

**Psychological Impact of Diagnosis and Surgery
In the Treatment of Early Stage Breast Cancer.**

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Declaration

This thesis has been composed by myself and the work contained herein is my own.

Signed

Abstract

Purpose: The aim of this study was to investigate the psychological impact of diagnosis and surgery in the treatment of early stage breast cancer. It was predicted that diagnosis of breast cancer would be associated with an acute stress reaction. Better psychological adjustment one month after surgery was predicted for women who had undergone breast-conserving surgery in comparison to patients who had received a mastectomy. Suppression of negative emotion in response to breast cancer diagnosis was predicted to be related to poorer short-term psychological adjustment.

Method: Twenty-nine women completed baseline psychological measures one week after receiving a breast cancer diagnosis. Follow-up measures completed one month after surgery were obtained in twenty five cases. Evidence of acute stress response was measured using scores for intrusive distress and avoidance on the revised Impact of Events Scale (IES, Horowitz, 1979). Psychological adjustment was assessed based on several key factors described in the literature concerning the psychosocial outcome of breast cancer: levels of psychological distress (anxiety and depression), measured using the Hospital Anxiety and Depression Scale (HAD, Zigmond & Snaith, 1983); coping responses obtained on the Mental Adjustment to Cancer Scale (MAC, Watson, Greer, Young et al, 1988b), and body image satisfaction, assessed using the recently developed Body Image Scale (BIS, Hopwood, Fletcher, Lee & Al Ghazal, 2001). Suppression of negative emotion was indicated by scores for control of negative emotion on an adapted version of the Basic Emotion Scale (Power, 2001).

Data analysis: Patient scores on psychological measures obtained one week after diagnosis and at follow up one month post-surgery were compared using a within and

between subjects repeated measures ANOVA. Patient age at diagnosis, and whether or not they were referred through screening, were then re-entered as covariates within the repeated measures design in post-hoc analyses. Backward multiple linear regression was carried out to examine emotional suppression as a predictor of adjustment assessed using the psychological measures completed at follow up post surgery.

Results: Evidence of acute stress response, indicated by clinical 'caseness' for intrusion and avoidance on the IES, was found in 28% of the sample assessed soon after diagnosis, with a proportion of patients (almost 20%) continuing to report high levels of intrusive distress and avoidance at follow up one month after surgery. As predicted, IES scores for intrusion and avoidance were significantly lower between assessment soon after diagnosis and at follow up after surgery ($F_{1,23} = 13.37$, $p < 0.05$). Consistent with previous reports in the literature, no effect was found for type of surgery on any of the measures used. Women who were younger at the time of diagnosis were, however, likely to be more anxious ($F_{1,23} = 4.48$, $p < 0.05$) and to experience greater levels of intrusive distress ($F_{1,23} = 4.86$, $p < 0.05$). Suppression of negative in response to diagnosis predicted higher levels of intrusive distress and avoidance at one month ($F_{2,22} = 6.24$, $P < 0.05$, $R^2 = .36$), and greater levels of dissatisfaction with body image ($F_{1,22} = 7.74$, $p < 0.05$, $R^2 = .32$). Results are discussed in relation to the previous literature, and in terms of implications for aspects of psychosocial care for breast cancer patients.

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Table of Contents	Page
Abstract	1-2
1. Introduction	3-52
1.1 Breast Cancer	3-9
Breast Cancer-Facts and Figures	3
Disease Types	3-4
Specialist Breast Care Units	4
Screening	4
Staging Classifications	5
Early and Advanced Disease	5
Prognostic Indicators	6-8
<i>Routine Prognostic Indicators</i>	6
<i>Nottingham Prognostic Index</i>	7
<i>Other Biological Markers</i>	7-8
Treatment of Early Stage Breast Cancer	8-9
Psychosocial Outcome of Early Stage Breast Cancer	9
1.2 Psychological Impact of Breast Cancer Diagnosis	10-15
Reactions to Diagnosis	10
Psychological Response to Severe Stressors	10-11
Traumatic Stress in Response to Life-Threatening Illness	11-12
Acute Stress Reactions associated with Breast Cancer Diagnosis	12-13
Adjustment over time	13-14
Traumatic Stress associated with Disease Recurrence	14-15
1.3 Longer-term Psychological Effects of Breast Cancer	16-22
Anxiety and Depression	16-17
Problems Determining Levels of Distress in Breast Cancer Patients	17-18
Psychological Impact of Breast Cancer on Body Image and Sexuality	18-20
Cancer Related Fears and Concerns	20-21
Impact of Breast Cancer on family and Social Functioning	21-22

1.4 Influence of Disease Stage and Recurrence on the Psychosocial Outcome of Breast Cancer	23-25
Disease Stage	23-24
Recurrence	24-25
1.5 Psychological Effects of Surgery in the Treatment of Early Stage Breast Cancer	26-38
Historical Perspective	26
Studies Comparing the Psychosocial Outcome of BCT with Mastectomy	26-28
Studies Comparing BCT with Mastectomy plus Reconstruction	28-30
Table 1.5: Summary of Studies Comparing Psychosocial Outcome of Breast-Conserving Surgery versus Mastectomy	31-38
1.6 Psychological Distress and Adjuvant Therapies	39-43
Radiotherapy	39
Chemotherapy and Hormone Therapy	40-43
Chemotherapy	40-41
Depression and Acceptance of Adjuvant Treatment	41
Palliative Chemotherapy in Advanced Disease	41-42
Hormone Therapy	42
Neoadjuvant Treatment	42-43
1.7 Individual Patient Factors Influencing Psychosocial Outcome	44-48
Age at Diagnosis	44-45
Premorbid Adjustment	46-47
Coping Styles	47-48
1.8 Issues of Treatment Decision Making and Choice	49-51
1.9 Aims and Objectives of Current Investigation	52
1.10 Hypotheses	53

2. Method	54-62
2.1 Design	54-55
Study Design	54
Calculation of Statistical Power/Expected Effect Size	54
Sample	54-55
2.2 Procedure	56-58
Patient Ethics	56
Patient Recruitment	56-57
Study Inclusion/Exclusion Criteria	57-58
2.3 Measures	59-62
Anxiety and Depression: <i>HAD</i>	59
Acute Stress Response: <i>IES</i>	59-60
Coping Responses: <i>MAC</i>	60-61
Body Image Satisfaction: <i>BIS</i>	62
Suppression of Negative Emotion: <i>BES</i>	62
3. Results	63-71
Statistical Analysis of Results	63
Testing of Hypotheses 1 and 2	63
3.1 Hypothesis 1	63-65
Evidence of Acute Stress Response	64-65
3.2 Hypothesis 2	66-71
Psychosocial Outcome of BC Surgery versus Mastectomy:	
(i) Anxiety and Depression	66-67
(ii) Coping	68-69
(iii) Body Image Satisfaction	70

