this was unattractive. Having decided surgical options, women often had to consider the 'pros and cons', the benefits and disadvantages, of accepting adjuvant therapy and whether they wished to proceed with treatment.

Weighing the 'pros and cons' between conservative surgery and mastectomy, Cathy related that she chose conservative surgery so as to conserve her breast and 'minimize treatment'. If she had chosen mastectomy, she stated that she would have opted for reconstruction, which would have required further surgical procedures and intrusion into her busy life. Post-treatment, she found the follow-up times (mammogram and physical assessment) very harrowing, especially when there were concerns about her tests or x-rays. She related how she had to "psyche herself up" (333) every time she was due for a check-up. She tried to organize her appointments (mammogram and clinic) so there was minimal waiting time between. Invariably this would be compromised by the hospital changing appointment times. Cathy said that if she got recurrence, or had to choose again, she would possibly decide to have a mastectomy: "Well I mean I probably wouldn't rush into it. My initial reaction would be 'cut it off'" (356). She contended that there was for and against:

I mean, from what I understand it's not likely to have any better outcome anyway, if there was a guarantee I could get back to a pair again I suppose. Well, it's something I'd have to think about and it's not going to happen again ... Well, I mean it's something I have to live with for the rest of my life. It could you know (386-394).

Cathy talked about how before she made her decision she had researched the literature on conservative surgery versus mastectomy. She said: "I got the impression that they hadn't been doing wide local's for that long, 10 years or something like that, which isn't very long" (479-480). Maximizing survival and minimizing disruption to her life was Cathy's primary focus, along with wanting to retain her body as intact as possible. However, the fear of recurrence in her affected breast continued to loom for her. There were 'pros and cons' for all options. As Cathy related, uncertainty was something she would always have to live with. It was a constant in her life since her encounter with breast cancer.

As discussed, reconstruction was a further option that required a weighing up of the 'pros and cons'. Sonya chose mastectomy with immediate reconstruction. This created a number of plus's and minus's for her as she was unfortunate to contract a staphylococcal wound infection following her surgery. This required multiple return trips to theatre for drainage (six in total; three with general anaesthesia and three with local). Luckily, she was able to retain the tissue expander and continue with expansion and reconstruction at a later date. The main setback for Sonya at this time, as well as the inconvenience of return trips to hospital, was the fact that every time she had a general anaesthetic it affected her short-term memory causing her to forget things. Sonya had an underlying medical condition, but it remained hypothetical that this, plus anaesthesia, was the cause of, or related to her memory lapses. Owing to general tiredness (result of her medical condition), and the on-going problems with her breast wound, Sonya decided to retire from her job of 30 years. At first she reduced her hours to part-time but she found she was still becoming profoundly tired and therefore decided to retire. Sonya related that because of the problems she had with her memory, she was reluctant to undergo further surgery. For example, the surgeon had offered to do reduction on her unaffected breast and at the same time perform nipple reconstruction on her reconstructed breast. She stated:

It's not a matter of how does it look, if I was younger I probably would. My husband takes me as I am. If I was to have another operation and it was easy to get it done, then I might think about having it done, but I wouldn't especially go and have it done if it meant another anaesthetic. I'm sure that every time I have an anaesthetic a little bit of my memory goes somewhere (466-471).

So although Sonya was pleased to be offered breast reconstruction (a 'house on the empty section') it also played a role in incurring other losses in her life. A decline in her general health meant that she had to consider early retirement. Reconstruction meant she didn't have to bother with a prosthesis (which she had related as another reason for choosing mastectomy) but this came at a cost.

Some women had to weigh the 'pros and cons' in relation to various other choices. Gill had undergone bilateral mastectomy and, unfortunately, developed lymphoedema in both arms. This had created a dilemma for her when, after her

second mastectomy, she accepted a further course of chemotherapy. Chemotherapy requires repetitive venopuncture and Gill related that she was constantly advised by people not to have injections on her 'affected side'. Well now she had both sides affected. How could she avoid venopuncture on her 'affected sides' especially as they both had lymphoedema? Gill requested to have a portacath inserted. This is a subcutaneous venous port, inserted into the chest wall, under general anaesthesia, which enables central venous access for chemotherapy. Although this protected her arms from further trauma (venous access is very difficult in lymphoedematous arms as well as potentially harmful) Gill related how as well as her mastectomy scars she now had another scar on her chest wall. In Gill's words:

Plus you end up with lots of scars around your chest, and it is really strange because although you've lost your breast, both your breasts, you still want your scars to be at the same height, symmetric, and then you have these others come (217-219).

So although the portacath protected her arms from further venopuncture (and the associated pain and potential worsening of her lymphoedema) it was at the cost of another scar on her chest wall; another battle wound.

Alaina talked about weighing the 'pros and cons' of wearing an ice cap during chemotherapy. This was aimed at preventing (or reducing) hair loss. The positive aspect of this was that she would retain her hair. The negative side was how painful and uncomfortable this procedure was: "You'd get this freezy head and then you were giddy as ever while the chemo was going around" (518-519). Alaina said that she wouldn't choose that option again.

In making choices the women did their best to predict the outcome; project the end result. There were inevitably positives and negatives, and often these were unpredictable at the time the decision was made. Rarely was there a definitive answer or a perfect solution.

### **Wanting (a definitive answer)**

Various studies were cited in the chapter two discussing what level of involvement patients desire in decision making. It was related that a key issue for them was that although they want to be given full information regarding treatment alternatives they

did not necessarily want to take full responsibility for making the final decision(s). One of the issues for women deciding options for breast cancer, however, is that the 'best' treatment option is not always definitive. Wide local excision and axillary dissection, or mastectomy may be equally satisfactory from a clinical perspective. The woman herself must decide which procedure is more compatible with her values or preferences.

As discussed earlier in this chapter, a number of women expressed that they felt this was problematic and that for 'some women' (they were generally referring to a third party) this was too difficult. Paradoxically, women who expressed this sentiment also expressed that they personally were glad to have been involved in deciding their treatment options. For example, Joanne relates:

Doctors don't seem to be able to say I would advise you to have this. They say "these are your options". A lot of women can't cope with that ... I know now a days you have to agree with treatment, but a lot of women, really, they can't make the decision. I would say I would have 'chemo', but some of them really would like a doctor to say (250-254).

Informed consent to medical procedures has come of age owing to the public's desire to be involved in their treatment decisions. It is now both a moral and legal obligation for a clinician to fully inform his or her patient of the risks and benefits of the various treatment options available (as discussed in chapter four). This is even more relevant when there is no definitive 'best treatment' or right answer, no 'perfect solution'.

### **Accepting (there are no perfect solutions)**

Whilst reconstruction was a welcome option for many women it was never a perfect option, as surgeons were careful to explain. Often reconstruction resulted in a less than satisfactory result cosmetically, however, some women still preferred this over no reconstruction at all.



Pam sought reconstruction three years after her original mastectomy as a solution to wearing an uncomfortable prosthesis. She talked about the reconstructive process (tissue expander reconstruction):

You had to have saline pumped into it. He'd just put the needle in and then puts the saline in. It takes about three months, then you're left for six months and then the permanent prosthesis is put in ... I'm glad I had that because I was relatively young, and to live with no breast, not looking, I mean it just looked ghastly ... at least I know I've got a 'bump' (172-180).

Although Pam was pleased she had had reconstruction, as it alleviated the need to wear a prosthesis (which she hated the discomfort of) it wasn't a perfect solution. She related humorously:

I mean, sometimes I get down to it and think, ooh, aren't they lucky they've got breasts, and they flop when they go running [Laughs]. I mean a lot of people don't want to go flop when they go running but I do. They don't want to be saggy, but I'd quite like to be saggy (448-450).

She also talked about her awareness of her reconstructed breasts when she gave someone a hug:

You know, I give people a hug. You know sometimes you hug people you haven't seen them for ages and I'm very conscious because they are so hard ... like tennis balls ... I'm so aware (451-453).

Thus, as stated above, there are rarely perfect solutions; one weighs the 'pros and cons'. Again, it was a matter of discerning value priorities, making decisions, and then taking the plunge.



## SUMMARY

In the first section of this chapter it was related how for some of the women it appeared that one particular option immediately became salient and was the option they committed themselves to. It was then revealed that in fact the women had often engaged in considerable thought which was often both reflective and pre-reflective. It was also discussed how choice could be extremely burdensome.

Most of the choices the women made regarding their treatment options for breast cancer had both positive and negative aspects. Choosing was rarely easy. The participants who chose mastectomy generally did so because it made them feel more confident they had done everything they could to be rid of their cancer. But this, of course, was at a cost. The women weighed the 'pro's and con's' of wide local excision versus mastectomy versus mastectomy and reconstruction and ultimately this came down to their own value priorities. For each there were pluses and minuses. Adjuvant therapy meant that the women were doing everything possible to prevent disease recurrence, but they also had to endure the treatment process. Whilst reconstruction could be considered a reparative process, it came at a cost, and it could never 'replace' the breast that had been lost. Some of the women viewed reconstruction quite distastefully (extra surgery - no guarantee regarding outcome) whilst others were very pleased to be given the option and were relatively pleased with the outcome.

Although the freedom to choose was burdensome, all women in this study felt it was important that they were involved in their treatment decisions. It also appeared to re-enforce their commitment to the treatment process and outcome. As identified throughout this study, coping with the diagnosis of breast cancer and its treatment can be problematic for both the women with the disease, and their doctors. Despite this, talking to women in the present study, there was a tremendous sense of courage and optimism. Despite the dark side of breast cancer, the women invariably related the positive aspects encountering this condition had had for them. There was this constant battle to reach a point of harmony, of consonance with their situation and treatment choices. Their choices had to be something they could accept; something that they felt they could live with. This will be the focus of chapter eight.

## **CHAPTER EIGHT**

### **Unifying 'the self' with treatment choices**

*My mortality is round and small and located in my left breast.*

*That breast, this body, have been changed forever...*

Susan Underwood (1990, p. 198).

#### **INTRODUCTION**

This chapter relates how women in the present study dealt with the twin issues of survival and cosmesis, when deciding treatment options, often struggling to find some kind of congruency. Choices were generally reached collaboratively with their clinicians, and sometimes with their partners and families. Ultimately, however, it was the woman who had to make the final choice(s). In making these choices she had to project what it would be like to live in the future with the choices she made.

This chapter draws from previous chapters to relate how "Unifying 'the self' with treatment choices" was determined to be the overarching, or integrating category. This is because it appeared that each woman had to go through a process of re-integrating her changed body, or altered self-concept (having encountered cancer) to regain a sense of her true self. It discusses how the participants described their struggle to make their decisions and then integrate these decisions into their lives. It also describes their struggle to retain a sense of control, their 'intactness', or 'authentic selfhood', and also how they struggled to come to terms with the fact of breast cancer. The women also talked about how they found renewed meaning in their lives, which they attributed to their encounter with breast cancer. This appeared to be associated with their coming to terms with their breast cancer and their treatment choices. The main categories in this chapter are:

- Making choices and living with those choices.
- Accommodating the fact of cancer: Re-integrating selfhood.
- Unifying 'self' with treatment choices.

Chapter eight concludes with the theoretical model that emerged from this study.

The model, which is in two parts, is followed with a discussion explaining how the major categories, subcategories and substantive codes are linked to what emerged as the core category.

## **MAKING CHOICES AND LIVING WITH THOSE CHOICES**

All women in the present study were involved in deciding their treatment options. None of the women, however, chose a treatment that was against their physicians' (surgeon and medical/radiation oncologist's) advice. All of the women accepted adjuvant therapy, if it was offered. Maximizing survival and retaining physical integrity were integral factors in the women's decision making. Participants stated that they felt being involved in making their treatment decisions helped them commit to those choices and also gave them a sense of control. Codes identified in this section are:

- 'Buying in' to personal choice.
- Struggling to preserve a sense of unity and body wholeness.

### **'Buying in' to personal choice**

Involvement in deciding treatment choices appeared to help each woman commit to her choices. For example, Julie stated that she thought it was important that she make her own decision regarding her surgical option, as this would reinforce her commitment. Although she told her family about her breast cancer, she didn't ask their opinion. She wanted to make her own treatment decisions:

I think basically I was being guided [by her clinicians] but nobody actually told me what I had to do, this or that, which is good. So, it's quite positive really (152-154)... I tend to be one of those people who goes out and searches and then makes a decision and then that's my decision, I've made it and then I buy into it (159-160).

She said how she thought (from the literature she read and the discussions she had with her surgeon) that reconstruction was regarded in a very positive manner and she decided to go for this option. Balance and symmetry were important to Julie, along with general physical appearance. Julie felt that it also relieved, to a degree, the sense of loss she experienced post-operatively. At least she didn't wake up to a totally flat chest on the affected side. As cited in chapter six, Julie stated: "You don't have that sense of loss – even when you wake up with a tissue expander for goodness sake" (59-60). Julie said, that for herself, she had to research her options, make her own decision, and then that was it, "that's my decision" (347).

Most of the women demonstrated considerable 'buy in' to their personal choices. For example, Gwen related that given the choice again, she would make exactly the same decision:

On looking back ... I wouldn't have done it differently. I would do exactly the same....Now I'm in a position to tell other people how I dealt with it and that there is a lot of life afterwards and it can be very positive (144-147).

It appeared women had to work at this 'buy-in', this commitment to choice. It was never easy. As cited in chapter six, Joanne related that she chose reconstruction because "I just wanted to put myself back to where I was. I didn't ever want to feel that I was not as I was" (153). She related how she had done practical things to help herself cope:

I felt that you need to be empowered when you have had cancer ... I was determined I'd be able to do all these things again, and I did, and that was fine. I just got myself up and running. There's always the fear, you always have that ... I took up yoga; I found that very empowering and really I feel that I've gone on from that and, 'I am who I am' (106-111).

Other women related how meditation, yoga, and books on positive thinking helped them cope with their stress during this time. Sonya related how her daughter was a great help: "She gave me some affirmations to read and say to myself and she was giving me Reiki<sup>5</sup> and massaging me and this was very helpful" (31-32).

Often the women had to work at committing themselves to 'the best clinical decision' as opposed to their preferred choice. Louise had limited options owing to the nature of her tumour and her small body frame. She underwent mastectomy and radiotherapy post-operatively. The skin over her chest wall was very fragile and tender owing to the fact it had to be stretched to achieve wound closure, and then endure the radiation. Louise spoke of how her breast cancer experience had given her a new outlook on life and courage to do something she should have done a long time ago, which was leave her husband after several years of an unsatisfactory

---

<sup>5</sup> A type of Eastern therapeutic touch and massage therapy (Blattner, 1981).

marriage. She now had a new partner. She talked about how, because of her breast cancer, she didn't expect to find another partner who would accept a single breasted woman:

My new partner, he's very good, you know I told him I'd had the mastectomy, you know, I really didn't think that would ever happen again [find a partner] because you do sort of, um. It's a very feminine part of you and it's, the thought, I didn't think any man would ever want to look at me again. It sounds silly, and, yeah, it didn't make any difference to him, he's quite okay about it (143-147).

Sonya related humorously about the wonderful innocence of children and how her son, who was only a toddler when she had her mastectomy, and was so used to her having just one breast, was "quite surprised to find that other women actually had two breasts" (149).

To review: Involvement in decision making appeared to help the women commit to treatment choices. These were difficult choices that often resulted in considerable personal morbidity in the quest to 'be rid' (chapter seven) of their cancer and improve their chances of long-term survival. They had to work at 'understanding' the choices they were required to make; they then had to survive the treatment process (chapter six: 'Understanding it', 'Putting up with it' and 'Getting on with it'). The women also lived in 'relationship with others'; with intimate partners, families, within a social network of 'others', or as Gilligan (1980) describes, a 'web of connection'; all of these factors contributed to their personal life situations and therein the decisions they made. Their personal value priorities with regard to body image, undergoing surgery, accepting further adjuvant therapy; these were all considered within the context of their personal life situation (see chapter six: 'contextual determinants').

### **Struggling to preserve a sense of unity and body wholeness**

Women also expressed their feelings regarding their struggle to preserve a sense of unity and wholeness. In chapter six it was related how Richelle stated that she preferred "not to be chopped about ... You know, we're given the skin to contain us and I'd rather it wasn't interfered with" (89-91). Richelle expressed the meaningfulness of her breasts in relation to her sense of 'embodied' womanliness.



She talked about how she had played “many mothers” (206) and how she felt being “large bosomed” (208) was part of that. Richelle was grateful for the option of wide local excision, which meant she could retain her breast. It was also related (in chapter six) how Richelle stated that although she was living on her own at present, she hoped this would not always be so and “as far as intimacy with the opposite sex goes, I would rather be entire” (214). Thus retaining bodily wholeness protected Richelle’s sense of embodied womanliness.

In chapter seven it was related that the women who could accept reassurances that conservative surgery was as safe as mastectomy were only too pleased to accept this option. Denise was cited (in chapter six) as saying that it would have been a ‘whole different ball game’ if she had been required to consider mastectomy and that she would probably have chosen immediate reconstruction. Hence, preserving ‘body wholeness’ was a high value priority for Denise (see chapter six: Discerning value priorities).

Retaining her body as intact as possible was also integral in Cathy’s decision making. She said she was quite pleased with the cosmesis of her wide local excision. Although she tended to avoid tight tops, she wore a normal bra. She stated: “I usually just wear those tea-shirt ones, just pull them on, they don’t do much for you but they make you feel a bit better” (347-349). She talked about how she had tried to project what her breast might look like after surgery, when she had made the decision to choose conservative surgery:

I mean it’s really hard to picture in advance, that there will be a physical change. Like Mr Xx did say, you might end up with a bit of a dent and stuff like that, which I did. But half the world wouldn’t know. Most of the world wouldn’t know. So, I mean, I know, if a lump was found again I would just go ‘cut it off’. You know, but not for the first time (350-356).