Influence of Other Factors on Adjustment:	
Age and Screening	70-71
3.3 Hypothesis 3	72
Influence of Emotional Suppression on Adjustment	72
4. Discussion	73-93
Overview	73
4.1 Summary of Main Findings	74-81
Evidence of Acute Stress Response	74-75
Psychosocial Outcome of BC Surgery versus Mastectomy	75-
Body Image	76-77
Cancer Related Fears and Concerns	77-78
Coping and Adjustment	78-79
Influence of Other Factors on Adjustment	79-81
Age	79
Screen Detected Cancer	80
Relationship Between Emotional Suppression and Adjustment	80-81
4.2 Methodological Limitations to the Present Study	82-86
Sample	82-83
Sample Size	82
Representativeness of Sample	82-83
Timescale	83
Rates of Participation in Study	84
Critique of Measures Used	85-86
4.3 Implications of Findings for Psychosocial Care of Breast Cancer Patients	87-89

4.4 Conclusions and Directions for Future Research	90-92
5. References	93-108

Appendices

1. Patient Information Sheet
2. Psychological Measures
3. Recent newspaper article

List of Tables

1.1 TNM classification and relationship to UICC Stage	5
1.2 Definition of risk groups and associated disease free survival rates at 5 yrs	6
1.3 Survival rates at 10 years for prognostic groups based on NPI values	7
1.4 Risk of psychological morbidity associated with disease prognosis	24
1.5 Summary of Studies Comparing Psychosocial Outcome of BCT v Mx	31-38
1.6 Patients at risk of psychological problems	44
2.1 Patient demographic details and information on disease/treatment variables	55
3.1 Mean IES total scores and results of repeated measures ANOVA	64
3.2 Mean IES intrusion scores and results of repeated measures ANOVA	65
3.3 Mean IES avoidance scores and results of repeated measures ANOVA	66
3.4 Mean HAD total scores and results of repeated measures ANOVA	67
3.5 Mean HAD anxiety scores and results of repeated measures ANOVA	67
3.6 Mean HAD depression scores and results of repeated measures ANOVA	67
3.7 Mean MAC FS-H scores and results of repeated measures ANOVA	68
3.8 Mean MAC AP scores and results of repeated measures ANOVA	69
3.9 Mean MAC FA scores and results of repeated measures ANOVA	69
3.10 Mean BIS scores and results of repeated measures ANOVA	70

1. Introduction

1. 1. Breast Cancer

Breast Cancer- Facts and Figures

Breast cancer is common, affecting 1 in 12 women (Breast Cancer Care, 1998). In the UK, breast cancer is the cause of 21,000 deaths each year, with prevalence rates for the disease around five times higher than this figure (Dixon & Sainsbury, 1998). Risk of breast cancer increases with age, and incidence is highest amongst women age 55-60. A relatively small proportion of breast cancers (5-10%) are genetic. Two genes have recently been identified (BRCA1 and BRCA2). The risk of developing breast cancer is increased three to four times for women with a first degree relative (mother, sister) who has the disease, and is higher still if the relative was younger (<50) when the disease was first diagnosed. Several risk factors are currently under investigation, but as yet no causal links have been established. These include environmental pollutants, smoking, diet, influence of contraceptive hormones, and hormone replacement therapy (Dixon & Sainsbury, 1998).

Disease Types

Breast cancer is not just one disease. There are two broad categories of breast cancer, invasive carcinoma and carcinoma *in situ* (Breast Cancer Care, 1998). Breast cancer arises within the terminal duct lobular unit. The most common type of breast cancer, accounting for up to 85% of cases, is invasive carcinoma of no special type (NST), often called invasive ductal carcinoma. Special types include invasive lobular

carcinoma, invasive tubular, cribriform, medullary and mucinous, with other types being less common. The prognosis is better for many of the special types. Carcinoma *in situ* refers to carcinoma cells confined to within the terminal duct lobular unit and the adjacent ducts, but which are not yet invaded through the basement membrane. Two main types have been described – ductal carcinoma *in situ* (DCIS) and lobular carcinoma *in situ* (LCIS).

Specialist Breast Care Units

Breast diseases, including breast cancer, are increasingly being treated at specialist units where close cooperation between surgeons, pathologists, radiologists and other medical staff allow rapid and accurate diagnosis with appropriate treatment to be offered to patients (Dixon & Sainsbury, 1998). Specialist breast nurses are appointed to all units dealing with breast diseases. Patients may be referred to specialist breast units either by their GP or as a result of screening. In some areas, specialist units are available within District General Hospitals, with patients required to travel to another hospital only for radiotherapy.

Screening

It is hoped that earlier identification of breast cancers will increase for women in the highest risk age group as a result of the National Breast Screening Programme (NBSP), which currently entitles women aged 50-64 to screening every 3 years. Many more patients with DCIS are now being diagnosed through breast screening, and it is hoped that detection of these early lesions will reduce subsequent incidence of invasive cancer (Dixon & Sainsbury, 1998).

Staging Classifications

Once breast cancer is diagnosed the patient is staged. The Tumour size-Node-Metastasis (TNM) classification is used. Tumour size and nodal status may change when the definitive histological report is available, thus TNM classifications are used clinically and should not be confused with pathological staging (Dixon & Sainsbury, 1998). Comparison of TNM and the older UICC classification still used sometimes is shown in Table 1.1.

Early and Advanced Disease

Breast cancers are typically described as either 'early' (stage I or II) or 'advanced' (stage III and IV) disease. This division is based on the criteria of 'operability'. The term early has been described as a misnomer, since true early breast cancer would be too small to detect (Dixon & Sainsbury, 1998). The term early therefore refers to the biology of the tumour.

T Is	in situ
T1	< 2cm (T1a ≤ 0.5cm, T1b > 0.5 - 1.0 cm, T1c > 1-2.0 cm)
T2	> 2-5 cm
T3	> 5cm
T4a	involvement of chest wall
T4b	involvement of skin (includes ulceration, direct infiltration, peau d'orange and satellite nodules)
T4c	a and b together
N0	No regional node metastasis
N1	Mobile ipsilateral nodes
N2	Fixed ipsilateral nodes
N3	Internal mammary node involvement (rarely clinically detectable)
M0	No evidence of metastasis
M1	Distant metastasis (includes ipsilateral supraclavicular nodes)
Correlation of UICC (1987) stage and TNM	
Stage I	= T1, N0, M0
Stage II	= T1, N1, M0; T2, N0-1, M0
Stage III	= any T, N2 or T 3, N1, M0 or T4, N0-2, M0
Stage IV	= any T, any N, M1

Table 1.1: TNM classification and relationship to UICC stage (Dixon & Sainsbury, 1998)

Prognostic Indicators

Routine Prognostic Indicators

Survival of patients with breast cancer depends on two factors: tumour stage (reflecting chronology, or how long the tumour has been present), and biological factors representing the biology or aggressiveness of the tumour (Dixon & Sainsbury, 1998). Routine prognostic factors include tumour size, histological grade (classified from I-III using the Bloom & Richardson system) and nodal status. Prognostic indicators are important in selecting adjuvant therapies for individual patients. Patients may be stratified based on the number of nodes involved, using tumour size and grade to stratify the node negative group. The different risk groups identified using this method and disease free survival rates at 5 years are shown in Table 1.2. Alternatively, a single prognostic index may be used, such as the Nottingham Prognostic Index (NPI) described below.

Risk Group	Definition	5 yr disease free survival (%)
<i>Node negative patients</i>		
◦ Low risk	Tumour < 1 cm in diameter	>90
◦ Intermediate risk	Tumour > 1 cm, grade I or II	75-80
◦ High risk	Tumour > 1cm, Grade III	0-60
<i>Node-positive patients</i>		
◦ Low and intermediate risk	1-3 axillary nodes involved	40-50
◦ High risk	4-9 axillary nodes involved	20-30
◦ Very high risk	> 10 axillary nodes involved	10-15

Table 1.2: Definitions of risk groups and associated disease free survival rates at 5 years (Dixon & Sainsbury, 1998).

Nottingham Prognostic Index

Tumour size, grade and nodal status may be combined to form a prognostic index which allows greater separation of survival curves than for each factor alone. The Nottingham Prognostic Index (NPI, Blamey, 1996) is the best known of these indices, based on retrospective, multivariate analysis of hundreds of cases where survival and time to relapse was well quantified, and confirmed by prospective application on a new patient set and through long term follow up (Blamey, 1996). Tumour grade, lymph node (LN) status (stage) and size are combined in the formula:

$$\mathbf{NPI = grade (measured 1-3) + LN stage (measured 1-3) + size (0.2 \times size \text{ cm})}$$

Thus, the higher the index, the worse the prognosis. Survival rates based on NPI values are shown in Table 1.3.

PROGNOSTIC GROUP	NPI VALUE	10 YEAR SURVIVAL (%)
EXCELLENT	≤ 2.4	94
GOOD	≤ 3.4	83
MODERATE I	≤ 4.4	70
MODERATE II	< 5.4	51
POOR	> 5.4	19

Table 1.3: Survival rates at 10 year for prognostic groups based on NPI values (Blamey, 1996)

Other biological markers

Other, newer biological factors related to the biology of the tumour have been identified using special biochemical or immunohistochemical tests, but as yet not all of these are in routine clinical use. Oestrogen receptors (ER) were the first of the biological markers

to be studied. Approximately 60% of tumours contain detectable ER. Although the difference in disease-free survival between those with node positive, ER tumours, and node negative, ER tumours is small (5-10%), survival after first recurrence is predicted by ER status, with ER positive patients living longer and having a better response to adjuvant chemotherapy or hormone therapy. It is now therefore recommended that all patients have their ER status estimated and recorded (Dixon & Sainsbury, 1998).

Treatment of Early Stage Breast Cancer

Treatment of patients with early stage breast cancer has two main goals - to achieve local disease control, and to treat any micrometastatic disease. Treatment for breast cancer most often involves surgical removal of part or all of the breast. The resulting disfigurement can be extremely distressing for some patients. There are two main types of operation: *partial mastectomy*, ranging from lumpectomy (wide local excision), in which the lump is removed together with small amounts of the surrounding tissue, to segmentectomy or quadrantectomy, in which approximately quarter of the breast is removed; and *total mastectomy*, in which all breast tissue is removed, usually either a simple mastectomy, which removes breast tissue alone, or a modified radical mastectomy, in which all breast tissue together with some chest muscle and some or all of the lymph nodes are removed (Breast Cancer Care, 1998). As many as 50% of women with early breast cancer will be cured either by surgery alone or in combination with post-operative radiotherapy, therefore it is important to define these patients to spare them further treatment (Dixon & Sainsbury, 1998). Adjuvant chemotherapy and/or hormone therapies recommended for some women with operable breast cancers can,

however, reduce the annual risks of death by about 30% for at least 10 years (Early Breast Trialists' Collaborative Group, 1992).

Psychosocial Outcome of Early Stage Breast Cancer

Improved methods of screening and diagnosis, and advances in treatment during the last few decades have meant that increased numbers of patients with operable breast cancer will now complete longer disease free intervals, with approximately 70% surviving at 5 years and beyond (Dixon & Sainsbury 1998). Increased survival rates have put new emphasis on quality of life for breast cancer patients, and on efforts to improve the psychosocial outcome of the disease and its treatment (Fallowfield & Clark, 1991). Although the meaning of breast cancer diagnosis has changed in recent years (Moyer & Salovey, 1997), breast cancer is an emotive subject, continuing to receive substantial media attention (Tait, 1996). Coping with cancer, its treatment and associated side effects and the consequent disruption to normal patterns of daily living is traumatic, and may be expected to cause a number of psychosocial problems for patients (Cull, Stewart & Altman, 1995). The literature concerning psychological adjustment in patients with early stage disease will be reviewed in following sections.

1.2. Psychological Impact of Breast Cancer Diagnosis

Reactions to Diagnosis

Reactions to cancer diagnosis vary considerably between individuals (Derogatis, Morrow & Fetting, 1983; Stanton & Snider, 1993), but feelings of fear, anxiety, anger, depression, and helplessness are common (Slevin, Nichols, Downer, et al 1996). Often, patients find themselves thrown from a state of apparent good health through a series of frightening transitions involving investigations and treatments with potentially unpleasant side effects. Fears concerning recurrence, pain and death, and feelings of loss of control and uncertainty are common (Bloom, 1982).

Emotional reaction to diagnosis of breast cancer and responses to various stages of treatment may be conceptualised as a process of adjustment. Theoretical models that applied to our understanding of this process are drawn from the literature on psychological adjustment to traumatic stressors, and to the effects of chronic illness or disease. The crisis intervention literature indicates that an important adaptation takes place in the first four to six weeks following the crisis, after which there is a return to normal function (Budin, 1998). It is important to detect patients who are not returning to their normal level of functioning in order that appropriate help can be offered (Watson, 1991).

Psychological Response to Severe Stressors

Diagnosis of breast cancer represents a potentially severe stressor (Moyer & Salovey, 1997). As diagnosis involves an actual or perceived threat to life or well being, it is considered to meet the criteria for traumatic stress as defined in DSM-IV (APA, 1994).

Post-traumatic stress disorder (PTSD) is a disorder of adjustment that occurs in response to a traumatic stressor. Most studies of PTSD have investigated the impact of trauma in response to severe stressors such as war or combat exposure (King, King & Fairbank, 1998), disaster (McFarlane & Papay, 1992; Ironson, Wynings, Schneiderman, et al, 1997), burn injury (Perry, Difede, Musgni, et al, 1992), or rape (Foa, Rothbaum, Riggs & Murdock, 1991). Severity of stressor is an important predictor of response (Breslau & Davis, 1987), however, since not all individuals exposed to the same stressor develop PTSD, other factors contribute to adjustment. These have been shown to include premorbid adjustment and personality (McFarlane, 1988). Individual's perception or appraisal of the event can influence both initial and long term reactions (Green et al, 1985; Foa et al 1991). The importance of the individuals' response to the stressor (fear, perceived threat to life or well-being, helplessness), in contrast to other ratings of severity of trauma, is emphasised in DSM-IV. PTSD is characterised by three groups of symptoms: intrusive re-experience (flashbacks, dreams or recurrent memories of trauma, intrusive thoughts); avoidance of reminders of the event, or emotional numbing; and autonomic over-arousal (sleep disturbance, hypervigilance, exaggerated startle response). Diagnosis of PTSD is made if symptoms are present for more than one month. If symptoms present within the first month after exposure to a stressor occurring, acute stress response may be diagnosed.