Although wide local excision meant Cathy had less physical disfigurement, she still lived with the fear of recurrence in the affected breast. She related how some time after her breast cancer treatment her husband said that he was “glad I didn’t have to have a mastectomy” (69) but didn’t try to influence her decision in any way at the



time. Cathy thought conservative surgery was the best choice for her, but it wasn't easy. Nothing was ever easy. She had endured a six-month course of chemotherapy during which she lost her hair, and all her energy for life. She related that it had taken her about a year to regain her usual energy and vigour. Maximizing survival whilst 'containing the crisis' (major category in chapter six) was never an easy pendulum to balance, especially when one has an eighteen month old son to care for. These were some of the 'contextual determinants' (chapter seven) in Cathy's decision making.

The struggle to preserve a sense wholeness, a sense of one's former self (before breast cancer), is also affected by how 'others' react (chapter six: 'living in relationship with others') and especially ones intimate partner. Margaret (as did other participants) related how the support she received from her husband was just so important to her coping:

I had a great deal of support from my husband, which I've heard talking to others, not everybody gets. A lady from the Cancer Society ... said that I was very lucky because she meet a lady who was married to a minister and divorced her because she wasn't whole, what a lovely, you know. And I've heard others say: "Well my husband doesn't seem the same towards me". Well I never found that at all, and it does make a lot of difference (125-131).

Margaret also stated how, after her reconstruction, she had teased her son that now she could go topless (She was talking about how as now she was sixty, she didn't think she would bother with nipple reconstruction.):

I don't go topless. I make jokes of course that I do. I said to my son, "now I've got my bust back I can go topless". You know what boy's are like [laughs]. Mothers aren't allowed to be naughty, you know, mum's are always pure in boys' eyes (480-482).

Although these were positive sides and outcomes of Margaret's struggle to retain her sense of wholeness and womanliness, in chapter six it was related how Margaret thought she had probably ignored, or denied her affected side for the first three years. She harboured the fear that she might soon die of the disease. She said how she had 'forgotten that side' of her body and that she never expected to survive. Margaret's

response to her breast cancer and mastectomy had been a polarity of awareness and avoidance. With time she had become more confident that she still had a future. Unifying 'the self' with treatment choice does not happen immediately, it takes time and hard work. As discussed in chapter seven under the code 'subconscious decision making', it also appears to occur on both a conscious and subconscious level at the same time.

In chapter six it was related how retaining body integrity, or body wholeness, had been important to Mary. She was relatively young and had a new partner. If local excision was an option then why not take it? She stated:

Well I sort of wanted to retain my physical look more than anything, well not more than anything, but I thought, well what's the point of taking it away if you don't have to take it away ... It's just like taking away a part of your body for no reason (451-454).

All of the women found follow-up times extremely stressful. Mary remarked how she left breast examination to the surgeon, as after all, she was "paying for him to check" (411). Searching for a lump is an unnerving experience. She really disliked having mammograms, more so because her initial tumour had not shown up on mammography. She wondered if it was worthwhile having them at all?

### **Summary**

In this, and previous chapters, it has been related how although women appeared to give priority to treatment that would offer them the best chance of survival, the more they talked, the more they voiced an equal concern for their 'body intactness'. Their breasts were part of their 'womanly wholeness', part of 'the self' as known. However, the women who chose or underwent mastectomy committed themselves to that choice and most appeared to have adjusted to the loss of their breast, over time. Those women who had undergone reconstruction accepted that it was never a perfect option. All women had altered contours; their breast scar(s) were always a reminder of their cancer. Whatever treatment women chose for their breast cancer, it still required an adjustment, or 're-unification' with the altered self; an adaptation to the fact of breast cancer, their altered bodies, their altered lives, and inevitably a greater awareness of the fragility of life itself.

## **ACCOMMODATING THE FACT OF CANCER: RE-INTEGRATING SELFHOOD**

All of the women interviewed talked about how breast cancer was an encounter with their mortality (not that they all used this term). They not only grieved the loss of a cherished body part, they also grieved the loss of their security and the belief that 'tomorrow would always be'. It took time to work through all these issues. In deciding treatment options they also had to sort out their own feelings about the importance of their breasts in relation to their sexuality. This was often at both a personal/private and a social/public level. Codes for this section are:

- Facing one's mortality.
- Integrating the personal and social self: Disclosing the fact of breast cancer.

### **Facing one's mortality**

Facing the reality of the cancer is facing one's fear of the unknown and uncertainty about the future. Participants with young children felt particularly vulnerable as the following excerpts relate.

Pam related her experience and how breast cancer had threatened her mortality. She had a young, school age family at the time her cancer was diagnosed. She related:

Until you've been through it you don't really know. I mean one minute you're fit and then the next minute your whole life is turned up-side down. Suddenly you have to think about your future and how long you're going to be here and all these ghastly things (481-486).

Pam's husband had also had major health problems requiring him to undergo major surgery a few years earlier, at the young age of 45 years. She related how she had supported him through his health crisis and how, in turn, he had supported her. Pam talked about her fears for her children:

My children ... were only in the fourth form ... You know, terrible for them. I remember my son saying, "Oh mum, I always thought you'd live forever", and I said, "I will". But you know they questioned

my mortality and I questioned it. You can't help but do these things. You know, this cancer is a beastly thing. You just don't know what's around the corner (486-491).

A number of women had friends who had encountered breast cancer. Some had done well, others had died of metastatic disease. Often the treatments their friends had undergone, or the options they had chosen, influenced how the women in the present study felt about their treatment options. For example, one of Alaina's friends, who had undergone mastectomy and delayed reconstruction, was dying at the time of the interview from metastatic disease. Alaina believed that this friend's recurrent disease, was a result of her having had a flap reconstruction, which delayed the detection of recurrent disease. She stated that this was one of the reasons why she personally would never consider reconstruction.

When undergoing adjuvant treatments, such as radiotherapy and chemotherapy, the women in the present study also came into constant contact with others undergoing similar treatments. Often a degree of camaraderie developed. Alaina talked about her experience:

I feel it sort of goes on and on because, before I got cancer, I had actually lost friends to breast cancer, so you automatically assume you're going to die anyway, and then after you've had the chemo and you're getting on with life ... the people you've made friends with having chemotherapy, they all die, one-by-one. This has a huge impact psychologically. The message is coming at you all the time that people die - you're loosing people you've befriended (11-18).

Surgical treatment options are to do with controlling local disease spread along with achieving an acceptable cosmetic result. Long-term survival is predicted by histology. It is a difficult concept for women to grasp that local recurrence has little relationship to distant disease spread; the seeds for this will have already been sown, prior to excision of the primary tumour (refer chapter two). Prognosis, however, is only a 'statistical probability'. Women in the present study were never given any guarantees about the risks of recurrence or survival, only probabilities. Hence facing one's mortality, living with uncertainty, was a cardinal fact of life after breast cancer.

### **Integrating the personal and social self: Disclosing the fact of breast cancer**

It was related earlier in this chapter, and in chapter six, how breast cancer occurs within the context of a woman's life; a life that is lived within a community of 'others'. The private and social side of breast cancer was something else that the women appeared to have to work through. How to tell other people, how to deal with other people's reactions and fears? This can be especially difficult when the woman herself is feeling totally vulnerable and in need of support, and yet still has to endure the burden of other peoples distress. Women in the present study talked about both disclosure and non-disclosure in relation to their cancer and treatment options.

Being frank appeared the most salient course of action to Julie. She talked about this:

People have said to me, "well, what is wrong with you, why did you go into hospital?" and I've just said to them, "look", and I've discussed it with them because too many people have the attitude this – the, the big C, you know, they sort of, they won't even call it what it is.

Well I say "look you've just got to accept that I've had cancer" (257-260).

Disclosing that she had decided to undergo tissue-expander reconstruction, Julie's male work colleagues became very interested in this process. She related their reactions on her return to work after insertion of her permanent implant:

When I came back from having the breast implant they all lined me up and said they expected me to come back looking like Dolly Parton.

"Fat chance!" I told them, "I didn't have the waist" [laughing] (253-255).

Revealing to others that one has breast cancer was extremely painful; a lot of this pain was, or is, concealed. Alaina talked about how, in a way, although she told her friends, and received tremendous support she also tried to hide a lot of her inner pain and despair:

It's sort of an incredible feeling and you are despite all the help and the support, it is sort of still on you because you're there in the middle of this circle and you're the only one who really knows how bad you feel and how much of a brave face you're putting on. And how much of other peoples fears are your fears. There's always that realisation that



it could all sort of go very badly wrong. You could die (279-287).

Telling others about her cancer was very also very difficult for Denise. She related she had always been a very private person and didn't want to tell anybody, at least not at the beginning. It just seemed to her that this would escalate the burden, as she would then have to deal with other people's fears and worries as well as her own. She stated: "I just thought well I'm not telling anybody" (266-269). But she related how people soon found out: "Yes, yes they did. And flowers started arriving" (274). Denise said that she was the first in her circle of friends to have had cancer so it was really frightening because "there really wasn't anything to share" (281).

Disclosing the fact of cancer is part of the social-meaning context in which women find themselves as they deal with this disease process, and make their own personal decisions regarding treatment. The above are just a few of examples of the process women went through in dealing with their breast cancer experience, making their choices and living with their choices thereafter.

'Cancer' and 'the female breasts' have their own social meanings, myths and taboos, and as social individuals these in-turn (either subliminally or overtly) appeared to affect the choices women made. Even in today's world, sexuality remains a relatively taboo subject. Women in the present study didn't talk overtly about intimacy or sexuality, it remained part of their private world (their private pain) but they did imply their struggle to feel comfortable with their nudity, with mirrors, with allowing their intimate partners to experience their changed bodies. There was obviously the fear of rejection, and the fear of revulsion in those who now had altered bodies through whatever surgery they had chosen. It has already been related earlier in this chapter how Louise said she didn't expect to find another partner - "I really didn't think that would happen" (145) - someone who would accept a woman who had had breast cancer and mastectomy.

It mattered greatly how their intimate partner's reacted to their altered bodies. Sonya related she wasn't concerned to have further surgery to improve her reconstructed breast saying that her husband "takes me as I am" (467). It was cited in chapter six that Pam said how she couldn't cope with getting undressed in front of her husband,



even now, after reconstruction: “Well, forever – even now I turn my back towards him” (147). It was not that he rejected her, but just how she herself felt about her altered body image.

### **Summary**

Breast cancer, as any cancer, causes great turmoil and emotional anguish. Breast cancer is both personal and political; it must be confronted at a personal and a social level. Re-integration of the ‘body’ and ‘self’, be it an altered self, takes time and hard work. In deciding treatment options women had to ‘best guess’ how they would cope with the treatments they decided. As discussed in previous chapters, their personal life histories and value priorities, along with their hopes for the future, were all factors in their decision making. As ‘embodied beings’, when choosing treatment options, they were not only deciding the contours of their bodies, but were often challenged to redefine their whole self-identity.

## **UNIFYING ‘SELF’ WITH TREATMENT CHOICES’**

### **Introduction**

In this section it will be discussed how, after intensive reflection on the data derived from interviewing women in this study, “unifying ‘the self’ with treatment choices” was identified as the overarching, or core category, present throughout this study. It appeared that women were constantly challenged not only to make, or accept, treatment choices or options, but also to integrate those decisions into their personal self-concept. Sub-categories to be discussed in this section are:

- Contours of embodiment.
- Embodiment and breast reconstruction.
- Integrating ‘choice’ and ‘self’.
- Core category: “Unifying ‘the self’ with treatment choice”.

### **Contours of embodiment**

Embodiment refers to the fact that we experience our bodies as our own, contingent with our personal self-concept. It appeared that the women in the present study somehow had to come to terms with the fact of cancer, the treatment they required, and the affects this would have on their physical body, as well as their personal and social selves. To make their treatment decisions it appeared they had to project

themselves into their future to consider how they would cope with the options they chose. As has been discussed, participants appreciated being involved in deciding their treatment options although often found it difficult bridging the knowledge-competence gap. None of the women, however, appeared to have major decisional dissonance (as stated in chapter seven, this may have been different if they had experienced recurrent disease). All women interviewed had accepted adjuvant treatment if their oncologist, or breast specialist, recommended it. Coming to terms with cancer, its treatment, and the choices they made, was a process that occurred over time – was still occurring.

Contrarily, some women appeared to come to terms with their situation, their altered body image, exceptionally quickly. For example, Alaina related her post-operative experience of seeing her wound for the first time:

It didn't just really ever bother me that I had one breast gone, and the nurses were quite surprised when I got up and had a shower and I took the dressing off. (397-399) ... They [the nurses] were flabbergasted and said, "oh, what did you think, are you alright", and I said yes, I wasn't surprised [laughs], I expected it to be gone. I would have been furious if it was still there (402-403).

As related in chapter seven, owing to a prolonged pre-diagnostic phase, Alaina (and others), 'just wanted rid' (chapter seven) of the cancer. She went on:

You know, I'd made up my mind how it was going to be. I would have been surprised if I still found some boob there (406-407) ... So I wasn't devastated to find that it wasn't there ... I just had to get rid of it [the cancer] (411).

Julie, who chose immediate reconstruction, believed that to a degree it helped protect against a sense of grief and loss. She went on to relate how she also had to convince herself that:

You've got to accept where you are at, and then go on from that point ... one foot in front of the other ... I suppose it does affect you deep down (264)... a lot of it is you think 'Why me?'" (269).

“Why me?” – “Why this?” were codes related in chapter five. The women struggled with the fact that their body, their breast(s), had developed a cancer. How could it be? What had they done or not done? There was a sense of betrayal, more especially if they thought they had done all the ‘right things’, like breast-feeding their babies. As Joanne stated (cited in chapter six): “I’ve breast fed four children; doesn’t mean a thing” (65-66).

In the previous section (and chapter six), it was related how Richelle regarded her bosoms to be part of her ‘embodied’ womanliness, symbols of nurturance and motherhood. This feeling of ‘embodiment’ was often lacking in the reconstructed breast. For example, it was related in chapter seven how Pam was conscious of the unnatural hardness of her reconstructed breasts, especially when she gave someone a hug: “You know, sometimes you hug people... I’m very conscious because they are so hard ... like tennis balls ... I’m so aware” (451-453). She also related “I try not to wear too tight a things – I mean there’s all these things you have to cope with really” (453-454).

Gill commented that she didn’t consider the option of reconstruction very seriously because:

I had read a bit about it, and seen photographs of reconstruction,  
and because I think, it’s never going to be the way it was anymore  
(78-79)...and I mean I don’t have a partner anymore (86) ... but at the  
same time I think I’m going to keep my options open (88).

Gill was related as saying (in chapter five): “I was quite fond of my breasts – and ah, yeah, they had given me a lot of fun and whatever else, I didn’t want to loose it – no not really” (69-70).

The women in this study did not experience their breasts as ‘body parts’. Women recalled the meaning of their breasts both in relation to nurturing their children and ‘implied’ their importance in relation to intimacy and sexuality. The later, however, remained largely their private world; their private pain.

### **Embodiment and breast reconstruction**

The concept of embodiment may help explain why some women viewed reconstruction in a somewhat abstract way. Replacing a body part, as in breast reconstruction, can never replace the 'responsive' breast that was. It can only ever be an approximation. The women appeared to have grieved the loss of their breast by mastectomy. As Pam related: "You know it's a dreadful thing to lose a breast – it's a threat to your femininity (149) ... to live with no breast, not looking, I mean it just looked ghastly...to be naked" (177-8). For some women reconstruction appeared to 'soften the blow'. Reconstruction was a compromise: 'better than a flat chest wall' (Julie); 'more convenient than wearing a prosthesis' (Pam, Sonya and Margaret). It was less of a reminder than a mastectomy scar: "At least I know I've got a 'bump'" (Pam, 178).

Contrarily, Joanne, was delighted with her reconstruction. She related:

Oh, I think reconstruction is really wonderful. It makes a tremendous difference. I mean, like a friend of mine, she always said she wouldn't have reconstruction, and then made the decision to have it, and she is just so thrilled ... it's a very personal thing (321-324).

For some of the women it re-created a degree of balance and symmetry. For example, Julie stated:

I suppose it was a matter of balance, everything I'd heard about, prosthesis *ex cetera*, it gave me a really negative attitude towards them. From a point of view of balance and what have you, I just decided that [reconstruction] was the best option really (181-182).

For other women in the study, however, it appeared that reconstruction did not equate with authentic self-hood; a reconstructed breast could never be part of their 'embodied being'. Re-embodiment of the reconstructed breast appeared to be a struggle, possibly never to be achieved totally. For example, Pam talked somewhat disdainfully about her reconstructed breast as "these great big things sticking out as hard as." (449). Pam was pleased she had undergone reconstruction, as she "hated" (461) the discomfort of her breast prosthesis, but her reconstructed breasts (she had

undergone bilateral reconstruction) did not feel part of her 'embodied' self. They were more abstract, as described above.

Other women in the study were less concerned to have reconstruction; in fact had little interest at all. Alaina related:

It wasn't that much of a huge blow to have one boob missing.  
I know some women are totally freaked out by that and there body  
image goes hey-wire. I probably didn't have that much of a high  
self-image, I don't know (392-394).

Yet other women in the study who had undergone reconstruction were pleased with their reconstructed breast(s), but it could be sensed that it was still regarded as a reconstructed breast, not quite the true self as known. It was something they were still coming to terms with. For example, Sonya related:

It's not a matter of how does it look – if I was younger I probably  
would [have further surgery to improve cosmesis] ...Last Sunday  
I was in my nightie and I went past the mirror and you see yourself  
and one is down there and one is up here, and you think well this is  
the one that needs to be fixed, not the one that has had a mastectomy,  
it needs to be lifted up. But if you put a bra on, nobody knows (477-481).

Thus women in the present study appeared to have worked at re-integrating their altered body image into their sense of personal selfhood. It seemed to be a process of coming to terms with their breast cancer and the treatment choices they had made.

### **Integrating 'choice' and 'self'**

It has been related throughout this study, that it appeared maximizing survival was the women's top priority, but minimising disfigurement (without cost to any survival advantage) was also an integral factor in their treatment choices. One just had to listen a little keener. The women readily accepted adjuvant therapies, tolerating the side affects and disruption to, and impairment of, their quality of life. The participants saw these as a far lesser evil than the risk of recurrent disease (even if the statistical advantage to be gained wasn't great, and for many women, a difficult concept to grasp). As has been related, some of the women were less concerned with

body image than were others. Yet some of the women stated they would have been devastated to undergo mastectomy, or mastectomy without reconstruction. For example, it was related in chapter six how Denise said that it would have been “a whole different ball game” (247) if she had had to consider mastectomy. It was a very personal choice. The women were constantly challenged to integrate (and some had transcended) their experiences, and their choices, with ‘the self’ as known. Therein the core category that evolved in this study was “Unifying ‘the self’ with treatment choice”.

**Core category: “Unifying ‘the self’ with treatment choice”**

As related in chapters five, six and seven, whatever decisions the women reached, it was never an easy process. Once they had made their choices it appeared they then began the work of committing themselves to those choices, or reaching ‘a point of salience and commitment to choice’ (chapter seven). It appeared, in some of the women, this unification of self with treatment choice contained elements of ‘transcendence’ over breast cancer. The women worked at coming to terms with their breast cancer, and the treatments they had chosen. This often appeared to enrich them and make them stronger people. Some of the more pertinent examples follow.

Margaret related that she felt, in retrospect, her treatment for breast cancer had not been so bad:

I think I was lucky. People say, “Oh well, you can’t say you’re lucky if you have breast cancer”. Yes, but the treatment I had wasn’t terrible treatment that a lot of people have got to have and then not survive at the end of it. I mean I’ve gone from 1995 to the year 2000 (180-183).

It was related in chapter six, and earlier in this chapter, that Joanne chose to have immediate reconstruction because “I just wanted to put myself back to where I was” (163). Joanne also stated: “I decided to have reconstruction at the same time because I don’t like surgery...I feel with surgery I’m not in control. So I didn’t want anymore. I wanted to be in control as much as I could” (96-99). Now, five years on, although still having further minor plastic surgery to improve her reconstruction, Joanne related that she had regained her original passion and love of life:



And people say, "Oh, but you're so wonderful". And I say, "but I'm not, I'm a perfectly normal person. This has been a blip in my life and now I'm okay, I'm carrying on"... But we're all different and I think it is, yeah, you can't query why one person does one thing and another something else (347-350).

It is often related how a crisis such as cancer that touches on our very mortality often brings us to re-assess our life situation and re-examine how we live our lives. Women in the present study re-iterated how much more they valued life and health since their cancer experience and how they didn't worry so much about the trivia and mundane affairs of life as much anymore. They now tried to give more attention to those that meant most to them and doing the things they enjoyed as opposed to doing the things they thought they should do. Louise related that she had gained a new confidence having faced the crisis of breast cancer:

I get out and do things. I go skiing. Last year we went to Club Med and they had a circus school there and I went on the trapeze, and I swung out and did a swing and the guy caught me – all the things I didn't think I would be able to do – and I was fine (154-157).

It was related in chapter seven that often women didn't have a great deal of choice if they wished to undergo the best clinical option for their particular cancer. Often "unifying 'the self' with treatment choice" was about coming to terms with what was regarded the best medical option. Mary, who underwent conservative surgery, said that if things had been different, if she'd had to consider mastectomy as the best option, then she would probably have accepted that fact. She related:

I mean, if he said he hadn't done it all and he'd have to do a mastectomy, I would have just said, "well you have to then". I probably wouldn't have felt too good about it at the time, but who knows how you would react? I think you'd just do what you have to do (557-559).

Participants appeared to rationalize their choices; accommodate them into their own persona. For example, Louise was advised that mastectomy was her best clinical option and in discussion with a plastic surgeon, she learned that reconstruction would

be very difficult and would probably have a poor cosmetic outcome. Louise therefore worked at accepting her mastectomy wound. She rationalized:

I'm not that big, I've got a really good prosthesis, I still wear a bikini, I still wear, you know, T shirts and things like that. No one ever notices (51-51).

Two of the participants related how their faith in God helped them cope with their cancer. For example, Gwen said:

I still have a purpose in life. I will get well and carry on and if not, well, then I will have to accept that, so. And I thought, well maybe it has come to me for a reason – because I can now be of help to others (189-191).

Gill also related that her faith in God gave her strength to cope: "I also must add that I am really grateful to know that my life is in God's hands. I really think that that's really important and I have had lots of people praying for me" (236-237). She also added how important the support she received from the medical and nursing staff during her treatment was to her:

I must say one other thing that has occurred to me and that is while all this is going on you're the centre of attention, you really are, and then when your treatment has finished and you go home you are left in a bit of a vacuum. And another thing, which is a bit strange, and a bit scary, is leaving all your doctors and nurses behind (238-241).

In the course of their interviews, participants in this study gave examples, in subtle ways, of how they had worked to come to terms with their breast cancer, and their treatment choices. It was more than an intellectual process; it required a coming to terms with an altered self. They tried to be positive and optimistic about their future and their lives, whilst always living with an element of uncertainty.

## SUMMARY

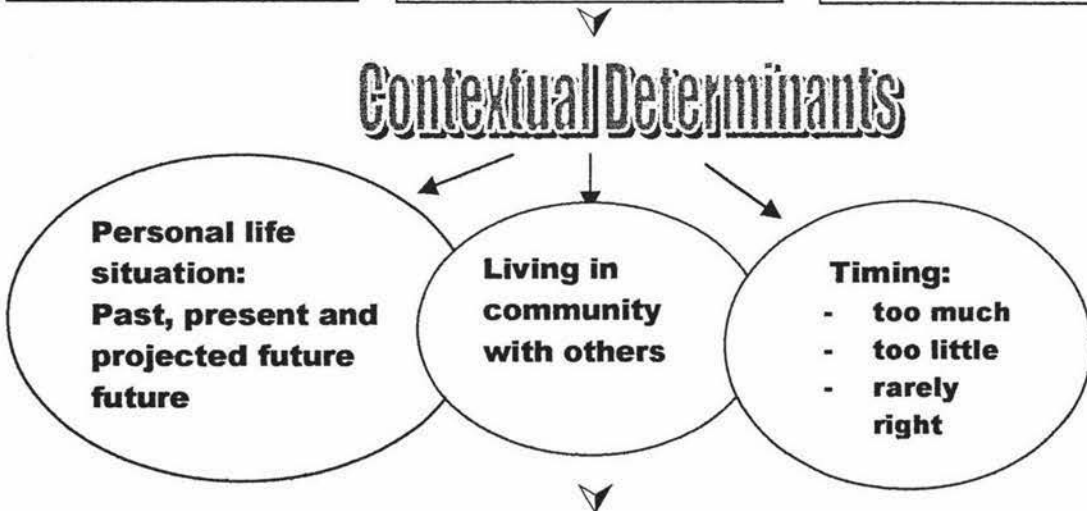
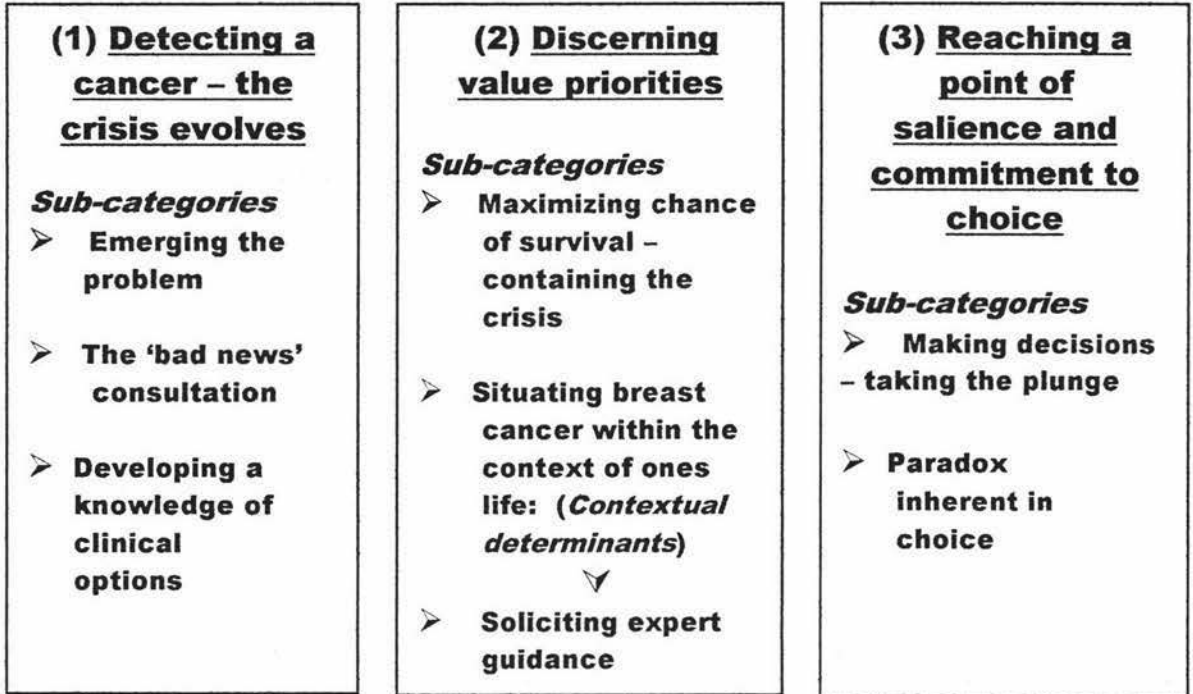
Deciding treatment options amidst the crisis of a breast cancer diagnosis was never an easy process. As related in chapter six, the context of women's individual lives, and personal histories, affected the decisions they made. Decisions regarding conservative surgery, mastectomy, mastectomy with reconstruction and adjuvant therapy required a value judgement on behalf of the women themselves. Their past, present, and vision of the future affected these decisions. In making their choices it appeared they considered both the private and the public self. They tried to make decisions that they felt they could live with both in the present, and in their future. Maximizing survival and containing the crisis (including loss of body integrity) were integral, not separate, factors. Trust in expert guidance was also very important. Chapter seven related that having decided their treatment option(s), women worked at developing a commitment to that choice. For every choice there were positives and negatives; women had to weigh the 'pros and cons'. Chapter eight has attempted to relate that all of the above takes time, and hard work. It starts at the beginning of a breast cancer diagnosis, or perhaps even pre-diagnosis. Women struggled to integrate the objectified (diseased) body with the self as known (the 'lived' body). This only came after a period of grieving and reconciliation. The overarching category was therefore determined to be "Unifying 'the self' with treatment choices".

The theoretical model that evolved from this research is set out on the next two pages. This is followed by a section explaining the model itself, and how the various categories and codes are interconnect.

## CONCEPTUAL FRAMEWORK (PART ONE)

# Breast cancer: the women's perspective on deciding treatment options

### THREE MAJOR CATEGORIES



### CORE OR 'OVER-ARCHING' (FOURTH) CATEGORY

## Unifying 'the self' with

- Making choices and living with those choices
- Accommodating the fact of cancer:  
Re- integrating selfhood

## treatment choices

## CONCEPTUAL FRAMEWORK (PART TWO)

### Substantive codes relating to each category

#### Detecting a cancer – the crisis evolves

##### **Emerging the problem**

- Finding a lump
- Screening detected breast cancer
- “Feeling devastated”

##### **The ‘bad news’ consultation**

- Receiving the bad news
- Facing a breast cancer diagnosis- hearing treatment alternatives
- ‘Flashbulb’ recall
- Receiving (and telling) ‘bad news’ difficult
- Concentrating on detail
- Feeling “out of control” – “on a roller coaster”
- Grieving potential losses: “Why me?” “Why this?”

##### **Developing knowledge of clinical options**

- Seeking information-gaining expertise
- Talking with others
- ‘Statistics unhelpful?’
- ‘Statistics helpful?’
- Choosing not to seek information
- Deciphering the jargon
- Getting it all together

#### Discerning value priorities

##### **Maximizing chance of survival – containing the crisis**

- Surviving the disease priority: preserving body wholeness integral
- Defying disembodiment
- Accepting adjuvant therapies: ‘Understanding it’ ‘Putting up with it’ and ‘Getting on with it’
  - Hormone therapy
  - Chemotherapy
  - Radiotherapy

##### **Situating breast cancer within the context of ones life (Contextual determinants)**

- *Personal life situation: Past, present and projected future*
- *Living in community with others*
- *Timing: too much - too little – rarely right*

##### **Soliciting expert guidance**

- Seeking expert advice
- Developing helping-trusting relationships with other experts

#### Reaching a point of salience and commitment to choice

##### **Making decisions – taking the plunge**

- Just ‘wanting rid’
- Deciding instantly
- Subconscious decision making
- Protecting body image
- ‘Fielding the knocks’

##### **Revealing the paradoxical nature of choice**

- Choosing (is never easy)
- Deciding (when choices are restricted)
- Weighing (‘the pros and cons’)
- Wanting (a definitive answer)
- Accepting (there are no perfect solutions)

#### Unifying ‘the self’ with treatment choices

##### **Making choices and living with those choices**

- ‘Buying in’ to personal choice
- Struggling to preserve a sense of unity and body wholeness

##### **Accommodating the fact of cancer: Re-integrating selfhood**

- Facing ones mortality
- Integrating the personal and social self: Disclosing the fact of breast cancer

##### **Unifying ‘self’ with treatment choices**

- Contours of embodiment
- Embodiment and breast reconstruction
- Integrating ‘choice’ and ‘self’
- **Core category: “Unifying ‘the self’ with treatment choice”**

## **THE WOMEN'S PERSPECTIVE ON DECIDING TREATMENT OPTIONS: THE MODEL**

Earlier in this research, as the data obtained in interviews was analysed (through a process of constant comparative analysis), a large number of substantive codes were identified. As the study progressed, a number of categories, which served to explain and connect these codes, emerged. (In grounded theory method this is referred to as theoretical coding.) Three major categories gradually evolved each of which formed the theoretical basis of an individual data chapter (chapters five to seven). Over time, a fourth category emerged which eventually became the 'core' or 'over-arching' category and served to link the whole 'process', or theory, together (chapter eight). For each major category, there were two or three sub-categories, and for each sub-category there were a number of substantive codes. It was from these broad categories, emerging from the substantive codes, that the theoretical model evolved.

The conceptual model itself is in two parts. Part one commences with the three major categories, and their sub-categories (these are illustrated in three rectangular boxes). These three categories formed the central theoretical codes for chapters five to seven, and also became the titles for each chapter. For example:

- Chapter five: Detecting a cancer – the crisis evolves.
- Chapter six: Discerning value priorities.
- Chapter seven: Reaching a point of salience and commitment to choice.

In the centre of the model, and developed from the sub-category 'Situating breast cancer within the context of one's life' (chapter seven), there are three circles containing what were identified as the 'contextual determinants' in the women's decision making. They included (circles left to right):

- The women's personal life situations (present, past and projected future).
- Living in the community with others (including 'living in relationship' with one's partner and family).
- Timing: Too much – too little – rarely right .



The fourth category, which emerged as the ‘core’ or ‘over-arching’ variable, was “Unifying ‘the self’ with treatment choice”. (This is shown at the bottom of the model encompassing the theoretical and substantive codes that pertained to this category.) This appeared to be the major, or over-arching theoretical code, that linked all the other codes and categories together.

Overall the model is linked (with arrow heads) to demonstrate how the (theoretical) categories and substantive codes were in fact a process that occurred, not only as the women made their treatment decisions, but as they came to terms with their cancer, and their choices, over time.

Part two of the model (set out in landscape view) provides a visual image of the substantive codes relating to each sub-category. Part two is the ‘inside view’ of the categories, which make up part one.

A number of theoretical propositions can be drawn from this model. These will be identified and discussed in chapter nine. Chapter nine will also discuss and compare the scientific, theoretical and philosophical literature relative to the findings of this study.

## **CHAPTER 9**

### **Discussion and recommendations**

*The real is a closely woven fabric*

Merleau-Ponty (1962/1996, p.X).

#### **INTRODUCTION**

Breast cancer is a threat to a woman's mortality as well as her personal sense of integrity and body wholeness. In the present study, maximizing survival evolved as the women's major concern but preserving body integrity was also an integral factor in decision making. It was also related how they encountered breast cancer within the context of complex social and personal life situations. Their past, present and projected future influenced the decisions they made. "Unifying 'the self' with treatment choices" was found to be the core category overarching the women's decision making. This process involved coming to terms with their breast cancer diagnosis, the sudden threat to their lives, their potentially altered bodies, and ultimately their altered selves. The women faced a continuous series of adjustments, both during the decision making time and certainly after. Three major theoretical categories were identified:

- (1) Detecting a cancer – the crisis evolves.
- (2) Discerning value priorities.
- (3) Reaching a point of salience and commitment to choice.

This final chapter will briefly discuss the major categories identified in the present study in relation to relevant literature and theoretical perspectives. The Glaserian grounded theory method requires that the literature is used for comparison and verification, and is reviewed after data analysis is complete, so as not to overly influence interpretation of the research findings. This chapter briefly relates literature directly relevant to the findings of the present study. Each section will conclude with a theoretical proposition relating to the category or theoretical code being discussed. The chapter will conclude by discussing:

- Implications of this study for clinical practice.
- Implications for education.
- The limitations of the present study.
- Recommendations for further research.

## **(1) DETECTING A CANCER – THE CRISIS EVOLVES**

This study began by describing the woman's experience of discovering she had breast cancer. Sub-categories were:

- Emerging the problem.
- The 'bad news' consultation.
- Developing knowledge of clinical options.

This section will discuss the present study in relation to theoretical and scientific literature related to these categories and their codes.

### **Emerging the problem**

Universally the women in this study expressed their shock at 'finding a lump', or being advised of an abnormality on screening mammography. This section briefly discusses theoretical aspects of shock and grief reactions. It also discusses how screening detected breast cancers have the potential to be 'minimized' or regarded as less significant than a clinically detected lesion, and therein perhaps encourage a degree of 'denial'.