Traumatic Stress in Response to Life-Threatening Disease

Several reports suggest a link between life-threatening illness or highly stressful medical procedures and the development of traumatic stress reactions in some medical populations. These include burns patients (Powers, Cruse, Daniels & Stevens, 1994)

and individuals experiencing cardiac events such as myocardial infarction, heart catheterisation, or coronary artery bypass surgery (Doerfler, Pbert & DeCosimo, 1994; Kutz, Shabtai, Solomon, Neumann & David, 1994). Only a few studies have investigated post traumatic stress symptoms in cancer patients. Intrusive thoughts concerning bone-marrow transplantation (BMT) and avoidance of reminders of treatment have been reported in paediatric BMT patients (Heiney, Neuberg, Myers & Bergman, 1994; Stuber, Nader, Yasuda, Pynoos & Cohen, 1991). PTSD-like symptoms have been reported in acute leukaemia patients who had undergone either BMT or conventional antileukemic therapy (Leskon, Ostroff, Mumma et al, 1992). In a study of male patients with Hodgkin's disease, Cella & Tross (1986) found that survivors of the disease showed more avoidant thinking about illness than healthy control patients. In another study of individuals with Hodgkin's disease, intrusive thoughts and avoidance of treatment reminders were inversely related to length of time since treatment completion (Kornblith, Anderson, Cella et al, 1992).

Acute Stress Reactions associated with Diagnosis of Breast Cancer

One or two studies have recently examined adjustment in breast cancer patients from a PTSD viewpoint. Acute Stress Response is described in a consecutive sample of 106 stage I and II breast cancer patients in Norway by Tjemsland et al (1996). Patients were assessed shortly after diagnosis (before surgery). Using the Impact of Events Scale (IES), nearly half of the patients (44%) reported high intrusive distress. Highest levels were found in younger, married patients. Patients with previous experience of breast cancer in a first degree relative tended to suffer less intrusive distress. Twenty-eight percent of patients received breast conserving treatment (breast conserving surgery

plus radiotherapy), although results for the whole sample were discussed together. Follow up was carried out 6 weeks post operatively, at which time almost all of the patients allocated to adjuvant treatment (39% chemotherapy, 52% endocrine therapy, 42% radiotherapy) had started this treatment. Intrusive distress at follow up was significantly lower than pre-surgery. At follow up, only 8% of patients reached levels of clinical 'caseness' on measures of both intrusive distress and avoidance. Potential predictor variables assessed before surgery included impairments in work, family and social functioning in the last year, negative life events in the last year, and health problems in the last 10 years. None of these variables was found to be statistically significant, although there was a trend for higher scores to be associated with more reported health problems in the previous 10 years. One third of the patients identified as possible PTSD at 6 week follow up had previously consulted their doctor for 'nervous problems'. Trauma studies in other populations have underlined the importance of premorbid factors in predicting subsequent adjustment, and suggest that response 4-6 weeks after the event is a better predictor than immediate response (Budin, 1998).

Adjustment over time

Cordova, Andrykowski, Kenady et al (1995) investigated PTSD-like symptoms in 55 breast cancer patients 6 months to 5 years post-treatment. Using a PTSD checklist corresponding to DSM-IV criteria (PCL-C, civilian version), and the Impact of Events Scale (IES), 5-10% of this sample were found to meet the diagnostic criteria for PTSD. Evidence of PTSD symptoms was associated with generally poorer quality of life, and was more commonly found in younger patients with lower incomes. Time since treatment, type of cytotoxic treatment, and stage of disease were unrelated to PTSD

symptoms. It is possible that the prevalence of PTSD in this sample is no different from that found in the general population. Dansky, Saunders & Best (1993) reported similar base rates of 4.6% in the previous 6 months, and a lifetime prevalence of 12.6% in an unselected sample of 4,000 women (mean age = 45 years). Specific PTSD-like symptoms may however be linked to aspects of diagnosis and treatment of cancer. For example, 49% of patients included in the Cordova, Andrykowski, Kenady et al (1995) study reported that they experienced recurrent, disturbing memories of cancer treatment, the most common of these related to side effects of surgery or chemotherapy. Physical anxiety reactions (nausea, palpitations, feelings of panic) when reminded of the cancer or of cancer treatment were reported in 35% of the sample. Prominent triggers were being in or near the hospital where they underwent treatment, and thoughts about treatment or recurrence. Although at 6 month follow up very few patients reached caseness on IES, frequently endorsed IES items included feelings of unreality (71%) and numbness (41%). Half of the patients reported trouble falling or staying asleep because of thoughts or pictures about their illness popping into their mind, and 1 in 4 reported bad dreams as a result. 1 in 2 patients reported that they avoided talking about their illness.

Traumatic Stress associated with Disease Recurrence

Stress response symptoms shortly after recurrence are reported by Cella, Mahon & Donovan (1990) for a sample of 40 cancer patients undergoing chemotherapy. The majority of patients in their sample showed evidence of high levels of avoidance symptoms, and almost half showed a high level of intrusive symptoms. The extent to which unpreparedness for recurrence predicted stress response symptoms was

investigated by the authors of this study. Those patients who reported a balanced concern about recurrence were found to be less prone to intrusive distress compared to patients who were either completely or not at all surprised by the recurrence. Greater intrusive distress was also reported amongst patients with first recurrence compared to those with two or more recurrences, suggesting that high levels of intrusive distress may be associated with recurrence. Similarly, Kaasa et al (1993), in their multi-centre study of 247 cancer patients (23% breast cancer) undergoing radiotherapy for recurrence in advanced disease, report that one-third of sample were above cut-off for intrusion and avoidance, closer to the acute response described in the Tjemsland et al (1995) study. Rates of psychological distress following recurrence of disease may be higher than observed after diagnosis of cancer (Alexander et al 1993; Cella et al 1990; Derogatis et al, 1983; Okamura et al; 2000; Silverfarb et al 1980). In their consecutive sample of 55 women with first recurrence of disease, Okamura et al (2000) found that 42% of the sample assessed 3 months after recurrence was confirmed met DSM criteria for major depressive disorder (7%) or adjustment disorders (35%). Disease free intervals of less than 24 months predicted diagnosis of psychiatric disorder. Since disease free interval is one of the most important prognostic indicators (Robertson et al 1992; Yamamoto 1998), earlier recurrence therefore indicated poorer prognosis. Younger age (< 50) and concurrent chemotherapy treatment were also associated with greater psychological distress.

1.3. Longer-term Psychological Effects of Breast Cancer

During the period from discovery of a lump to hearing the diagnosis and having the operation, thoughts and coping resources may be centred on coping with what is seen as an immediate threat to life, and the physical recovery from the operation. Longer term implications including worries about recurrence, body image, or reaction of partner to breast cancer treatment may not be considered until after the patient returns home from hospital and starts to feel physically better, at which point some women may begin to feel emotionally worse (Fallowfield & Clark, 1991). Although diagnosis of breast cancer initially evokes responses of grief, anger and intense fear, 'most women face the crisis and master it without major psychological disorder or sexual dysfunction' (Schover, 1991).