Although there is no universally accepted theoretical perspective on grief, the five-stage model prescribed by Kubler-Ross (1970) has received wide acknowledgment, particularly in the nursing literature. These stages include (1) denial and isolation (2) anger (3) bargaining (4) depression and finally (5) acceptance. A number of these (or related stages) were recognizable in the present study and were identified in the codes: "Why me?" "Why this?", "Feeling out of control – on a roller coaster". The women described a sense of bewilderment that they should have encountered breast cancer and disbelief that it could happen to them. They also described impaired concentration and the inability to make decisions owing to their state of shock at a cancer diagnosis. One woman also spoke about a sense of 'aloneness' (isolation) as she tried to disguise her inner turmoil so as not to distress others. Yet this was the context in which women had to decide their treatment options, options that would affect both their lives and bodies irrevocably. Kubler-Ross describes 'acceptance' as her final stage in the grief cycle. In the present study it appeared that women all struggled to 'contain the crisis' and come to terms with their condition.

They appeared to work towards a degree of 'acceptance' of their breast cancer and their treatment options, whatever they chose.

Four women in the present study had their cancer detected via screening mammography. These women generally perceived their cancer as being "small, the lowest grade, caught early, slow growing – all those things that could possibly be fortunate in the circumstances" (Richelle, 80-81). It was easy to see how screening detected cancers could be minimized, or denied, especially if women underwent conservative surgery. For example, Richelle was cited (in chapter five) as saying: "I was, and still am, in complete denial, really. I'm not ill, I didn't have anything happen to me, I'm fine, just a bit different here and there" (16-17).

Farmer (2000, p. 310) states that there is a tendency amongst protagonists of screening mammography to minimize the disease in women diagnosed via this modality. Farmer performed a qualitative study to assess psychological morbidity in women with screening detected breast cancer. In her study she described how surgeons presented a very optimistic picture, "a new cognitive model", of this disease, that is, "a-symptomatic, requires only minor surgery, is unlikely to spread, and is curable". Screening detected breast cancer was treated as almost a positive event, such as 'how lucky women were' that their cancer has been detected early. Women were rarely given full treatment options. It was assumed a priori that they would undergo conservative surgery. Yet as Farmer states, screening detected cancer still has the potential to seed micro-metastases; some women will die from their disease. She warns that when this starts to happen, there will be anger, as women feel cheated by a programme that they believed promised them a cure. In the present study, all women with screening detected breast cancer were advised of the various treatment options. Two of these four women chose mastectomy. One stated she wanted mastectomy as she didn't want the fear of cancer recurring again in the same breast. The other woman who underwent mastectomy chose to because of the histology of her cancer, and its potential to reoccur both in the remaining and contralateral breast (Joanne underwent bilateral mastectomy and immediate reconstruction).

### **The 'bad news' consultation**

The women in this study were relatively generous regarding their physician's communication styles relating that it must be an extremely stressful task having to repeatedly inform women that they have cancer. It appeared all clinicians were 'up-front' with the news, then spent time going through the details with each woman. All surgeons encouraged their patients to take time in making their decisions regarding their surgical options. There is considerable literature on physician-patient communication, but as this study is about the women's perspective on deciding treatment options, the present discussion will limit itself to studies relating to breast cancer and patient-physician communication only.

Clinicians are faced with the dilemma of how much information to give when treatment outcomes are often unclear because of the unknown origin of this disease, its capricious nature, and the uncertainties surrounding recommendations for the best therapy. Almost fifty years ago, Bacon, Renneker and Cutler (1952) suggested that the surgeon should steer a middle course between terrifying obscurantism and equally terrifying un-absorbable information. They also recommended that the clinician use language that would dispel ignorance without dispelling hope. This advice may be easily given, but it appeared in the present study, difficult to achieve. The women appeared to have struggled with the complex medical terms and concepts related to them. They looked for reassurance, where often none could be given owing to the limited knowledge the clinician had available to him or her at the time (pre-operatively). Clinicians were 'cautiously optimistic' trying to be as honest as possible. 'Telling the bad news' is not an easy communication, for either the patient or clinician (Taylor, 1988).

Decades on, physicians use a variety of communication styles for 'Telling the bad news'. Schain (1990) talks about the 'assessment-disclosure-assessment' style. She relates that in these difficult communications, it is not uncommon to recognize "a struggle for power and control, either subtle or blatant, that permeates the transaction" (p. 919). She affirms Shapiro and Goodman's (1980, p. 108) advice to clinicians that most women want "an ally to share in their ordeal" and not an authority figure who will "direct their drama". Certainly in the present study the

women looked to their clinicians as someone they could trust and put their faith in. The women were dependent on their physicians for their 'expert advice'. One could sense the occasional 'power struggle'; for example, Denise wanting her surgery 'the next day' (chapter five) and Pam, wanting a mastectomy despite there being no definitive diagnosis, at the time, that the lump that occurred in her remaining breast was cancerous (see chapter seven).

An ethnographic study by Taylor (1988), titled *'Telling bad news': physicians and the disclosure of undesirable information*, identified three phases of physician communication: preamble, confrontation and diffusion of telling the news. Taylor reported physician characteristics described as the 'experimenter' and the 'therapist'. The experimenter tended to use facts and scientific data to support his treatment suggestions freely admitting doubt and uncertainty where it was present. The therapist preferred to use euphemisms to hard facts and other messages to soften the blow. Therapists said they only offered information if asked for it. Taylor relates that either method tended to reduce the need to individualize characteristics, which enabled them to 'operationalize' a "rigid, predetermined, yet efficient disclosure policy" (p.113). Various aspects of these styles of communication could be noted in the present study. It was evident that one or two of the surgeons tended to use a 'set patter' in relating information: there was a hint of the 'experimenter' or, for a better description, the 'scientist'. It appeared that some surgeons/physicians felt that providing the women with statistical information was the most honest and least the patronizing way of giving advice. There was no evidence of the use of euphemisms by the women's clinicians in this study.

### **Developing knowledge of clinical options**

In relating their stories the women used medical terms when explaining their tests and diagnoses. Sometimes their understanding appeared to be a little eschewing, but overall women had a good grasp on the terminology and had appeared to decipher and adopt the common jargon of surgical and medical oncology. Most of the women believed they had received adequate information.



As discussed in the literature review (chapter two), the majority of women state that they want information, good or bad, to help them make decisions regarding treatment options (Fallowfield et al. 1994; Hughes, 1993; Richards et al., 1995; Roberts et al. 1994). The question of how much women want to be involved in decision making, however, remains open to debate (Beaver et al., 1996; Bilodeau & Degner, 1996; Degner et al. 1997; Degner & Sloan, 1992; Hack, Degner, & Dyck, 1994; Luker et al., 1996). There was little doubt, however, in the present study that the women wanted information about their breast cancer and treatment options. Most of the women, however, had a mild suspicion about 'statistics' owing to the fact that they had been unlucky enough to get breast cancer in the first place, or as Joanne described it, "fallen in the first hole" (293). Margaret thought statistics were a bit like a lotto game adding, "and I've never won the lotto" (436). Overall, however, the women in the present study were very active participants in deciding their treatment options.

#### **The theoretical proposition to be drawn from the categories/theoretical codes**

In the present study women universally described the diagnosis of breast cancer as a major life crisis. Their reactions were congruent with the theoretical literature on shock and grief. The women appeared to struggle with the information they were given regarding their various treatment options. Although clinicians' communications styles varied, most used statistics to present information as objectively as possible, regarding possible treatment outcomes. To participate effectively in their treatment plan, most of the women in the present study sought further information on breast cancer.

The theoretical proposition to be drawn from the categories identified in this section is therefore: *Detecting a breast cancer is an existential crisis and is the context in which women are required to decide their treatment options. Developing knowledge of clinical options appears to assist women to gain a level of expertise and regain a sense of control over what is happening to them.*

## **(2) DISCERNING VALUE PRIORITIES**

Chapter six identified how the women's value priorities were central to their decision making. They were also reliant on the 'expert guidance' of their clinicians to make 'clinically safe' or 'medically appropriate' treatment decisions. The major categories relating to this theme were:

- Maximizing chance of survival – containing the crisis.
- Situating breast cancer within the context of one's life.
- Soliciting expert guidance.

### **Maximizing the chance of survival – containing the crisis**

Maximizing their chances of survival appeared to be the major priority for women in the present study, however, this was balanced with the struggle to 'contain the crisis' so as they could cope with their situation. This included the disruption breast cancer had caused to their lives (and other people's lives) and their bodies. 'Accepting adjuvant therapy' was a further code discussed in this section. These therapies often caused considerable morbidity (especially chemotherapy) and disruption to the women's lives. Despite this the women readily accepted that this was the price they had to pay to protect their future, no matter how small this protection might be.

Although the psychological morbidity experienced by women undergoing mastectomy and conservative surgery may not be consistently measurably different (as reported in the psycho-social literature), it appeared in the present study that women who underwent conservative surgery experienced less impact in relation to body image. Conversely, they appeared to harbour more fear with regard to local recurrence than the women who underwent mastectomy do. It seemed that the women who had chosen mastectomy over conservative surgery had either adjusted to their mastectomy wound, or had gone on to have reconstruction. Those who had undergone reconstruction were either very pleased, had either reached a level of satisfaction, or in some cases, acceptance, of the cosmetic outcome and 'feel' of their reconstructed breast(s). Three of the five women who chose wide local excision indicated they would have been devastated if they had had to undergo mastectomy and said they probably have gone with the option of reconstruction.

Chapter two reported a number of studies which stated that fear of cancer and its possible recurrence appeared to be the "compelling factor in determining a woman's preference for treatment" (Fallowfield, Hall, Maguire & Baum, 1990, p. 579). Schain, Wellisch, Pasnau and Landsverk (1985) state that patients who had reconstructive surgery at the time of mastectomy (immediate) or within one year (early) had significantly less recall of distress than those women who had delayed reconstruction. Leinster, Ashcroft, Slade and Dewey (1989), however, found no difference in body satisfaction between women who chose breast conservation surgery or mastectomy with or without reconstruction. Women, who chose conservative surgery, however, said they would have been devastated to have to have mastectomy. Vice versa, women who had mastectomy would have been unhappy to undergo conservative surgery related to fear of recurrence. Stevens, McGrath, and Druss (1984) report that women who pursue delayed reconstruction tend to have a greater sense of mutilation, are more depressed, and often undergo surgery to eliminate the need to wear an uncomfortable external prosthesis. The present study concurred with most of this although satisfaction appeared to be related to women's salience with the choices they made. In making choices the women appeared to commit themselves to those choices, irrespective of what those choices were.

In relation to accepting adjuvant therapies, the present study concurred with other research that suggests women generally accept their clinician's advice regarding the need for further treatment. Penman et al. (1984) reported that 'trust in the physician', 'belief that the treatment would help', and 'fear of recurrent disease' were the reasons women accepted adjuvant therapy. In the present study women accepted adjuvant therapy if it was offered. They felt that even if only a small statistical (survival) advantage could be gained from treatment it was worth it and they were willing to tolerate any side-effects or inconvenience that might be incurred.

In researching the 'women's perspective' on deciding treatment options the multi-dimensional nature of their decisions became apparent. The present study sought to reveal the 'why' of decisions as opposed to the 'what' one's. It was also a retrospective look, and therefore had this added insight. Women related a variety of

reasons for their choices. It was often a very individual and personal matter, but overall there was also a strong commonality; women wanted to maximize their survival whilst still maintaining their 'body intactness' as much as possible. However, this too was an individual matter. For some women this meant undergoing mastectomy, along with reconstruction. Other women thought mastectomy was a small price to pay to be rid of the cancer. Yet three other women said they would have been devastated to undergo mastectomy, but 'would cross that bridge' if they had to. Adjuvant therapy was about 'maximizing survival', and in the present study all women accepted any adjuvant therapy that was offered.

### **Contextual determinants: Situating breast cancer within the context of one's life**

This section took a slightly philosophical turn to discuss the more individual life situations and circumstances of women diagnosed with breast cancer, which gave meaning to their decisions. Invariably the women's life experiences, family histories and their personal life situations were major factors influencing their decisions. These were called 'contextual determinants' and were coded as personal life history, situation and living in community with others. Timing in relation to diagnosis and treatment was another contextual determinant which affected women's decision making. A brief discussion follows to link the existentialist view to the findings of the present study.

#### ***Personal life history and situation***

The concepts of personal life situation and history were aligned with a number of philosophical views on personal freedom. The phenomenological-existentialist view is that humans are expressive beings by virtue of belonging to a culture; a culture which is nourished, sustained and continued by its community of people, and therein, the community itself has an expressive unity (Taylor, 1979). From this perspective, people are seen to 'inhabit' their world as opposed to merely 'living in an environment' (which is aligned to the traditional, rationalist view). Importantly, people inhabit their worlds in an involved and concerned way. Relationships, meanings and membership constitute the person within that community. As Sartre (1969, p. 482) states:

Much more than he [sic] appears to 'make himself,' man seems  
'to be made' by climate and the earth, race and class, language,

the history of the collectivity of which he is part, heredity, the individual circumstances of his childhood, acquired habits, the great and small events of his life.

Human beings are always pushing towards a projected future, drawing on a lived past, and making choices in the present that actualize future possibilities. Because of this 'situatedness' people are never able to be either entirely free, or freely choosing, nor 'unfree' but are "embodied in life" (Taylor, 1979, p. 21). Thus human beings both constitute and are constituted by their world (Sartre, 1969). Choices are made within this context.

In some aspects this view is congruent with the 'sociological' perspective underlying the grounded theory method, symbolic interaction. From the social-behaviorist standpoint, this view, simply related, sees human beings as 'subjects' who act towards things based on meanings as opposed to 'objects' reacting to a stimulus, which was the traditional school of thought in the sociological and psychological sciences (Blumer, 1969). 'Meaning' is acquired through a lifetime of association with other people, within a specific society and culture that has its own peculiar beliefs and habits. Basic to the development of meaning is the human ability to have a self-concept which is developed through interaction and experience with other people, events and the situations they encounter (Blumer, 1969; Mead, 1934). Decisions and choices are made in relation to the individual's self-concept.

Both of these views were congruent with the present study. The women's past, present and projected future influenced their decisions. They were also affected by the context of their present life situation and life roles be it they were career women, mothers, wives, or other. Their experience of 'others' having breast cancer, the choices they had made (and their outcomes) also influenced women's decisions.

Feminist theory offers a further perspective on human nature noting that human behaviour is also gender specific (as discussed in chapter two). Whereas male moral thinking and decision making is described in terms of rational constructs and abstract moral principles, such as those of autonomy and justice, female thinking is described more in terms of non-rational constructs, notably feelings of care, empathy,



compassion, love, sympathy and friendship (Gilligan, 1982). In making decisions women are more inclined to consider what affect their choices will have on others. Certainly in the present study women considered the affect their treatment (and treatment outcomes) would have on their loved others. For example, Cathy toyed with the idea of mastectomy (to be rid of the fear of recurrent disease in the affected breast) but knew that if she chose mastectomy, then she would want to have reconstruction. With an eighteen-month toddler to care for, this option was out of the question. She couldn't possibly afford the 'time out' extra surgery would require. She accepted the offer of chemotherapy so as to gain every protection against recurrent disease. It was related in chapter six that Cathy said, "I can't be sick – I'm this child's mother", meaning 'I have to survive to care for, and love, this child'. Two of the participants' husbands had lost their mothers from breast cancer; these women appeared to try and 'protect' their husbands realizing the grief their husbands were experiencing now that their wives too were threatened by this condition. Margaret tried to protect her father who had lost his second wife from breast cancer and was the same age as Margaret when she died. All of these factors affected how the women in the present study reacted to their breast cancer and ultimately the decisions they made.

Choosing one's path in life, one's self project, is an inherent quality of human action (Blumer, 1969). From an existentialist perspective, Sartre (1969, pp. 71-78) explains how the problem of choice and responsibility often become an agonizing burden: "I emerge alone and anguish in confronting the unique and original project which constitutes my being...Anguish is the reflective apprehension of freedom itself". Anguish or anxiety is inherent in making difficult decisions, and was the case in the present study. Coping with cancer often becomes a new 'life project'. Although women in the present study were pleased to be involved in deciding their treatment options, it was never easy, it was never painless. They chose the options that they felt they could best live with, both in the present, and in their future.

It appeared the findings of the present study concurred in various ways with all three philosophical or theoretical perspective's (existentialist, symbolic-interactionist, and the feminist) on what it means to be a human being faced with difficult choices.



Choices, which could alter the course of their lives, and without which, could threaten life itself.

### **Soliciting expert guidance**

As discussed earlier (the 'bad news' consultation'), throughout the present study the patient-physician communication and the relatively long-term association that developed, was an extremely important one. Not only did women take information and advice from their clinician they also looked for reassurance and support. They had considerable faith in their clinician's competence and expertise; that he or she would guide or advocate for them, if they should make 'unwise' treatment decisions.

Chapter two discussed how social scientists have dichotomized patient responses into two types: *monitors* and *blunters* (Schain, 1990). *Monitors* are the people who want to know everything they can about a threatening or challenging situation, whereas *blunters* want to be protected from the full impact of frightening or painful information. Alternatives to this are 'active, passive and collaborative' decision making preferences (Bilodeau & Degner, 1996; Degner et al., 1997; Degner & Sloan, 1992). It appeared, in the present study, that participants had a range of these responses at different times, and at times, in the same participant. This was more to do with blocking information that could be overwhelming. For example, a lot of the literature women read started off with statistics about how many women get breast cancer each year and how many die of the disease. Sonya related that she stopped reading because of this. The women in the present study may have concurred with Cousins (1989, p. 12) who remarked "Statistics obscure souls...whole lives get gobbled up by whole numbers".

Schain (1990) relates that many surgeons would view their first and foremost responsibility to be that of technical competence and caring for the patient's physical welfare. She states that it is not clear whose responsibility it is for attending and managing the patient's emotional distress. She says that medical school education in this facet has been sadly lacking. Schain believes that two serious culprits interfering with a more humanistic and empathic interaction between the physician and patients are both "time and professional training" (p. 931). She suggests that what is essential in communicating a cancer diagnosis and prognosis is that the physician be

“honest, compassionate, and life affirming” (p. 931). Restrictions on time and perhaps an ‘avoidance’ of the emotional burden by clinicians were evident in the present study. However, it was also obvious that a number of clinicians went out of their way to create time. Richelle and Julie related that they were given the last appointments of the day (for their ‘bad news’ interview) and although their appointments were extremely late, the clinician was willing to take as much time with them as they wanted. (Julie related that she worked out it was a ‘bad sign’ getting the last appointment of the day.) Rarely did women find fault with or complain about their clinicians. Sincerity, integrity and willing advocacy appeared to balance the negatives. It appeared that over time most of the women developed a relatively collegial relationship with their clinicians, although the imbalance of ‘knowledge and power’ could still be intuited. This is where the category ‘Soliciting expert guidance’ evolved, as women were highly dependent on their clinicians’ knowledge, skill and wisdom to guide them in deciding their treatment options. However, it was mostly a collaborative decision-making process as Julie related (chapter seven): “Basically I was being guided but nobody actually told me what I had to do” (153).

**Theoretical proposition to be drawn from these categories/theoretical codes:**

Women in the present study went through a process of discerning their value priorities in deciding the treatment options they preferred. This involved reflecting on their past, present and projected future which they always lived ‘in relationship’ with others. ‘Expert guidance’ was very important to women, but overall they preferred a collaborative decision making process. In the end, the final choice was theirs. This aligned with a number of theoretical/philosophical perspectives on what it is to be a human being faced with making choices. ‘Trust in expert guidance’ was namely related to the felt ‘competency gap’. This was congruent with medical and social science literature. It appeared that the women had to best gauge how they personally would cope with their chosen treatment option(s). This was often an unknown equation at the time of decision making.

The following theoretical proposition therefore emerged from the categories and codes in this section: *In discerning their value priorities, women reflect on their past, present and projected future, which is always lived in relationship with others. 'Expert guidance' is also very important; women prefer a collaborative decision making style in deciding their preferred treatment options.*

### **(3) REACHING A POINT OF SALIENCE AND COMMITMENT TO CHOICE**

Chapter seven related the various points of view the women had on deciding their treatment options. All women had their own reasons for the particular choices they made. Having made their decisions it appeared women worked at committing themselves to those choices. There were always positives and negatives with every option. Breast cancer was encountered within a social context; women had to contend with 'other peoples' reactions to their having experienced this condition (although this was often more covert than overt). The two central categories identified were:

- Making decisions – taking the plunge.
- Paradox inherent in choice.

#### **Making decisions – taking the plunge**

It appeared that some women made their choices quite quickly - 'deciding instantly'. However, on further analysis it became obvious that there was considerable background thought behind these decisions. Universally women wanted information, although not too much statistical information.

Chapter two examined medical and social science studies which have investigated how women decide treatment options for breast cancer. It was identified that although women want full information regarding their breast cancer and treatment options, this did not necessarily translate that they personally wanted the responsibility for that decision (for example: Beaver et. al, 1996; Bilodau & Degner, 1996; Richards et al. 1995; Waterworth & Luker, 1990). Schain (1990) expressed the fact that woman are neither uninformed, nor naïve, about breast cancer, but

bombarded by fact and figures regarding the outcome probabilities associated with one type of therapy versus another, can leave them in a state of high anxiety. This is especially so when faced with making an irrevocable personal choice.

The present study concurred with these studies. The women were well informed about their options but preferred collaborative decision making owing to both their anxiety and the complexity of the various options. Joanne, who was a member of the Breast Cancer Support Service, and occasionally visited women both pre and post operatively, said that she thought there was now too much responsibility put on women to make their treatment decisions. Although she personally wanted this opportunity, she stated that some women with whom she had been involved found this too burdensome. The participants in the present study, however, believed it was important that women make their own decisions, particularly when it is a matter of personal preference, as opposed to a known clinical advantage or disadvantage (which was generally based on statistical probability).

### **Paradox inherent in choice**

Chapter seven identified the inherent anxiety and paradoxical nature of choice. For all things there were positives and negatives; for every decision there were multiple possibilities. Deciding their treatment options meant the women had a degree of freedom in deciding how they wanted their breast cancer to be treated, however, involvement also passed on 'ownership' for those decisions. As previously stated this could be both affirming but also burdensome.

In the existentialist view, human beings are considered to be unique and free to choose personal meaning in life, to make personal choices: "It is through free and responsible decisions that man becomes authentically himself" (Macquarrie, 1973, p. 4). With each choice, however, there are numerable possibilities. Some will offer opportunity, and in-turn some will be limiting in other ways. Sartre (1969) relates that choices are generally made without full knowledge of the outcomes, yet with full responsibility for consequences. Anxiety is inherent in choice, as it is always associated with a degree of resistance.

In making decisions regarding their treatment choices women in the present study weighed the 'pros and cons' of each choice; it appeared that there was generally a degree of both acceptance and resistance. Indeed, a number of women appeared to have experienced considerable anxiety in making their choices, although their overriding anxiety appeared to be, 'just wanting rid' of their cancer (refer chapter seven). Another anxiety was the uncertainty regarding prognosis, and whether they would survive to have a future. Their choices were always contingent on the prospects their choices held for ensuring that indeed they had a future and women readily accepted any adjuvant therapy that they were offered.

### *Social expectations*

In the present study there was also a 'social' side to the women's choices. Until recently, breast cancer was a relatively 'hidden' disease, enmeshed in society's various taboos about cancer and sexuality. These were issues women had often absorbed through a subconscious socialization, and which also affected their decision making with regard to body image and how it is to be a woman in our society. In a historical social context (Anglo-Saxon heritage) personal health has always been treated as a private matter. Until relatively recently, breast cancer (or any other illness) was generally kept private. People still refer to the 'big C' rather than even mention the word cancer. Cancer involving bodily organs related to sexuality is engendered with even more taboo. This is related very succinctly in the following prose by Underwood (1990, p. 202):

But this grief is silent, a secret. I hide the knowledge of this lump  
rather than share it. I find it hard to say, "I have a lump in my breast".  
Something stops me from talking about my breast in the same way that I  
might talk about my arm or my leg or my eye.

Underwood reflects how her experience and socialization regarding 'breasts' were paradoxical. When she was young, breasts were for the most part something soft; they were comfy things that belonged to other people's bodies. A soft place to lay her head when she cuddled on her mother's knee. But for some reason they were also impolite; something you didn't mention. Somehow this experience and socialization becomes part of women's experience.



A central tenet of feminism is that women's invisible, private wounds often reflect social and political injustices (Dalton, 1989). Audre Lorde (1980a) wrote how it is expected that the application or implantation of silicone gel is expected to return a woman to the physical and emotional state she enjoyed prior to her encounter with breast cancer. She lodged criticism at such groups as 'Reach to Recovery' in America (Breast Cancer Support Service in New Zealand) for its emphasis on cosmesis and the physical pretense that a prosthesis will conceal the fact of cancer. Lorde (1980a, p. 44) retorted that "Not even the most skillful prosthesis in the world could undo that reality, or feel the way my breast felt, and either I would love my body one-breasted now, or remain forever alien to myself". Her cry was that after breast cancer she was a warrior - not a victim (Lorde, 1980b).

Colyer (1996) related that it is widely acknowledged that a small number of women will develop significant problems adjusting to body image result of mastectomy. This distress can be experienced not just in terms of an impaired sense of femininity or sexuality but can have a profound impact on the 'whole' of the person. Revelation of this distress can be hindered by a fear of stigma as a consequence of women living in a culture and society where womanhood is bound up with having a perfect body and blemish-free appearance. This results in many women concealing their loss and grief, both physically and emotionally, in an outward desire to appear 'normal'. This is partly supported by the pressure to conform to society expectations. The wearing of an artificial breast prosthesis, or reconstruction, could be said to be in this category.

Women in the present study were influenced by their gender socialization; to have breasts, to wear a prosthesis, and to be attractive. Indeed, breast cancer is both 'personal and political'. The women in this study related having to deal with their breast cancer on many levels. First they had to try and cope with their own emotions which threatened to overwhelm them (chapter five: feeling "out of control" – "on a roller coaster"; "just devastated"; "Why me?" "Why this?"). Next they had to deal with 'others' emotions; their partners, families, friends and work colleagues. In deciding their treatment options they had to confront their own beliefs about femininity and body image as well as weighing up what was important to them in life. For example, did they want to undergo major surgery so as to have



reconstruction, with its inherent risks, or would they settle for wearing a prosthesis? Did they want to bother with a prosthesis at all? (Louise related how it gave her a sense of freedom when she was at home, not to bother with a prosthesis at all, but that she always put it in when she went out.) Most women, however, felt more confident to wear a prosthesis, if they hadn't undergone reconstruction (or had conservative surgery). Body image was important, but it did not appear to be the overriding priority for most women in this study. Surviving was their first priority. Concerns for body image were integral, but definitely secondary, and often dealt with after issues around survival had been fully explored. This is wherein some women preferred to leave the option of reconstruction until later. They didn't want to close this option, but would prefer to deal with it later. They wanted to first see how they coped; if their mastectomy scar was a problem (or their coping with it was) then this option could be revisited later. The women also related how that now, after their encounter with breast cancer, they had different value priorities in life. They valued each day for what it was, for just being alive and part of it, and they tried to spend it as wisely (and as happily) as they could. There was an indication of transcendence over suffering; these women were survivors, not victims, of cancer.

**Theoretical propositions relating to these categories:**

In the present study it was obvious that the women engaged in considerable reflective (and pre-reflective) thought before they reached their treatment decisions. Decisions were always both enabling and limiting; women therefore had to weigh the pros and cons for each choice they made. This concurred with the existentialist literature on choice and decision making and also the feminist literature regarding women's gender socialization regarding breasts and femininity.

The following theoretical proposition is prescribed for this section: *Reaching a point of salience and commitment to choice only comes after considerable reflective, and pre-reflective thought. For all choices there are positives and negatives. One has to accept that there are rarely any definitive answers or perfect choices.*

## **CORE CATEGORY: UNIFYING 'THE SELF' WITH TREATMENT CHOICES**

Chapter eight brought together all of the issues discussed above under what was identified as the core variable: Unifying 'the self' with treatment choice. As this study was a retrospective view of how women came to decide their treatment choices, it became 'entwined' with how they had coped or adjusted to those decisions. However, as stated by Sartre (1969, p. 499) the "urgency of the past comes from the future" and the women's choices were always directed toward their future. In making treatment choices, possible or probable outcomes could only be anticipated. If treatment was successful, it appeared, in the present study, that women began the work of re-integrating the 'altered' self into their (new) personal self-concept. Central categories in chapter eight were:

- Making choices and living with them.
- Accommodating the fact of cancer: Re-integrating selfhood.
- Unifying 'the self' with treatment choice.

### **Making choices and living with them**

Overall it appeared women decided the treatment options they felt they could best live with, or cope with. The women for whom options were limited appeared to work at accepting what was, or had to be. At the time of interview, most of the women had reached a degree of acceptance of the fact of their breast cancer and appeared to have 'integrated' the experience into their lives. It was now less for-ground and more 'background', as time and 'disease free survival' created some distance from the event. It appeared it was often re-affirming for them (in the interview) to realize they had come this far.

As stated earlier in this chapter, the existential-phenomenological view is that human beings are always pushing towards a projected future, drawing on their past lived experience, and making choices in the present that actualize future possibilities (Heidegger, 1927/1962). However, in illness, one's ability to project oneself into the future in desired ways is temporarily or permanently altered (Bishop & Schudder, 1991). This often creates a sense of fear and hopelessness. In the present study, fear of recurrent disease was a constant. Multiple authors (Mullan, 1985; Nelson, 1996;

Schmale, Morrow, Schmitt, 1983) have documented the often-pervasive uncertainty experiences linked to cancer survival. In exchange however, as Nelson's study reported, this can often be a growth-producing aspect of the condition as well. Nelson found that women often had a renewed sense of freedom, which allowed them to express themselves more honestly. Carter (1990, p. 280) reported similar findings saying, "cancer gave them permission to live more healthfully, and to change attitudes, behaviours and lifestyles". In the present study Louise and other women reported how they had a renewed confidence in themselves and would now do things that once they would never have even considered. For example, it was reported in chapter eight how Louise had swung on a trapeze at a circus – done things she would never have dared before breast cancer.

### **Accommodating the fact of cancer: re-integrating selfhood**

Each of the human and social sciences have their own theoretical/philosophical perspective on what it is to be a human being. It has been related that the theoretical perspective underlying the grounded theory method rests on the general tenets of Blumer's version of symbolic interactionism derived from the work of G.H. Mead (1934). Mead (1934), a social behaviorist, believed that human beings very definitely distinguish between 'the self' and 'the body'. He stated that the body operates in a very intelligent fashion without there being 'a self' involved in the experience. "The self has a characteristic that is an object to itself, and that characteristic distinguishes it from other objects and from the body" (p. 136). This type of object is different from all other 'objects' and Mead states can be regarded as "a conscious – a term which indicates an experience with and of one's self" (p. 137). This concept of 'the self' is not incongruent with how the women in the present study appeared to perceive their overall self-concept that was altered by their experience of cancer, and their chosen treatment option. For a time their 'breast' became an object to them, an object that was diseased, and was a threat to their lives. This was in sharp contrast to their breasts as known, before cancer. Breasts that 'had given them a lot of fun' (Gill); breasts that had 'fed their children' (Richelle, Joanne), and had been symbols of motherhood, nurturance (Richelle), womanly sexuality and more. 'Breasts' that were (unconsciously) part of themselves.

### **Unifying the self with treatment choice**

When a threat such as a breast cancer presents itself, the woman's breast becomes a 'threat', both to her selfhood, and her life. Women must make choices about (a) their treatment so that they can continue to live and (b) their bodies and how they will be after treatment. For a time 'the breast' becomes an objectified body part. Yet there is a dichotomy. It is still a part of the 'lived body' which embodies one's self-concept and gender identity. The contours of one's body are the contours of the 'self as known'. Therein both fear of death, and fear of disfiguration are integral factors in deciding treatment options. Loss of a breast is more than just the loss of a body part - it is loss of part of the self. As Underwood (1990, p. 205) relates:

Finding a lump in the breast can be a touchstone in a woman's life.

A breast is more than 'equipment to lure with' or a 36-C, or a portable milk bar. It is more than a symbol of motherhood, or a symbol of sexuality, or a symbol of objectification and degradation. It is all that and more. Our bodies manifest our being in the world. The essentials of our living are called into question when our bodies remind us of our finitude, calling us home to dwell.

Hence, another theoretical proposition that can be drawn from this study is: *Deciding treatment options is more than making objective treatment decisions about what surgery to have, and whether to have adjuvant therapy or not. It is about deciding how one will "be-in-the-world" (Merleau-Ponty, 1962/1996, p. 79) after an encounter with breast cancer.*

Decisions regarding choice of treatment and adjuvant therapy are integral factors in relation to how one experiences 'the self'. For some women body image is of extreme concern, whereas for others it is less important. Ultimately the woman herself must discern her value priorities, make her treatment decisions, and then commit herself to those choices. The 'what' of those decisions appeared less important than the process itself. The support and guidance women received was also integrally important. Women in the present study appeared to come to terms with treatment decisions when they had been actively involved in making those decisions.

In western culture, breasts are associated with womanliness and sexuality. This begs the question as to where a woman's femaleness resides. Yet as Merleau-Ponty (1962/1996) states: 'There is no explanation of sexuality that reduces it to anything other than itself, for it is already something other than itself, and indeed, if we like, our whole being' (p. 171). As Thompson (1988, p.xxii) states: "a woman's nourishing function and her sexual attractiveness rest in her whole being, not in her breasts alone". Breast cancer, however, calls upon a woman to confront these issues at a very personal level. Nancy Datan (1989, p. 183), a feminist writer, also having experienced breast cancer writes: "Circumstances victimize; the individual coping response is part of the struggle for survival". Bettelheim (1979, p. 24) states: "[Holocaust] survivors are not alone in that they must learn to integrate an experience which, when not integrated is either completely overwhelming, or forces one to deny in self-defence what it means to one personally in the present". This passage is congruent with the findings of the present study. Women had to work at integrating their encounter with breast cancer and their treatment choices, into their lives, into 'the self' as known. In this study it was related how two women explained how they had 'denied' their disease: Margaret said she neglected 'that side' of her body (chapter seven and eight) and Richelle, stated, having had conservative surgery, it was easy to deny it had ever happened to her (chapter five). Ultimately, however, it appeared these two women had reached a level of consonance; had come to terms with their breast cancer experience.

### *Contours of embodiment*

A philosophical concept that was poignant to the present study was the phenomenological notion of 'embodiment'. Merleau-Ponty (1962/1996) who examined the phenomenology of perception, relates how in illness the smooth functioning of the body is impaired; body parts that have become problematic or dysfunctional are objectified. They no longer feel part of 'the self' as known. Disease appears to alter the individual's normal relation with her or his body. It is no longer viewed as friend but rather as an "untrustworthy enemy" (Cassell, 1982, p. 643). The term 'embodiment' refers to the normally experienced 'lived body' as opposed to the body in illness when it becomes somewhat objectified. For example, in the case of the woman with breast cancer the diseased breast becomes the focus of attention - a 'body part'.



The existential-phenomenological view regards human beings as 'embodied subjects' as opposed to merely 'objects' in the world. As stated by Cassell (1982, p.639): "Suffering is experienced by persons, not merely by bodies, and has its source in challenges that threaten the intactness of the person as a complex social and psychological entity". Merleau-Ponty (1962/1996, p. 81) states:

What it is in us which refused mutilation and disablement is an I committed to a certain physical and inter-human World, who continues to tend towards his [her] world despite handicaps and amputations and who, to this extent, does not recognise them *de jure*.