Anxiety and Depression

Depression and anxiety are the most commonly reported reactions to breast cancer. Earlier reports indicated high levels of psychological problems in breast cancer patients (Maguire, Lee & Bevington, 1978; Morris, Greer & White, 1977; Kemeny, Wellisch & Schain, 1988; Meyer & Apergren, 1989; Schain, Edwards, Gorrell et al, 1983). More recent studies suggest that the majority of women do not experience long term emotional distress, and psychological adjustment improves over time (Irvine, Brown, Crooks et al, 1991). Several reports indicate that levels of distress following diagnosis and treatment of breast cancer are lower than previously reported (Carver, Pozo, Harris et al 1993; Cella, Tross, Orav et al 1989; Penman, Bloom, Fotopoulis et al 1986; Stanton & Snider, 1993; Wolberg, Romsaas, Tanner & Malec, 1989), or no different from women treated for other types of cancers or in the general population (Worden &

Weisman, 1977; Lansky, List, Hermann et al, 1985). Some of this distress might therefore be transient, with only a small number of women experiencing unremitting and substantial morbidity (Baider, Rizer & Kaplan De-Nour, 1986; Bloom, Cook, Fotopoulos et al, 1987; Fallowfield & Clark, 1991).

Problems Determining Levels of Distress in Breast Cancer Patients

There are particular difficulties in determining levels of distress in breast cancer patients (Moyer & Salovey, 1997). For example, symptoms of depression such as sleep and appetite disturbance, inability to concentrate, apathy and loss of interest in usual activities may be confounded with those resulting from cancer treatment (Wellisch, 1988). Psychiatric labels might therefore wrongly be assigned to cancer patients (Peterson, 1984; Turk & Salovey, 1985). It has been suggested that indicators of depression in breast cancer patients might therefore be those symptoms considered more psychological such as feelings of worthlessness, extreme irritability, and recurrent thoughts of suicide and death as well as sleep problems, concentration difficulties and loss of interest in activities (Wellisch, 1988; Maguire, Lee & Bevington, 1978).

A second problem in examining distress associated with breast cancer is that anxiety and depression have tended to be assessed using self-report measures only, and many of the studies have failed to use common diagnostic criteria (Moyer & Salovey, 1997). The available studies have tended to assess patients at different stages in treatment (Wellisch, 1988), and have often used relatively small samples (Lansky, List, Hermann et al, 1985), presenting further difficulties with interpretation of findings. Psychological morbidity varies across studies according to the method and timing of assessments (Carroll, 1998). However, psychological distress may continue long after treatment is

completed (Watson, 1991). Longer term emotional problems such as depression, anxiety and hostility have all been described in the literature, as well as low self esteem and a decreased sense of personal control (Rabinowitz, 1997).

Psychological Impact of Breast Cancer on Body Image and Sexuality

Because of its impact on women's body image and sexual identity, breast cancer is thought to be uniquely threatening to the self-concept and psychological integrity (Moyer & Salovey, 1997). Derogatis (1986) proposes that body image and sexual functioning are separate but integrally related components of self-image and of psychological adjustment. Changes in body image following mastectomy are well documented in the literature (Bloom, Cook, Fotopoulos et al, 1987; Golden, 1983; de Haes & Welvert, 1985; Hopwood & Maguire, 1988; Margolis, Goodman & Rubin, 1990; Polivy, 1977). The only consistent finding across studies comparing psychosocial outcome of breast conserving therapy (BCT) with mastectomy (reviewed in a later section) is for advantages of BCT in terms of body image (Moyer, 1997). This finding appears to be consistent despite body image being assessed in a number of different ways: feelings about physical appearance and sexual desirability; shame and embarrassment about one's body; and measures of body image. Since BCT involves less physical mutilation than mastectomy, the finding that it results in better body image satisfaction is, however, considered circular by some researchers (Hall & Fallowfield, 1989). To the extent that body image may have a significant impact on psychological adjustment for some women this effect may not be trivial (Moyer & Salovey, 1997). Breast reconstruction offers a way to improve body integrity and possibly adjustment after mastectomy (Moyer, 1997) and can even result in cosmetic outcomes superior to

those of breast conserving surgery (Cady & Stone, 1990; Taylor, Lichtman, Wood et al 1985). Level of satisfaction with body image amongst women who undergo reconstruction after mastectomy is reported to fall between that of women treated with mastectomy without reconstruction and women who receive breast-conserving surgery (Mock, 1993; Wellisch, DiMatteo, Silverstein et al 1989).

Due to our cultural association of the breast with femininity and sexuality, loss or disfigurement can threaten women's sense of attractiveness, and may alter sexual relations (Moyer, 1997). Altered body image is likely to affect feelings of sexual desirability and confidence, however, problems in sexual relationships while one partner is being treated for cancer 'can result from reasons other than disfiguring effects of surgery' (Moyer & Salovey, 1997). Studies investigating sexual difficulties have suggested that as many as one third of patients report specific sexual problems (decreased frequency of intercourse or difficulties with orgasm) after treatment for breast cancer (Anderson & Johimsen, 1985; Bransfield, 1983). Sexual functioning is dependent on many variables however. For example, women experiencing sexual difficulties at three months post-surgery have been reported to show evidence of greater psychological distress (anxiety, depression) and poorer overall adjustment (Schover, 1991). Premorbid sexual functioning is likely to be highly relevant, and may predict sexual dysfunction after treatment. Yurek, Farrar & Anderson (2000) investigated the sexual and body change sequelae in 190 women diagnosed and surgically treated for regional breast cancer. The study compared three surgical groups: mastectomy with breast reconstruction, mastectomy without reconstruction, and BCT. Increased risk of sexual dysfunction and body image dissatisfaction post-operatively was found in post-menopausal women receiving mastectomy, with or without

reconstruction, and amongst women who showed evidence of negative sexual schemas. The stage of treatment at which women are investigated may be a crucial factor. Adjuvant radiotherapy contributes to fatigue and loss of libido, thus disrupting sexual functioning in the first 12 months or so following surgery (Schover, 1991). For women receiving chemotherapy, in addition to hair loss that can make one feel unattractive, other side effects such as fatigue and nausea can reduce sexual interest (Halifin, Althausen, Goldstein, et al 1990). The experience of physical pain is also related to problems relaxing and in enjoying physical intimacy. Fear and feelings of depression and anger experienced during the course of treatment may also contribute to lack of interest in intimacy in addition to disfigurement or effects of adjuvant treatment (Moyer & Salovey, 1997). Comparisons of sexual satisfaction between breast cancer patients and healthy controls may therefore be confounded by functional restrictions resulting from the disease and its treatment (Beckham & Godding, 1990).

Cancer Related Fears and Concerns

Whereas early studies suggested that fear of losing the breast was the primary cause of distress, more recent work has shown that fear of cancer rather than concern about the effect of surgery is the primary reason for distress. It is suggested by Schain, d'Angelo, Dunn et al (1994), that it is only since the use of breast conservation therapy has become widespread that 'we have begun to factor out the relative contribution of the type of surgery, rather than the diagnosis of life threatening disease, to the psychological adjustment of women with breast cancer'. For example, in their sample of 269 women, Fallowfield et al (1990) found that only 12% of women gave breast loss as their primary focus of concern, with 59% more distressed at the prospect of having

cancer. Fears about cancer recurrence and death are often identified amongst women treated for breast cancer (Ganz, Schag, Polinsky et al 1987; Jones & Greenwood). Disfigurement associated with mastectomy may remind women of the threat of cancer (Aaronson , Bartelink, van Dongen & van Dam,1988). On the other hand, women treated with breast-conserving surgery may worry more about cancer returning because less of the breast has been removed or had doubts about the effectiveness of breast conserving treatments (Fallowfield et al 1986; Massie & Holland, 1991; Ward, Heidrich & Wolberg, 1989).