Merleau-Ponty's words appear particularly relevant to the present study. Breast cancer is perhaps unique in terms of the personal and social meanings of 'the breast' in relation to gender and sexuality. In analysing sexuality, Merleau-Ponty (1962/1996, p. 157) states: "Sexual life is one more form of original intentionality ... an 'intentional arc'...which gives way in the patient, and which, in the normal subject, endows experience with its degree of vitality and fruitfulness". It takes time to regain this vitality, this renewed sense of self; one's 'embodied' being.

In the present study the code, 'Contours of embodiment' related how women had to come to terms with their scars, their altered contours, their afflicted souls. Somehow they had to unite this into their personal sense of self. Over time they appeared to go through a process of re-integration of the 'object' body, which they discussed in terms of their cancer and treatment choice, and the 'lived body' which was everything else they talked about. It was the lived body that constituted both the private and public/social self.

It is often related how a crisis such as cancer, that touches on one's mortality, forces re-assessment of one's life situation and/or how we live our lives. Underwood (1990, p. 205) relates that it is our bodies that manifest our being in the world and how "the essentials of our living are called into question when our bodies remind us of our finitude". Most all of the women in the present study re-iterated how much more they now valued life and health. They gave more attention to the people that meant most to them, and doing the things they enjoyed as opposed to doing the things they



thought they should do. As 'embodied beings', in choosing treatment options, they were not only deciding the contours of their bodies, but were challenged to redefine their whole self-identity.

The concept of embodiment as identified in the present study sought to express how a woman's breast is more than just a 'body part'; it also embodies her womanliness, which is part of her sense of self. It is part of her past, present and future self. It may particularly have memories associated with growing up, with love and sexuality, with nursing one's children.

**The theoretical proposition that evolved from these categories:**

Having compared the findings of the present study with the philosophical literature, the following theoretical proposition is prescribed: *Unifying 'the self' with treatment choice is a process of accommodating the fact of cancer, facing one's mortality, coming to terms the treatment chosen, and adjusting to an altered body, an altered 'self' after breast cancer.*

**IMPLICATIONS FOR NURSING PRACTICE**

This section has two parts. Part one will consider the implications this study has for nursing in understanding the complexity of treatment choice in breast cancer and other healthcare decisions. It will discuss how the theoretical model that emerged in the present study has implications for nursing, be it caring for women with breast cancer or any other illness conditions. Part two will discuss the role of 'breast care nurse' (an advanced practitioner or nurse specialist role) and its evolution as a member of the multi-disciplinary breast care team in the United Kingdom and United States of America, and more recently, in New Zealand. The format is as follows:

- The implications of the present study for nursing practice.
- The theoretical model: application to practice.
- The role of the 'breast care nurse'.

**The implications of the present study for nursing practice**

The concept of 'embodiment' emerged as an important, central, theoretical code in the present study. Gadow (1980) suggests that in earlier days, nursing was more

concerned with the immediate comfort of the patient and was more involved with the 'lived body'. She relates that with the rise of professionalism, and the mechanistic model of the body, a new dichotomy has arisen between the personal and the professional. The nurse in her professional mode takes an objective stance when dealing with the mundane intimacies of bodily care. The concept of 'professionalism' dictates that the patient's body is treated as 'object' as opposed to 'subject' or person. Yet for the patient, his or her body is subjective and personal. She states that the dichotomy for the patient is between the "body as a private, a lived reality, and a public object open to inspection" (p. 93). This can be a paradigm of sharp contrast.

Gadow (1980) states that the nursing role must assist patients to become self-determining in ways that express "the full and unique complexity of their values" (p. 97). This requires that nurses relate to people in their totality by bringing together the body object and the lived body. She coins the term 'existential advocacy' (previously discussed in chapter four) which she describes as "participating with the patient in determining the personal meaning which the experience of illness, suffering, or dying is to have on the individual" (p. 97).

In caring for the patient with breast cancer, this study would prescribe that the nurse be aware of the multi-factorial nature of breast cancer. The woman is threatened on many levels; her body intactness is threatened, as too is her life, and life projects. What can also be gained from the present study is that reaching a level of commitment to choice, of integrating choice into one's personal self, is a process that takes time and requires 'others' support if it is to be achieved successfully. Healing cannot take place in a vacuum - it requires care and nurturing. Benner (1994, p. xvii) states that our "medical metaphors have more to do with repairing and treating failed bodies than with promoting health or nurturing and facilitating the recovery of socially engaged, skilled bodies". It is hoped that a better understanding (and therein a greater practical wisdom) of how it is for women newly diagnosed with breast cancer, deciding their treatment choices, will assist nurses involved in the care of these women and therein assist these women in negotiating this life crisis.

### **The theoretical model: application to practice**

With regard to the more universal application of the theoretical model identified in the present study, it may not be too difficult to apply it to other conditions or situations, particularly in surgical or medical oncology. For example, the theoretical model in this study describes the process patients go through when learning of a cancer diagnosis, but could equally apply to any other health problem. This will now be discussed in greater depth.

The process generally begins with a visit to their clinician because of some symptom that the person has become aware of, or possibly for a routine health check. This model would predict that initially individuals are likely to experience a state of shock and disbelief when it is confirmed that their health status has in fact altered. They will then seek to gain more knowledge and information about their changed condition, or the 'condition' itself and will likely seek expert advice and guidance from their clinician(s). Individuals will then discern their own personal value priorities in relation to the particular treatment options that they have been required to consider. Their treatment priorities will be decided within the context of their past, present and projected future life situations. Timing in relation to coming to terms with their condition, and making treatment decisions will be variable between different people. Hopefully, with adequate professional (and other) guidance, the person will reach a point of salience and commitment to the choices they may be required to make. Whatever choices are made, it should be expected that there will be positive and negative aspects; choices are generally both enabling and limiting. Choices are also made within 'a web of connections' (Gilligan, 1982), within a network of 'others'. They will be subjected to personal and social expectations, which will be both supportive, and sometimes burdensome. It can be hoped that, given time, the individual will be able to integrate the health-illness experience into their lives and personal self-concept. This experience may mean that they are never quite as before, but possibly they may transcend their previous way of being to appreciate life in a new and meaningful way. Of course, some individuals will not. Some will succumb to their condition. Importantly, all of these people need to be understood and cared for as unique individuals who have a life history, their own personal needs and aspirations, and who live in community, or 'in relationship', with important others.

A particular example from surgical oncology, would be the patient who has a diagnosis of colo-rectal cancer, and who may have to make decisions regarding the type of surgery he or she prefers. For example, if a low rectal tumour is diagnosed, options may include formation of a jejunal pouch to maintain continence, or a permanent colostomy. Decisions regarding adjuvant chemotherapy/radiotherapy may also be required. Individuals are therefore challenged to make choices, or discern their value priorities, in relation to a number of treatment options. The final outcome may include coming to terms with an altered body image, and function, if an ileostomy or colostomy is required, as well as coming to the terms of the fact of cancer. This is just one example from general surgery (surgical oncology), but this theoretical model could equally apply to decision-making for many other illness conditions.

It can be seen from this discussion that this model could be relatively easily generalised to other decision-making (health-care) situations. This will be discussed further in the section 'implications for further research'.

### **Role of the 'breast care nurse'**

Chapter two of this thesis discussed how in the not too distant past treatment for breast cancer equaled mastectomy, plus or minus radiotherapy to the chest wall. Today choices are much more complex. Although a considerable number of women will still require mastectomy/axillary dissection, many are offered conservative surgery. Routinely, women undergoing mastectomy will be offered the choice of reconstruction. Adjuvant chemotherapy, hormone therapy or both, is commonly recommended based on accumulative evidence from large cohort studies. Advantages to be gained, however, are often proportional to the statistical chance of micro-metastases and can be a difficult concept for women to grasp. Owing to all of the above care of women with breast cancer has become a sub-specialty of general (and plastic) surgery and oncology (medical and radiation). This in itself has the potential to fragment care, as more 'experts' become involved. Changing models of care (for example peri-operative surgical units and 'super wards') and an international trend towards reduced hospital-days stay can also result in fragmented care. For example, a Scandinavian study looking at expressed needs of women

undergoing breast surgery in a short-stay setting reported one participant saying "I wish staff had more time for the patient. Now one is only a 'parcel' and not a patient" (Boman, Andersson & Bjorvell, 1997, p. 29). There is the inherent danger for care to become impersonalized, focussed only on patient's immediate physical needs and early discharge; care focussed on the 'object body' as opposed to 'the person'.

In the present study, the women who had contact with a breast care nurse found this contact extremely helpful. They appreciated the nurse for the knowledge and for the emotional support that was provided during the peri-operative period. The advantages to be gained by the appointment of a 'breast care nurse' were also discussed in chapter two of this study (McArdle et al., 1996). In the United Kingdom and the United States of America, the position has an established role within the multi-disciplinary team. Tait (1995, p. 42) who played a founding role in establishing this position points out:

Breast care nurses are located at the juncture between the dominant influences of surgery, psychology, and to a lesser extent, oncology. They are poised between medical and scientific knowledge of the disease and the illness experience of their patients and have to mediate between medical practice and its distressing impact on their patients' lives.

Tait relates that in both hostile and supportive settings these nurses have had considerable courage and tenacity in developing their roles within the multi-disciplinary breast team and that there are many ways in which they have improved care. However, she relates that in the future, these nurses will be continually challenged to justify the particular aspects of their practice, such as clinical decision making as well as the affects such decisions have on patient outcomes. Consequently more work will be needed in this area.

In New Zealand, the role is becoming more established (especially where breast care centres operate: for example, Auckland, Wellington, Lower Hutt, Invercargill and Dunedin) and a Breast Care Specialist Nursing Course has been offered on a bi-annual basis at Whareki Polytechnic since 1999. However, it is still a relatively new



role, and requires a degree of groundbreaking, along with appropriate professional support.

It is recommended that the appointment of a dedicated nurse specialist to become a companion in the arduous journey of breast cancer, from diagnosis, treatment, and into the early post-operative phase, is an essential element of quality health-care. This role requires a high level of tenacity, skill and knowledge at the advanced practice/nurse specialist level to be a credible and effective member of the multi-disciplinary breast care team. It is hoped that the present study may be of interest to nurses presently in (or considering) this role.

### **IMPLICATIONS FOR NURSING EDUCATION**

This study is 'grounded' in the experience of the fourteen women who participated. It provides nursing with 'evidence' of this group of women's experience of deciding treatment options for breast cancer. This study reaffirms the philosophical perspective of a number of nurse theorists from the 'humanistic' paradigm, notably Benner (1985), Benner and Wrubel (1989), Bishop and Scudder (1991), Parse (1981, 1995, 1997) and Paterson and Zderad (1976). These theorists take an existential-phenomenological view of the person conceiving him or her to be an embodied, relational, and complex human being. These theorists generally take an eidetic<sup>6</sup> view of illness the general characteristics of which include the perception of loss of wholeness, loss of certainty, loss of control, loss of freedom to act and loss of the familiar world. These characteristics were congruent with the woman's experience of breast cancer and the context within which the woman is called upon to make important treatment decisions. It is affirming that nursing already has a theoretical grounding on which nursing education can promote practice and continuing research. It is hoped that this study will re-affirm that nursing is about caring for the whole person, the 'lived body' as opposed to the 'object body' (e.g. "the mastectomy in cubicle three").

This study also identifies the growing specialization within nursing and the need for educational opportunities that can support this growing sophistication. There are



now a number of courses internationally for cancer nursing, and 'breast care nursing' is a growing developmental area that requires this level of support. As stated previously, a 'breast care' nursing course has been offered at Whareki Polytechnic since 1999. It is hoped the demand for this course will continue as the role of 'breast care nurse' becomes more established in our tertiary institutions across the country.

Lastly, it is hoped the theoretical model that emerged from this study could have a wider interest for nursing scholars, both in education, practice and research, as they explore the human response to illness, or an altered health status. It would appear that this model could have general application to a variety of health-illness continuums, and it is hoped that other nurses may find this model of interest and explore its potential for further development.

### **SUGGESTIONS FOR FURTHER RESEARCH**

The findings of this study led to a deeper theoretical/philosophical analysis of the women's experience of deciding treatment options for breast cancer. The concept of embodiment in relation to women with breast cancer could be a fruitful area for further study, possibly from a phenomenological perspective. Feminist issues were also evident in relation to issues around body image, breast reconstruction, the wearing of breast prostheses and societal expectations. Further study in these domains, could add to a wider perspective of women's experience of breast cancer as this condition becomes an ever increasing 'epidemic' in society and concern to women's lives.

As stated previously, the theoretical model that emerged could be developed in a number of directions. Research could be undertaken to gauge its applicability to other areas of health practice in which nurses are engaged. There are also numerous concepts within the model that could be explored further. For example, how women perceive the nursing role in breast cancer, further research into how women perceive the adequacy of the health care information they receive (there is some research on

---

<sup>6</sup> 'Eidetic' characteristics are those that are essential to the thing-itself and that remain unchanged regardless of any varying empirical features (Toombs, 1987).

this) and women's preferences for patient-professional communication and autonomy of choice.

### **LIMITATIONS OF THE PRESENT STUDY**

This study was restricted by the boundaries of working within the context of a thesis programme, to be completed within a certain time frame. It was also disappointing that Maori, and women from other cultures, were unable to be recruited to this study, which would have added a wider perspective, and possibly other dimensions to the study.

The fact the study was 'retrospective' meant the study was reliant on women's recall of events and therein there was a degree of 're-interpretation'. This could be regarded as both a positive and negative. The positive aspect of this was that it demonstrated that over time, most women appeared to have come to terms with their cancer and the treatment options they had chosen. If they had been interviewed at the time of decision making it would be unlikely that they would have had this insight.

On the negative side, it is possible this study recruited a biased sample of women who coped successfully with their cancer and deciding treatment options. However, studies on psychological morbidity, cited in chapter two, generally report that the majority of women (60-80%: Fallowfield & Hall, 1991; Fallowfield, Hall, Maguire and A'Hern, 1994) adjust over a period of 12 months to 2 years. Colyer (1996) relates that it is widely acknowledged that a small number of women will develop significant problems adjusting to body image result of mastectomy. It is therefore acknowledged, that a study population of only fourteen women, may not include every women's perspective on deciding treatment options. It is the researcher's opinion however that this study does (a) reflect the perspective portrayed by the fourteen women interviewed and (b) her professional opinion that this group of women was a representative sample.

The value of the present study is that it has provided the women's perspective on deciding treatment options, and has given some insight into the process women go through in coming to terms with their condition, and integrating this experience into their lives and their sense of self. If this study had been prospective, it would not

have provided this insight. Although studies have been undertaken with women during the diagnostic and decision-making time (eg, Cimprich, 1999), there are ethical considerations related to this, and it was decided not to explore this avenue for the present study. This also relates to the fact that this study excluded women with recurrent disease. It was felt these women already had enough stress coping with their condition, without being involved in research interviews. This subset in itself could be the focus for future research, if these ethical concerns were resolved.

## **CONCLUDING STATEMENTS**

This study used the grounded theory method to try and explicate the 'women's perspective' on deciding treatment options for breast cancer. The conceptual framework that evolved through interpretation of the data indicated the complexity of decision making at this stressful time. The medical and surgical treatment of breast cancer is constantly evolving. It is hoped, in the year 2000, this study has at least given an overview on the women's perspective of the 'state-of-the-art' treatment of breast cancer from the 'consumers perspective'.

Predeger (1996) suggests that all nurses need to hear the dialogues of woman that have endured breast cancer; look deeply into the struggles these women have faced. It is hoped that any nurse involved in the care of women with breast cancer, who takes the time to read this study, will feel empowered to enter that care partnership and to offer their understanding and support. A woman's encounter with breast cancer is often described in the literature as a journey. Predeger said it is a journey which has inherent struggles and challenges, that it is an "exemplar of the human condition" (p.48). The focus of this study was to consider the beginning of that journey and how women decide their preferred treatment options; treatment options that will alter the contours of their bodies and their lives. Women spoke frankly about their cancer, revealing what were often profoundly uncomfortable truths. They had done battle with cancer and it had left its irrevocable mark. Yet these women were courageous, often humorously relating their misfortune and the trials associated with a cancer diagnosis. Most appeared to have reached a level of acceptance and had integrated their experience of cancer, and their treatment choices, into their lives. These women were not victims, they wore the sign of the Amazon – "the one who shoots arrows" (Metzger, 1988). These women were warriors.

## GLOSSARY OF TERMS

adjuvant therapy	Chemotherapeutic or hormonal treatment for post-surgical patients who has, as yet, no clinically detectable disseminated disease (Siminoff & Fetting, 1991).
benign	A term used to denote the opposite of malignant (Roper, 1969).
conservative surgery	> Less than mastectomy. Generally this denotes wide local excision of the tumour and axillary sampling or dissection (depending on clinical indication).
cytology	Microscopic study of cells.
DCIS	Ductal carcinoma in-situ.
FNA	Fine needle aspiration.
frozen section biopsy	Special histological examination involving freezing and staining technique to give an immediate answer as to whether tissue is malignant or benign.
GP	General practitioner.
histology	Microscopic study of tissues.
malignant	"Virulent and dangerous" (Roper, 1969, p. 305). Invasive.
mammography	Special x-ray procedure of the breast/ breast tissue.
metastatic/metastasis	Transference of disease from one part of the body the other (Roper, 1969).
Tamoxifen	Anti-oestrogenic agent used to treat women with oestrogen sensitive breast tumours to prevent growth of known or possible metastases (often regarded as adjuvant).
wide local excision	Excision of the tumour with a 1 cm a margin of normal tissue (Dixon, 1995).

## **APPENDICES**



## APPENDIX A

### LETTER OF INTRODUCTION AND INFORMATION SHEET

#### Research Topic:

#### **Deciding treatment options for breast cancer**

My name is Lynn Harwood and I am presently working towards a Master of Arts degree in nursing. In accordance with this, I am presently undertaking research for my thesis. My research supervisor is Martin Woods, a lecturer in the School of Health Sciences, Massey University. I am also employed as a charge nurse in general surgery at Wellington Hospital wherein we care for women undergoing surgery for breast cancer, hence my interest in the chosen topic.

I am interested to learn how women decide their preferred treatment options when faced with the diagnosis of breast cancer. I am interested in 'how' and 'why' women decide a particular type of treatment for breast cancer.

Although there is considerable medical research exploring which treatments women choose, few studies have investigated the reasons women themselves give for their treatment choice(s). I hope that this research will provide the means to a better understanding of this experience as well insight into some of the important issues for women when they are called on to make these decisions.

I would like you to consider participating in this study. I am seeking women whom:

- (a) have experienced a breast cancer diagnosis six months to five years ago.
- (b) made a decision about their treatment options.

Your input would require one, possibly two interviews, of approximately 1-2 hours duration. The first interview would be to obtain your story of how you discovered your breast cancer and your personal experience of deciding your preferred treatment option(s). The second meeting would be to verify with you, my interpretation of what was said. These interviews would take place between November 1999 and July 2000.

*... please see next page ...*



The interview(s) will be informal, as if we were having a conversation. I will invite you to begin by telling me your story: how you came to know you had breast cancer, and what happened from there. A tape recorder will be used to record the interview with your permission. If you volunteer to participate in this study you will be invited to ask any further questions you may have about the project. If you wish to proceed, you will be asked to sign a consent form before our first interview commences.

The research data gathered from you will be treated with utmost confidentiality. Your name or other identifiable material will not be available to anyone other than the researcher. If a transcriber is employed this person will be required to sign a separate confidentiality agreement before commencing. Every effort will be made by the researcher to maintain your anonymity throughout the research project. Only a pseudonym or a number will refer to each participant.

You are invited to take part in this study understanding that your involvement is entirely voluntary.

If you decide to take part in this study then you are reminded that:

- a) You have the right to decline to take part or to withdraw from the research at any time.
- b) You also have the right at any time during your participation to
  - ask any questions about the research
  - refuse to answer any question
  - request that the recorder be switched off
  - examine the transcripts
  - terminate the meeting at any time
  - be informed of the outcome of the study (on completion of the project).
- c) The proposed study will have no connection whatsoever with your on-going care or treatment at Wellington Hospital, Capital Coast Health Ltd.
- d) Recalling distressing events can re-awaken painful memories. Alternatively, reflection can be helpful. If you find the research causes you any distress it is important you let the researcher know. Under no circumstances will your researcher ignore your request for help. If you require support in this regard, it will be given, or sought on your behalf, with your permission.
- e) Any audio tapes, transcripts, notes, computer diskettes will be stored in a secure place for the duration of the research. On completion of the research, the audio-tapes will be returned to you, if you so desire, or destroyed. Any remaining material, such as the transcripts used in data gathering, will be stored in a secure area for auditing purposes.

*... please see next page ...*

- f) A summary of the research will be made available to you at the completion of the study.
- g) A thesis will be prepared from the completed research, and this may be followed by academic papers, journal articles and possibly conference material based on this research.

If you are willing to take part in this research, or would like to hear more about it, please contact me, preferably by phone:

**Lynn Harwood, (04) 5899-860**

You may also, at any suitable time and for any appropriate reason regarding this research, contact my supervisor:

Martin Woods  
School of Health Sciences  
Massey University  
Private Bag 11 222  
Palmerston North  
Tel. (06) 356 9099, extension 2241.

## APPENDIX B

### CONSENT TO PARTICIPATE IN STUDY

#### Deciding treatment options for breast cancer

This is to confirm that I have read the details of the Information Sheet and had the details of the study explained to me. Any questions that I have asked have been answered to my satisfaction, and I am aware that I can ask further questions at any time.

I am aware that I have the right to withdraw from the study at any time and/or decline to answer any questions I do not wish to answer.

I agree to provide information to the researcher on the understanding that my name will not be used anywhere in the research, and that the researcher will undertake to take adequate precautions in regard to anonymity when using direct quotations or commentaries within the thesis. These precautions will also be extended to any other named persons or institutes.

I agree/do not agree to the initial interview being audio taped. I have also been advised that I have the right to ask the recorder be switched off at any time during the interview.

I agree to participate in this study under the conditions set out in the information sheet.

Signed.....

Name .....

Date .....

## **APPENDIX C**

### **RESEARCHERS REFERENCE LIST OF QUESTIONS FOR PARTICIPANTS**

I would like you to tell me about the time when you discovered you had breast cancer?

Can you tell me what happened for you? It might be easiest to start from the beginning and talk about how you discovered you had breast cancer?

Did you have to make decisions about what treatment you would undergo?

What were some of the processes you went through trying to reach a decision?

What would you say were some of the factors that influenced your decision?

How do you feel about the choice that you made now?

Is there anything you would have differently now?

## REFERENCES

- Alderson, P., Madden, M., Oakley, A. & Wilkins, R. (1994). *Women's views of breast cancer treatment and research. Report of a pilot Project 1993*. London: University of London, Social Science Research Unit.
- Bacon, C.R., Renneker, R., Cutler, H. (1952). A psychosomatic survey of cancer of the breast. *Psychosomatic Medicine*, 14 (6), 453-460.
- Bard, M., Sutherland, A.M., (1955). Psychological impact of cancer and it's treatment. *Cancer*, 8, 656-672.
- Bartelink, H. van Dam, F., van Dongen, J. (1985). Psychological effects of breast conserving therapy in comparison with radical mastectomy. *International Journal of Radiation Oncology and Biological Physics*, 11, 381-385.
- Beaver, K., Luker, K.A., Owens, R.G., Leinster, S.J., & Degner, L.F. (1996). Treatment decision making in women newly diagnosed with breast cancer. *Cancer Nursing*, 19 (1), 8-19.
- Benner, P. (1985). Quality of life: a phenomenological perspective on explanation, prediction, and understanding in nursing science. *Advances in Nursing Science*. 8 (1), 1-14.
- Benner, P and Wrubel, J. (1989). *The Primacy of Caring*, New York, Addison-Wesley.
- Bettelheim, B. (1979). *Surviving and other essays*. New York: Knopf.
- Biley, F.C. (1992). Some determinants that effect patient participation in decision-making about nursing care. *Journal of Advanced Nursing*, 17, 414-421.

- Bilodeau, B.A. & Degner, L.F. (1996). Information needs, sources of information, And decisional roles in women with breast cancer. *Oncology Nursing Forum*, 23 (4), 691-696.
- Bishop, A.H. and Scudder, J.R. (1990). *The practical, moral and personal sense of nursing*. New York: State University of New York Press.
- Blattner, B. (1981). *Holistic Nursing*, Englewood Cliffs, N.J: Prentice-Hall.
- Blum, R.H. & Blum, D.S. (1988). Psychosocial care of the cancer patient: guidelines for the physician. *Journal of Psychosocial Oncology*, 6, 119-35.
- Blumer, H. (1969). *Symbolic interactionism: perspective and method*. Englewood Cliffs, New Jersey: Prentice-Hall.
- Boman, L., Andersson, J., Bjorvell, H. (1997). Needs expressed by women after breast cancer surgery in the setting of a short hospital stay. *Scandinavian Journal of Caring Sciences*, 11, 25-32.
- Boston Women's Health Book Collective (1971). *Our bodies, Ourselves: A book by and for women*. New York: Simon and Schuster.
- Bostwick, J. (1995). Breast reconstruction following mastectomy. *Ca – A Cancer Journal for Clinicians*, 45 (5), 289-304.
- Brearley, S. (1990). *Patient participation: the literature*. UK: Royal College of Nursing Research Series, Scutari Press.
- Brody, D. (1980). The patient's role in clinical decision making. *Annals of Internal Medicine*, 93, 718-722.
- Brown, R. & Kulik, J. (1982). Flashbulb memories. In: U. Neisser (Ed.). *Memory observed*. (pp. 23-40). San Francisco: Freeman & Co.



- Brownlea, A. (1987). Participation: myths, realities and prognosis. *Social Science and Medicine*, 25 (6), 605-614.
- Cady, B. (1984). Lymph node metastases: Indicators, but not governors, of survival. *Archives of Surgery*, 119, 1067-1072.
- Cady, B. & Stone, M. (1990). Selection of breast-preservation therapy for primary invasive breast carcinoma. *Surgical Clinics of North America*, 70 (5), 1047-1059.
- Cady, B., Steele, G.D., Morrow, M., Gardner, B., Smith, B.L., Lee, N.C., Lawson, H.W., and Winchester, D.P. (1998). Evaluation of common breast problems: Guidance for primary care providers. *CA- A Journal for Clinicians*, 48 (1), 49-63.
- Campbell, S.H. (1986) The meaning of breast cancer/mastectomy experience, *Humane Medicine*, 2 (2), 91-95.
- Carter, B.J. (1990). *A phenomenological study of survivors of adult cancer*. Unpublished doctoral dissertation, University of California, San Francisco, California.
- Cassell, E.J. (1982). The nature of suffering and the goals of medicine. *The New England Journal of Medicine*, 306 (11), 639-645.
- Charmaz, K. (1983). The grounded theory method: an explication and interpretation. In R.M. Emerson (Ed.). *Contemporary field research*. (pp. 109-126). Boston: Little, Brown Company.
- Chilvers, C.E., & Deacon, J.M. (1990). Editorial: Oral contraceptives and breast cancer. *British Journal of Cancer*, 61, 1-4.
- Christensen, J. (1990). *Nursing partnership: A model for practice*. Wgtn., NZ: Daphne Brassell Ass.

- Cimprich, B. (1992). Attentional fatigue following breast surgery. *Research In Nursing and Health*, 15, 199-207.
- Cimprich, B. (1999). Pretreatment symptom distress in women with newly diagnosed breast cancer. *Cancer Nursing*, 22 (3), 185-194.
- Code of Health and Disability Services Consumers' Rights* (1996). The Health and Disability Commissioner, Ministry of Health, Wellington.
- Collins, J.P. & Simpson, J.S. (1998). Guidelines for the surgical management of breast cancer. *New Zealand Guidelines Group*, Auckland, New Zealand: Enigma Publishing.
- Colyer, H. (1996). Women's experience of living with cancer. *Journal of Advanced Nursing*, 23, 496-501.
- Coney, S. (1990). *Out of the frying pan: Inflammatory writing 1972-89*. Auckland, N.Z: Penguin Books.
- Cousins, N. (1989). *Head first: The biology of hope*. New York: E.P.Dutton.
- Corbin, J. & Strauss A.L. (1990). Grounded theory research: procedures, canons and evaluative criteria. *Qualitative Sociology*, 13 (1), 3-21.
- Datan, N. (1989). Illness and imagery: Feminist cognition, socialization and gender identity. In M. Crawford & M. Gentry (Eds). *Gender and Thought: Psychological perspectives*. (175-187). NY: Springer-Verlag.
- Dean, C. (1987). Psychiatric morbidity following mastectomy: Pre-operative predictors and type of illness. *Journal of Psychosomatic Research*, 26 (3), 385-392.

- Degner, L.F., Kristjanson, L.J., Bowman, D., Sloan, J.A., Carriere, K.C., O'Neil, J., Bilodau, B., Watson, P. & Mueller, B. (1997). Information needs and decisional preferences in women with breast cancer. *JAMA*, 277 (18), 1485-1492.
- Degner, L.F. & Sloan, J.A. (1992). Decision making during serious illness: what role do patients really want to play? *Journal of Clinical Epidemiology*, 45, (9), 941-950.
- Denzin, N. & Lincoln, Y. (1994). Introduction: entering the field in qualitative research. In N. Denzin & Y. Lincoln (Eds.). *Handbook of Qualitative Research*. (pp. 1-17). London: Sage.
- Dixon, J.M. (1995). *ABC of breast diseases*. London: BMJ Publishing Group.
- Donaldson, S.K. & Crowley, D.M. (1978). The discipline of nursing. *Nursing Outlook*, 113-120.
- Ehrenreich, B. & English, D. (1979). *For her own good: 150 years of the experts' advice to women*. London: Pluto Press.
- Elstein, A.S., Rovener, D.R. & Holzman, G.B. (1982). Psychological approaches to decision making in health care. In R.B. Deber & G.G. Thompson (Eds.). *Choices in Health Care: Decision making and evaluation of effectiveness*. Toronto: University of Toronto Press.
- Faden, R.R. & Beauchamp, T.L. (1986). *A history and theory of informed consent*. Oxford: Oxford University Press.
- Fallowfield, L., Baum M., and Maquire, G. (1986). Effects of breast conservation on psychological morbidity associated with diagnosis and treatment of early breast cancer. *British Medical Journal*, 293, 331-334.

- Fallowfield, L.J. and Hall, A. (1991). Psychosocial and sexual impact of diagnosis and treatment of breast cancer. *British Medical Bulletin*, **47** (2), 388-399.
- Fallowfield, L.J., Hall, A., Maguire, P., Baum, M. & A'Hern, R.P. (1994). A question of choice: results of a prospective 3-year follow-up study of women with breast cancer. *The Breast*, **3**, 202-208.
- Farmer, A.J. (2000). The minimisation to clients of screen-detected breast cancer: A qualitative analysis. *Journal of Advanced Nursing*, **31** (2), 306-313.
- Farragher, B. (1998). Psychiatric morbidity following the diagnosis and treatment of early breast cancer. *Irish Journal of Medical Science*. **167** (3), 166-9.
- Fisher, B. (1996). Personal contributions to progress in breast cancer research and treatment. *Seminars in Oncology*, **23** (4), 414-427.
- Gadow, S. (1980). Existential advocacy: philosophical foundation of nursing. In S.F. Spiker and S. Gadow. (Eds.). *Nursing, Images and Ideals*. (pp. 79-101). New York: Springer.
- Gadow, S. (1985). Nurse and patient: The caring relationship. In A.H. Bishop and Scudder, Jr. (Eds.). *Caring, curing, coping: Nurse, physician, patient relationships* (pp. 31-43). University, AL: University of Alabama Press.
- Gadow, S. (1989a). An ethical case for patient self-determination. *Seminars in Oncology Nursing*, **5** (2), 99-101.
- Gadow, S. (1989b). Clinical subjectivity: Advocacy with silent patients. *Nursing Clinics of North America*, **24** (2), 535-541.
- Ganz, P.A. (1988). Patient education as a moderator of psychosocial distress. *Journal of Psychosocial Oncology*, **6**, 181-97.

- Gilligan, C. (1982). *In a different voice*. Cambridge, MA: Harvard University Press.
- Gilligan, C. (1987). Moral orientation and moral development. In E.F. Kittay & D.T. Meyers (Eds.). *Women and moral theory*. (pp. 19-33). Totowa, New Jersey, Rowman & Littlefield.
- Glaser, B.G. & Stauss, A.L. (1965). The discovery of substantive theory: a basic Strategy underlying qualitative research. *The American Behavioural Scientist*, 8 (6), 5-12.
- Glaser, B.G. & Stauss, A.L. (1967). *The discovery of grounded theory*. Chicago: Aldine Publishing Company.
- Glaser, B.G. (1978). *Theoretical sensitivity*. Mill Valley, California: The Sociology Press.
- Glaser, B.G. (1992). *Basics of grounded theory analysis*. Mill Valley, California: The Sociology Press.
- Gray, P. (1988) Cancer in the breast. In L.H. Lifshitz (Ed.). *Women's Poetry on Breast Cancer: Her Soul Beneath the Bone* (p. 36). USA, University of Illinois Press.
- Greenlee, R.T., Murray, T., Bolden, S., & Wingo, P.A. (2000). *Cancer Statistics*, 50 (1), 7-33.
- Hack, T.F., Degner, L.F. & Dyck. (1994). Relationship between preferences for decisional control and illness information among women with breast cancer: A quantitative and qualitative analysis. *Social Science Medicine*, 39 (2), 279-289.
- Hall, A. & Fallowfield, L. (1989). Psychological outcome of treatment for early breast cancer: A review. *Stress Medicine*, 5, 167-175.

- Heidegger, M. (1962). *Being and Time* (J. Macquarried & E. Robinson, Trans.). New York: Seabury. (Original work published 1927.)
- Henderson, I.C. & Mouridsen, H. (1988). Effects of adjuvant tamoxifen and of cytotoxic therapy on mortality in early breast cancer: An overview of 61 randomized trials among 28,896 women. *New England Journal of Medicine*, *319*, 1682-1692.
- Holloway, I. & Wheeler, S. (1996). *Qualitative research for nurses*. Great Britain: Blackwell Science.
- Holt, B. (1998). Breast cancer organisations overseas and in NZ. *Breast Cancer Action: Aotearoa NZ Newsletter*, *19*, 2.
- Hudis, C.A. and Norton, L. (1996). Adjuvant drug therapy for operable breast cancer. *Seminars in Oncology*, *23* (4), 475-493.
- Hughes, E. (1959). The study of occupations. In R. Merton & V. Broom (Eds). *Sociology Today*. New York, Basic Books.
- Hughes, J. (1982). Emotional reactions to the diagnosis and treatment of early breast cancer. *Journal of Psychosomatic Research*, *26* (2), 277-283.
- Hughes, K. (1993). Decision making by patients with breast cancer: the role of information in treatment selection. *Oncology Nursing Forum*, *20* (4), 623-628.
- Illich, I. (1974). *Medical Nemesis: The Expropriation of Health*. London: Calder and Boyars.
- Ingelfinger, F.J. (1980). Arrogance. *The New England Journal of Medicine*, *25*, 1507-1511.