Impact of Breast Cancer on Family and Social Functioning

The impact of breast cancer extends beyond the patient to her partner, family and social network (Northouse, Cracchiolo-Caraway & Appel, 1991). There is evidence that some husbands experience considerable distress when their partner is diagnosed and treated for breast cancer (Baider & Kaplan de Nour, 1984; Zahlis & Shands, 1993) irrespective of type of surgery received (Omne-Ponten, Holmberg, Bergstrom et al 1991). The importance of the partner's involvement in the treatment decision-making process has been highlighted, and spouses who are involved have been shown to report better sexual satisfaction both before and after surgery (Holland & Rowland, 1990). Involving partners in giving information about what to expect during the course of treatment is helpful in reducing the feelings of helplessness than can often be reported by partners (Northouse & Peters-Golden, 1993). Dealing with the uncertainty, as well as the physical and psychological effects of breast cancer treatment can be stressful and disruptive for families and may influence work, financial, or other family plans (Hilton, 1993). Positive consequences have also been documented however, including increased closeness and caring within the family, family members becoming more

helpful, and learning that others cared about them (Zemore, Rinholm, Shepel & Richards, 1989). Family functioning appears to be related to marital functioning and communication which facilitates the use of constructive family problem-solving processes, whereas poor marital functioning negatively affects families coping (Lewis, Woods, Hough & Bensley, 1989). With regard to support from the wider social network, there are some reports of inadequate support being provided, or of failure of others to understand that issues of survival had superceded cosmetic concerns (Peters-Golden, 1982). Other studies have indicated that patients report increased rather than reduced social support from family and friends (Zemore & Shepel, 1989). Assessment of patients levels of social support, and the perceived quality of this support is therefore important.

Factors Influencing Psychosocial Outcome of Breast Cancer

The psychosocial outcome of breast cancer is influenced by a number of disease and treatment related variables, as well as individual patient factors. These are discussed in detail in the following sections.

1.4 Influence of Disease Stage and Recurrence on the Psychosocial Outcome of Breast Cancer

Disease Stage

Prevalence of psychological distress in cancer patients depends on many factors beyond diagnosis. The majority of studies have investigated depression and anxiety in patients with early stage disease. It has been suggested that psychological morbidity may be lower in women with screen detected breast cancer (Farmer, Payne & Royle, 1995). Reasons for this are suggested as due to women receiving more reassurance of an early diagnosis and treatment, 'while the benefits of screening are emphasised, along with a conceptual model of early, curable disease' (Caroll, 1998). There has been limited research on patients with more advanced disease. Pinder, Ramirez, Black et al (1993) report that 25% of patients with advanced breast cancer obtained clinically significant scores for either depression or anxiety using the Hospital Anxiety and Depression Scale (HAD), a measure which excludes most symptoms that may result from physical illness or treatment. Poor functional status was strongly associated with depression in this study. At least one other study (Hopwood, Howell & Maguire, 1991) reports similar findings. Previous work that included patients with other cancers (Derogatis, Morrow & Fetting et al 1983) also reported high prevalence of psychological disorder associated with poor prognosis and advanced tumour status. Stage of disease or associated complications (e.g. pain, effects of treatment), the presence or absence of metastases, particularly in the central nervous system, and functional physical status may significantly influence occurrence of psychological distress in cancer patients (Derogatis, 1986).

The prognosis for cancer patients is influenced by several factors including disease type, stage, and location. Using these three criteria, the American Psychological Association (1992) distinguish three risk groups for developing psychological morbidity (low, medium, and high), shown in Table 1.4. When disease is localised and controlled, risk of psychological morbidity is low, and emotional reactions tend to stabilise over the first year. In patients with regional disease, psychological adjustment is variable and adjuvant therapies themselves may increase experience of distress. In systemic or aggressive disease, psychological morbidity is higher. Interventions with patients in this group tend to focus on adjustment to disease and existential issues.

PSYCHOLOGICAL MORBIDITY RISK	EXTENT OF DISEASE	TREATMENT/MANAGEMENT	PROGNOSIS
LOW	LOCALISED/ STAGE I OR II	SINGLE MODALITY	FAVOURABLE 70-90% (5YRS)
MEDIUM	REGIONAL STAGE II /1 ST RECURRENCE	COMBINED THERAPY	GUARDED 40-60% (5 YRS)
HIGH	DISTANT/ STAGE IV / 1 ST RECURRENCE REGIONAL / RAPID PROGRESSION	DEBULK/ PALLIATIVE /SYMPTOM CONTROL	DISMAL 15-40% (1 YR) 4-15% (5 YRS)

Table 1.4: Risk of psychological morbidity associated with disease prognosis (*American Psychological Association, 1992*)

Recurrence

Rates of psychological distress following recurrence of disease may be higher than observed after diagnosis of cancer (Alexander, Dinesh & Vidyasagar, 1993; Cella, Mahon & Donovan, 1990; Derogatis et al, 1983; Okamura, Watanabe, Narabayashi, et al; 2000; Silverfarb, Maurer & Crouthamel, 1980). In their consecutive sample of 55

women with first recurrence of disease, Okamura, Watanabe, Narabayashi et al (2000) found that 42% of the sample assessed 3 months after recurrence was confirmed met DSM criteria for major depressive disorder (7%) or adjustment disorders (35%). Disease free intervals of less than 24 months predicted diagnosis of psychiatric disorder. Since disease free interval is one of the most important prognostic indicators (Robertson, Dixon, Nicholson et al, 1992; Yamamoto, Watanabe, Katsumata et al, 1998), earlier recurrence therefore indicated poorer prognosis. Younger age (< 50) and concurrent chemotherapy treatment were also associated with greater psychological distress.

1.5. Psychological Effects of Surgery in the Treatment of Early Stage Breast Cancer

Historical Perspective

The earliest reports of psychological reactions to breast cancer were published in the 1950's. In their now seminal papers, Bard & Sutherland (1955) and Renneker & Cutler (1952) described the responses of women who had undergone radical surgery, for whom removal of the breast was considered to be the main cause of psychological distress, in particular depression. These early reports were important in first drawing attention to the psychological problems of distorted body image, anxiety and depression associated with breast cancer treatment, and challenged the then prevailing view that patients would simply adjust over time after 'removal' of the cancer. The early accounts were, though, largely anecdotal, and were based on reports of women who had undergone radical mastectomy, involving removal of the breast and underlying muscles leaving a deformed chest wall. Previously, women discovering a breast lump faced just one option: biopsy, and if indicated, radical mastectomy. As this was usually carried out in a single procedure, women would often discover whether or not a breast had been removed only upon waking from their operation (Moyer & Salovey, 1997). Today, a two stage procedure is used, with biopsy carried out prior to surgery. Breast conserving surgery is available, and there are options for reconstruction following mastectomy.