- Kaplan, A. (1964). *The conduct of inquiry: Methodology for behavioural science*. San Francisco, California: Chandler Pub.
- Kaufmann, C.L. (1983). Informed consent and patient decision-making: two decades of research. *Social Science and Medicine*, 17, 1657-1664.
- Kasper, A. (1994). A feminist, qualitative methodology: A study of women with breast cancer. *Qualitative Sociology*, 17 (3), 263-281.
- Katz, J. (1984). *The silent world of the doctor and patient*. New York: Free Press.
- Kelsey, J.L & Bernstein, L. (1996). Epidemiology and prevention of breast cancer. *Annual Revue of Public Health*, 17, 47-67.
- Kemeny, M.M., Wellisch, D.K., Schain, W.S. (1988). Psychological outcome in a randomised surgical trial for treatment of primary breast cancer. *Cancer*, 62, 1231-1237.
- Kennedy, I. (1981). *The unmasking of medicine*. London: Allen Unwin.
- Kinne, D.W. (1991). The surgical management of primary breast cancer. *Ca - A Cancer Journal for Clinicians*, 41 (2), 71-84.
- Koch, T. (1996). Implementation of a hermeneutic enquiry in nursing: philosophy, rigour and representation. *Journal of Advanced Nursing*, 24, 174-184.
- Kohlberg, L. (1981). *Essays of moral development*. San Francisco: Harper and Row.
- Kubler-Ross, E. (1972). *On death and dying*. New York: Macmillan Pub. Co.
- Kuhn, T.S. (1979). *The structure of scientific revolutions*. (2nd ed.). Chicago: University of Chicago Press.

- Kushner, R. (1988). Forward. In L.H. Lifshitz (Ed.). *Women's Poetry on Breast Cancer: Her Soul Beneath the Bone* (pp. xiii-xvi). USA, University of Illinois Press.
- Leder, D. (1984). Medicine and paradigms of embodiment. *The Journal of Medicine and Philosophy*, 9, 29-43.
- Leinster, S. Ashcroft, J., Slade, P., Dewey, M., (1989). Mastectomy vs. Conservative Surgery: Psychological effects of patient's choice of treatment, *Journal of Psychosocial Oncology*, 7, 134-144.
- Lewin, K. (1951). *Field theory in social science*. N.Y: Harper & Row.
- Lifshitz, L.H. (Ed.). (1988). *Her soul beneath the bone. Women's poetry on breast cancer*. Urbana: University of Illinois.
- LoBiondo-Wood, G. & Haber, J. (1998). *Nursing Research: Methods, Critical Appraisal and Utilization*. (4<sup>th</sup> ed.). St. Louis: Mosby.
- Lorde, A. (1980a). *The cancer journal* (2<sup>nd</sup> ed.). San Francisco: Spinsters Ink.
- Lorde, A. (1980b). After breast cancer: I am a warrior, not a victim. *Savvy*, 68-69.
- Luker K.A., Beaver, K., Leinster, S., & Owens, R.G., Degner L.F. & Sloan, J.A. (1995). The information needs of women newly diagnosed with breast cancer. *Journal of Advanced Nursing*, 22 (1), 134-141.
- Luker, K.A., Beaver, K., Leinster, S., & Owens, R.G. (1996). Information needs and sources of information for women with breast cancer: a follow-up study. *Journal of Advanced Nursing*, 23, 487-495.
- Macquarrie, J. (1972). *Existentialism*. NY: Penquin Books.

- Maguire, P. (1989). Breast Conservation versus Mastectomy: psychological considerations, *Seminars in Oncology*, 5, 137-144.
- Maguire, P. (1990). The psychological consequences of the surgical treatment of breast cancer. *Surgery Annual*, 76-91.
- Maguire, P., Lee, E.G., Bevington, D.J., Kuchemann, C., Crabtree, R., & Cornell, C. (1978). Psychiatric problems in the first year after mastectomy. *British Medical Journal*, 279, 963-965.
- Maguire, P., Tait, A., & Brooke, M. (1980). A conspiracy of pretence. *Nursing Mirror*, 10, 17-19.
- Maguire, P. Tait, A., Brooke, M., Thomas, C. & Sellwood. R. (1980). Effect of counselling on the psychiatric morbidity associated with mastectomy. *British Medical Journal*. 281, 1454-1456.
- Martini, C. (1981). Discussion. *World Health Forum*, 2, 197-198.
- Maunsell, E., Brisson, J., Deschenes, L. (1989). Psychological distress after intitial treatment for breast cancer: A comparison of partial and total mastectomy. *Journal of Clinical Epidemiology*, 42 (8), 765-771.
- Mead, G. (1934). *Mind, self and society*. Chicago: University of Chicago Press.
- Meleis, A. (1991). *Theoretical Nursing: Development and Progress* (2<sup>nd</sup> ed.). Philadelphia: J.B. Lippincott Co.
- Merleau-Ponty, M. (1996). *Phenomenology of perception*. (C. Smith. Trans.) London: Routledge. (Original work published 1962).

- Metzger, D. (1988). I am no longer afraid. In L.H. Lifshitz (Ed.). *Women's Poetry on Breast Cancer: Her Soul Beneath the Bone* (p.71). USA, University of Illinois Press.
- Morse, J.M. (1989). Qualitative nursing research: a free-for-all? In J.M. Morse (Ed.). *Qualitative Nursing Research*. (pp. 14-22). Maryland, Rockville: Aspen Pub.
- Moore, M.P. & Kinne, D.W. (1995). The surgical management of primary invasive breast cancer. *Ca - A Cancer Journal for Clinicians*, 45 (5), 279-288.
- Morris, T., Greer, H.S. and White, P. (1977). Psychological and social adjustment to mastectomy. *Cancer*, 40, 2381-2387.
- Morris, J. & Royle, G. (1988) Offering patients a choice for early breast cancer: a reduction in anxiety and depression in patients and their husbands. *Journal of Social Science*, 26 (6), 583-585.
- Mullan, F. (1985). Seasons of survival: reflections of a physician with cancer. *New England journal of medicine*, 313: 170-173.
- McArdle, J.M., George, W.D., McArdle, C.S., Smith, D.C., Moodie, A.R., Hughson, A.V., & Murray, G.D. (1996). Psychological support for patients undergoing breast cancer surgery: a randomised study. *British Medical Journal*, 312 (7034), 813-816.
- McCool, W.F., Stone-Condry, M., & Bradford, H. (1998). Breast health care: A review. *Journal of Nurse-Midwifery*, 43 (6), 406-430.
- Nelson, J.P. (1996). Struggling to gain meaning: Living with the uncertainty of breast cancer. *Advances in Nursing Science*, 18 (3), 59-76.
- Nightingale, F. (1860). *Notes on Nursing: What it is and what it is not*. London: Harrison.

- Nixon, A.J., Troyan, S.L. & Harris, J.R. (1996). Options in the local management of invasive breast cancer. *Seminars in Oncology*, 23 (4), 453-463.
- Northouse, L. (1989). The impact of breast cancer on patients and husbands. *Cancer Nursing*, 12, 276-284.
- O'Gorman, E.C. & McCrum, B. (1988). A comparison of the self-perceptions of women who have undergone mastectomy with those receiving breast reconstruction. *Irish Journal of Psychiatric Medicine*, 5, 26-31.
- Orem, D. (1980). *Nursing: Concepts of practice*. (4<sup>th</sup> ed.). St Louis, Mosby.
- Parse, R.R. (1981) *Man-Living-Health: A Theory of Nursing*, Pennsylvania, John Wiley & Sons.
- Parse, R.R. (1995). *Illuminations: The human becoming theory in practice and research*. New York: National League for Nursing Press.
- Parse, R.R. (1997). The human becoming theory: The was, is and will be. *Nursing Science Quarterly*, 10 (1), 32-38.
- Parse, R.P., Coyne A.B. & Smith, M. (1985). *Nursing Research, Qualitative Methods*, Bowie, MD: Brady.
- Parsons, T. (1951). *The Social System*. New York: The Free Press.
- Paterson, J.G. & Zderad, L.T. (1976). *Humanistic Nursing*, New York: John Wiley & Sons.
- Pauker, S.G. (1982). Prescriptive approaches to decision making. In R.B. Deber & G.G. Thompson (Eds.). *Choices in Health Care: Decision making and evaluation of effectiveness*. Toronto: University of Toronto Press.

- Penman, D.T., Holland, J.C., Bahna, G.F., Morrow, G., Schmale, A.H., Derogatis, L.R., Carnrike, C.L., & Cherry, R. (1984). Informed consent for investigational chemotherapy: Patients' and physicians perceptions. *Journal of Clinical Oncology*, 2 (7), 849-855.
- Pierce, P.F. (1988). Women's experience of choice: Confronting the options of treatment for breast cancer. In J.K. Harness, H.A. Oberman, Lichter, A.S., Adler, D. & Cody, R.L. (Eds.). *Breast Cancer: Collaborative Management*. (pp. 273-292), Chelsea, MI: Lewis Publishing Co.
- Pierce, P.F. (1993). Deciding on breast cancer treatment: A description of decision behaviour. *Nursing Research*, 42 (1), 22-28.
- Popper, K.R. (1963). Conjectures and refutations: *The growth of scientific knowledge*. N.Y: Harper & Row.
- Powles, J. (1973). On the limitations of modern medicine. *Science, Medicine and Man*, 1: 1-34.
- Pozo, C., Carver, C.S., Noriega, V., Harris, S.D., Robinson, D.S., Ketcham, A.S., Legaspi, A., Moffat, F.L. & Clark, K.C. (1992). Effects of mastectomy versus lumpectomy on emotional adjustment to breast cancer: a prospective study of the first year post surgery. *Journal of Clinical Oncology*, 10 (8), 1292-1298.
- Predeger, E. (1996). Womanspirit: A journey into healing through art in breast cancer. *Advances in Nursing Science*, 18 (3), 48-58.
- Public Health Commission (1995). *Projections of cancer burden in New Zealand: Analysis and monitoring report 5*. Wellington, New Zealand.
- Quint, J.C. (1963) The impact of mastectomy. *American Journal of Nursing*, 63 (11), 88-92.



- Rakusen, J. & Phillips, A. (1978). *Our Bodies, Ourselves*. London: Allen and Lane.
- Rawlinson, M.C. (1982). Medicine's discourse and the practice of medicine. In V. Kestenbaum (ed.). *The humanity of the ill*. (pp. 69-85). Knoxville, TN: University of Tennessee Press.
- Richards, M.A., Ramirez, A.J., Degner, L.F., Fallowfield, L.J., Maher, E.J. and Neuberger, J. (1995). Offering choice of treatment to patients with cancers: A review based on a symposium held at the 10<sup>th</sup> Annual Conference of the British Psychosocial Oncology Group, December 1993. *European Journal of Cancer*, 31a (1), 116-123.
- Richardson, A. (1983). *Participation*. London: Routledge and Kegan Paul.
- Roberts, C. S., Cox, C., Reintgen, D., Baile, W. & Gibertini, M. (1994). Influence of Physician communication on newly diagnosed breast patients' psychologic adjustment and decision-making. *Cancer Supplement*, 74 (1), 336-341.
- Roper, N. (1969). *Livingstone's dictionary for nurses* (13<sup>th</sup> ed.). London: E. & S. Livingstone Ltd.
- Rosser, J.E. (1981). The interpretation of women's experience: A critical appraisal of the literature on breast cancer. *Social Science Medicine*, 45 (2), 57-65
- Roy, C. (1984). Introduction to nursing: An adaptation model (2<sup>nd</sup> ed.). Englewood Cliffs, New Jersey: Prentice-Hall.
- Sartre, J.P. (1969). *Being and Nothingness: An essay in phenomenological ontology*. (H. Barnes, Trans.) New York: Citadel Press. (Original work published 1943).
- Schain, W. (1988) The sexual and intimate consequences of breast cancer treatment. *Ca: AE Journal for Physicians*, 38 (3), 154-161.

- Schain, W. (1990). Physician-patient communication about breast cancer: A challenge for the 1990s. *Surgical Clinics of North America*, 70, 917-36.
- Schain, W.S. & Fetting, J.H. (1992). Modified radical mastectomy versus breast conservation: psychological considerations. *Seminars in Oncology*, 19 (3), 239-243.
- Schain, W.S., Wellisch, D.K., Pasnau, R.O., & Landsverk, J. (1985). The sooner the better: A study of psychological factors in women undergoing immediate versus delayed reconstruction. *American Journal Of Psychiatry*, 142 (1), 40-46.
- Schmale, A.H., Morrow, G., Schmitt, M. (1983). Well-being of cancer survivors. *Psychosomatic Medicine*, 45, 163-169.
- Schön, D.A. (1992). The crisis of professional knowledge and the pursuit of an epistemology of practice. *Journal of interprofessional care*, 6 (1), 49-63.
- Schumacher, K.L. & Gortner, S.R. (1992). (Mis)conceptions and re-conceptions about traditional science. *Advances in Nursing Science*, 14 (4), 1-11.
- Scott, D.W. (1983). Anxiety, critical thinking and information processing during and after breast biopsy. *Nursing Research*, 32, 24-28.
- Scott, J.R., DiSaia, P.J., Hammond, C.B., Spellacy, W.N. (Eds.). (1994). *Danforth's obstetrics and gynaecology*. 7th ed. Philadelphia: J.B. Lippincott.
- Shapiro, L. & Goodman, A. (1980). *Never say die: A doctor and patient talk about breast cancer*. New York: Appleton-Century-Crofts.

- Silva, M.C. & Rothbart, D. (1983). An analysis of changing trends in philosophies of science on nursing theory development and testing. *Advances in Nursing Science*, 1-13.
- Siminoff, L.A. & Fetting, J.H. (1991). Factors affecting treatment decisions for a life-threatening illness: the case of medical treatment of breast cancer. *Social Science Medicine*, 32 (7), 813-818.
- Siminoff, L.A., Fetting, J.H. & Abeloff, M.D. (1989). Doctor-patient communication about breast cancer and adjuvant therapy. *Journal of clinical oncology*, 7 (9), 1192-1200.
- Starr, P. (1982). *The Social transformation of American medicine*. New York: Basic Books.
- Stern, P.N. (1994). Eroding grounded theory. In J.M. Morse (Ed). *Critical Issues in Qualitative Research Methods*. (pp. 210-223) London: Sage.
- Stevens, L.A., McGrath, M.H., Druss, R.G. (1984). The psychological impact of immediate breast reconstruction for women with early breast cancer. *Plastic Reconstructive Surgery*, 73, 619-628.
- Storlie, F. (1970). *Nursing and the social conscience*. New York: Appleton-Crofts.
- Sutherland, H.J., Llewellyn-Thomas, H.A., Lockwood, G.A., Trichter, D.L. & Till, J.E. (1989). Cancer patients: their desire for information and participation in treatment decisions. *Journal of the Royal Society of Medicine*, 82, 260-263.
- Tait, A. (1995). Describing breast care nurses. In A. Richardson & J. Wilson-Barnett. (Eds). *Nursing Research in Cancer Care*. (pp. 27-47). London: Scutari Press.

- Taylor, C. (1979). *Hegel and modern society*. Cambridge: Cambridge University Press.
- Taylor, M. (1988). 'Telling bad news'" physicians and the disclosure of undesirable information. *Sociology of Health and Illness*, 19 (2), 109-132.
- Taylor, S.E. (1983) Adjustment to threatening events: A theory of cognitive adaptation. *American Psychologist*, 6, 133-145.
- Thomasma, D.C. (1983). Beyond medical paternalism and patient autonomy: a model of physician conscience for the physician-patient relationship. *Annals of Internal Medicine*, 98, 243-248.
- Thompson, P. (1988). Introduction. In L.H. Lifshitz. (Ed.). *Her soul beneath the bone. Women's poetry on breast cancer*. (pp. xix- xxii). Urbana: University of Illinois.
- Toombs, S. (1987) The meaning of illness: A phenomenological approach to the patient-physician relationship. *The Journal of Medicine and Philosophy*, 12, 219-240.
- Tuckett, D., Boulton, M. Olsen, C. & Williams, A. (1987). *An approach to sharing ideas in medical consultation: Meetings between experts*. Tavistock: London.
- Tversky, A. & Kahneman, D. (1981). The framing of decisions and the psychology of choice. *Science*, 211, 453-458.
- Underwood, S. (1990). Touchstone: Finding a lump in the breast. *Phenomenology + Pedagogy*, 8, 198-207.
- Valanis, B.G. & Rumpler, C.H. (1985). Helping women to choose breast cancer treatment alternatives. *Cancer Nursing*, 8 (3), 167-175.

Van den Berg, J. (1980). *The psychology of the sick bed*. New York: Humanities Press.

Veronesi, U., Paganelli, G., & Galimberti (1997). Sentinel-node biopsy to avoid axillary dissection in breast cancer with clinically negative lymph nodes. *The Lancet*, 349, 1864-76.

Wainstock, J.M. (1991). Breast Cancer: Psychosocial consequences for the patient. *Seminars in Oncology Nursing*, 7 (3), 207-215.

Walsh, M. & Ford, P. (1991). *Nursing Rituals: Research and rational actions*. London: Heinemann Press.

Waterworth, S. & Luker, K.A. (1990). Reluctant collaborators: do patients want to be involved in decisions concerning care? *Journal of Advanced Nursing*, 15, 971-976.

Watson, J. (1979). *Nursing: The philosophy and science of caring*. Boston: Little, Brown, & Co.

Watson, J. (1981). Nursing's scientific quest. *Nursing Outlook*, 29 (7), 413-416.

Watson, J. (1985). *Nursing: Human science and human care*. Norwalk, CT: Appleton Century Crofts.

Ward, S., Heidrich, M.S. & Wolberg, M.D. (1989). Factors women take into account when deciding upon type of surgery for breast cancer. *Cancer Nursing*, 12 (6), 344-351.

Wear (1993). "Your breasts/sliced off": Literary images of breast cancer. *Women & health*, 20 (4), 81-100.

Weiss, G.B. (1985). Paternalism modernised. *Journal of Medical Ethics*, 11, 184-187.

Williamson, C. (1996). Breast cancer: asking patients what they want. *British Medical Journal*, 313, 506-507.

Wiseman, A. (1979). *Coping with cancer*. NY: McCraw-Hill.

Wood, W.C. (1996). Management of lobular carcinoma insitu and ductal carcinoma insitu of the breast. *Seminars in Oncology*, 23 (4), 446-452.

Woodward, J. & Richards, D. (1977). *Healthcare and popular medicine in nineteenth- century England*. London: Croom Helm.

Worden, J.W. & Weismann, A.D. (1977). "The fallacy of postmastectomy depression. *The American Journal of Medical Sciences*. 273, 169.