Studies Comparing the Psychosocial Outcome of BCT with Mastectomy

As breast conserving therapy (BCT) became more widely available, studies comparing the psychosocial outcome of BCT with mastectomy emerged. Over 40 studies have now been carried out comparing the psychosocial outcome of breast conserving

therapy (BCT) with mastectomy (Mx), summarised in Table 1.5. The earlier studies (Sanger & Rezinkoff, 1981; Beckman, Johansen, Richardt & Blichert-Toft, 1983; Schain, Edwards, Gorrell et al, 1983; Meyer & Aspergen, 1989) typically used small samples ($N < 40$) and were based on retrospective follow-up of patients at various stages post-surgery. These studies found no significant difference in overall psychological adjustment, with the only difference between BCT and Mx groups found in relation to feelings about body image, which were better in BCT groups. Subsequent studies using larger samples (Fallowfield, Baum & Maguire, 1986; Kemeny, Wellisch & Schain, 1988; Lasry, Margolese, Poisson et al 1987; Ganz, Schag, Lee, et al 1992), and a number of well designed, prospective studies (Pozo, Carver, Noriega et al 1992; Goldberg, Scott, Davidson et al, 1992) report broadly similar results. Several comprehensive reviews of studies comparing the psychosocial outcome of BCT with mastectomy have thus concluded that although there may be some advantage to BCT versus mastectomy for body image and sexual functioning, no substantial evidence of better overall psychological adjustment for BCT has been demonstrated (Carlsson & Hamrin 1994; Fallowfield & Clark, 1991; Hall & Fallowfield, 1989; Kiebert, de Haes, van de Velde, 1991; Schain & Fetting, 1992).

A recent, well-designed meta-analysis of investigations reported between 1981 and 1995 was carried out by Moyer (1997). Effect sizes (ES) were calculated for different categories of psychosocial outcomes reported in the literature and weighted by sample size. Factors related to study design which may have influenced ES were examined, including method of assignment to treatment (randomised versus non-randomised), and length of time since surgery (less than 12 months versus 12 months or more). Mean weighted ES for measures of psychological adjustment, marital-sexual adjustment, and cancer related fears and concerns were small (0.2), with only body/self-image

demonstrating a medium (0.4) ES (Cohen, 1988). Advantages for BCT were increased for patients assessed more than one year post-operatively, and for patients who were not randomised to treatment. Better psychological outcomes for BCT more than one year after surgery may be due to psychological distress associated with adjuvant treatment during the first year. Post-operative distress also may be compounded by secondary problems such as pain, loss of sensation, stiffness, and swelling in the arm of the operated side, even following breast conserving surgery (Maunsell, Brisson & Deschenes, 1993). Women treated with different types of surgery may experience distress for different reasons. Fallowfield et al (1986) report in one study, for instance, that lumpectomy patients were concerned by feelings of fatigue and their slow recovery after a small operation, whereas mastectomy patients who did not expect a swift recovery found that treatment was less difficult than anticipated. Different procedures may be related to different levels of specific feelings, for example, cancer itself may be associated with anxiety, whereas breast loss or disfigurement may be associated with depression (Deadman, Dewey, Owens et al, 1989). Similar to the conclusions of previous reviewers, Moyer (1997) observes that 'unexpectedly, many of the findings have been equivocal and typically show a lack of substantial benefits for breast-conserving surgery as compared with mastectomy'. To the extent that even small effect sizes may be clinically significant, however, demonstration of an advantage for BCT on quality of life is considered important (Moyer, 1997).

Studies Comparing BCT with Mastectomy plus Reconstruction

Relatively few investigations have compared women treated with mastectomy plus reconstruction to women treated with breast-conserving surgery. In one study, body-

image and satisfaction with surgery was superior in the breast-conserving surgery group, but no difference was found in sexual adjustment or fear of cancer recurrence (Noguchi, Kitawaga, Kinoshita et al 1993). In a second study, no difference was found between groups in body image, psychosocial adjustment to illness, and satisfaction with sexual relationships (Schover, Yetman, Tuason et al, 1995). Schain, d'Angelo, Dunn et al (1994) compared psychological outcome for women randomised to BCT versus mastectomy with or without reconstruction. They reported better outcomes for patients assigned to BCT, with no benefit of having reconstruction to the mastectomy group. Another study which compared psychosocial outcome of BC with mastectomy and reconstruction (Schover, Yetman, Tauson et al 1995) concluded that choice of local treatment had little impact on psychosexual function or psychological distress, whereas adjuvant chemotherapy was associated with longer term impairments in quality of life. A recent study reported by Nissen, Swensen, Ritz et al (2001) compared outcome in relation to quality of life for a total of 198 women who underwent one of three surgical procedures: breast-conserving surgery; mastectomy alone; and mastectomy with reconstruction. Baseline quality of life questionnaires were completed pre-operatively. Questionnaires were completed again at 1, 3, 6, 12, and 18 months post surgery. The results demonstrated that other than body image, aspects of quality of life were no better amongst women who had undergone breast-conserving procedures or mastectomy with reconstruction than for those who had undergone mastectomy alone. Women who had undergone mastectomy with reconstruction in fact showed evidence of greater distress at 18 months. This study highlighted several important points with regard to factors other than type of surgery that are likely to have had significant effects on women's adjustment and quality of life. Women in the mastectomy with reconstruction group, for example, were likely to be younger, require more extensive

surgery with a longer surgical recovery period than the BC group, and be recommended subsequent treatment with chemotherapy. Women who received BC were also likely to have significantly smaller tumours than either of the mastectomy groups.

Table 1.5
Summary of Studies Comparing Psychosocial Outcome of Breast-Conserving Therapy versus Mastectomy

Authors/ Journal	Sample	Design	Timescale	Outcome
Sanger & Reznikoff (1981). <i>Cancer.</i>	40 (20 BC + RT; 20 Mx)	Non-randomised. Retrospective follow up	2 mths – 4.5yrs post- surgery	No difference between groups in psychosocial adjustment. BC greater overall body satisfaction.
Beckman, Johansen, Richardt & Blichert-Toft (1983). <i>Dan. Med. Bull.</i>	22 (11BC+RT; 11 Mx)	Non-randomised. Retrospective follow up	7-12 mths post- surgery	Less change in body image satisfaction/ feelings of sexual attractiveness in BC group. No group difference for fear of cancer recurrence.
Schain, Edwards, Gorrell et al (1983). <i>Breast Cancer Res. & Treat.</i>	38 (18 BC + RT ± CT; 20 Mx ±CT)	Randomised. Retrospective follow up	<2 - 20 mths post- surgery	No significant difference between groups in overall psychosocial outcome. Less negative body image in BC group.
Ashcroft, Leinster & Slade (1985). <i>JRSM.</i>	40 (BC + RT; Mx ± RC. No numbers given)	Some patients randomised, some given choice.	Pre- surgery; 3 mths + 1 yr post- surgery	Few differences between groups but better body image satisfaction in BC group.
Bartelink, van Dam, & van Dogen (1985). <i>Int. J. Rad. Oncol. Biol. & Physics.</i>	172 (114 BC ± RT ± CT; 58 Mx ± CT)	Retrospective follow up of consecutive cases	1-2 yrs post- surgery	BC group had more positive body image, less fear of recurrence.
de Haes & Welvaart (1985). <i>J. Surg. Oncol.</i>	39 (21 BC + RT; 18 Mx)	Randomised. Retrospective follow up	11 + 18 mths post- surgery	No difference between groups in psychosocial or sexual functioning and for fear of recurrence/death. Greater body image satisfaction in BC group.

Steinberg, Juliano & Wise (1985). <i>Am. J. Psych.</i>	67 (21 BC ± RT ± CT; 46 Mx ± CT)	Non-randomised. Choice of treatment for half of BC group. Retrospective follow-up	14 mths post-surgery	No difference between groups for depression. BC group had better overall body image satisfaction/sexual functioning.
Taylor, Lichtman, Wood et al (1985). <i>Cancer.</i>	66 (26 BC ± RT ± CT; 31 MX ± RT ± CT; 9 RM ± RT ± CT)	Non-randomised. Retrospective follow up	2-60 mths post-surgery	Extensiveness of surgery and overall psychosocial adjustment correlated. RM group had more decline in quality of relationships.
Baider, Rizer & Kaplan De-Nour (1986). <i>Gen. Hosp. Psych.</i>	64 (32 BC ± RT ± CT; 32 M ± CT)	Non-randomised. Retrospective follow up	18 mths post-surgery	No difference between groups in psychosocial outcome.
Fallowfield, Baum & Maguire (1986). <i>BMJ</i>	101 (48 BC ± RT ± CT; 32 M ± RT ± CT)	Randomised. Retrospective follow up	4-32 mths post-surgery	No significant differences between groups. Anxiety or depression in 38% BC group and 33% M group.
Ganz, Schag, Polinsky et al (1987). <i>Cancer.</i>	50 (19 BC + RT; 31 MX)	Non-randomised. Retrospective follow up	3-5 wks post-surgery	No difference between groups in psychological difficulties/sexual dysfunction. MX group more likely to have reduced quality of life.
Lasry, Margolese, Poisson et al (1987). <i>J. Chron. Dis.</i>	123 (36 BC + RT ± CT; 44 BC ± CT; 43 M ± CT)	Randomised. Retrospective follow up	< 1-9 yrs post-surgery	No group differences in depression. Body image satisfaction greater in BC group.
Wolberg, Tanner,	206 (96 M—no choice; 56 M—	Non-randomised. Prospective		Psychosocial data reported for just 39

Romsaas et al (1987). <i>J. Clin. Oncol.</i>	choice; 54 BC -choice)	study.		of eligible patients. Less depression and anxiety in women who chose BC.
Aaronson, Bartelink, van Dongen & van Dam (1988). <i>Euro. J. Surg. Oncol.</i>	75 (44 BC ± RT ± CT; 31 RM ± RT ± CT)	Randomised. Retrospective follow up	2-4 yrs post-surgery	No difference between groups on psychological distress. Better body image satisfaction and fewer sexual difficulties in BC group. More fear of recurrence in RM group.
Kemeny, Wellisch & Schain (1988). <i>Cancer.</i>	52 (25 BC ± RT ± CT; 31 RM ± RT ± CT)	Randomised. Retrospective follow up	6 mths – 4 yrs post-surgery	No significant differences between groups on overall psychological distress. BC group had less body image change and fewer sexual difficulties.
Morris & Royle (1988) <i>Soc. Sci. Med.</i>	30 (10 M –no choice; 7 M-choice; 13 BC -choice)	Non-randomised. Prospective		No difference between BC and M groups for psychological distress but better outcome for patients offered choice.
Holmberg, Omne-Ponten, Burns et al (1989). <i>Cancer.</i>	99 (37 BC ± RT; 62 MX ±RT ±CT)	Non-randomised. Retrospective follow up	4 + 13 mths post-surgery	No differences between groups for overall adjustment/sexual functioning. More psychological distress in Mx group at 13 mths.
Levy, Herberman, Lee et al (1989). <i>J. Clin. Oncol.</i>	191 (111 BC ± RT ± CT; 80 Mx ± CT)	50% both groups randomised. Prospective	5 days + 3mths post-surgery	Few group differences for randomised sample. In non-randomised

				sample BC group more distressed and experienced decrease in emotional support over time.
Maunsell, Brisson & Deschenes (1989). <i>J. Clin. Epidem.</i>	227 (80 BC ± RT ± CT; 147 Mx ± RT ± CT)	Non-randomised. Retrospective follow up of consecutive cases	3 + 18 mths post-surgery	Greater psychological distress in BC group at 3 mths. No group differences at 18 mths but overall distress high (35%) for both groups.
Meyer & Aspergen (1989). <i>Acta Oncol.</i>	58 (28 BC + RT; 30 Mx)	Non-randomised. Retrospective follow up of consecutive cases	5 yrs post-surgery	No difference between groups on psychological morbidity. Better body image satisfaction in BC group.
van Heeringen, van Moffaert & de Cuyper (1989). <i>Psychother. & Psychosomatics.</i>	102 (18 BC + RT; 84 M + RT)	Non-randomised. Prospective	During post-surgery period	No group difference in depression scores.
Wellisch, DiMatteo, Silverstein et al (1989). <i>Psychosomatics.</i>	51 (22 BC + RT ± CT; 15 Mx + RT ± CT; 14 Mx ± CT)	Non-randomised. Prospective	Pre-surgery; 6mths + 1-3 yrs post-surgery	No significant group differences for psychological distress, sexual functioning, or fear of cancer recurrence. Better body image satisfaction in BC group.
Wolberg, Romsaas, Tanner & Malec (1989). <i>Cancer.</i>	191 (41 BC ± RT ± CT; 78 Mx ± RT ± CT; 72 Benign Breast Biopsy)	Non-randomised. Prospective	Before diagnosis; 4-8 mths + 16 mths post-treatment	No difference between groups on psychosexual functioning.

Fallowfield, Hall, Maguire & Baum (1990). <i>BMJ</i> .	269 (115 BC ± RT ± CT; 154 Mx ± CT) Choice = 43 BC + 19 Mx.	Non-randomised. Prospective	Pre-surgery; 2wks + 4wks + 12 mths post-surgery	No difference between groups in anxiety/depression scores at 12 mths. Less distress in patients offered choice of surgery.
Margolis, Goodman & Rubin (1990). <i>Psychosomatics</i>	54 (32 BC ± RT ± CT; 22 Mx ± RC ± CT)	Non-randomised. Retrospective follow up	3-4 yrs post-surgery	No difference between groups for psychological distress. Better body image satisfaction/sexual functioning in BC group.
McArdle, Hughson & McArdle (1990). <i>Br. J. Surgery</i>	119 (67 BC ± RT ± CT; 52 M ± RT ± CT)	Non-randomised.	6 + 9 + 12 mths post-surgery	Higher depression/anxiety and insomnia in Mx group.
Langer, Prohaska, Schreiner-Frech et al (1991). <i>Psychotherapie Psychosomatik Medizinische Psychologie</i>	79 (20 BC + RT ± CT; 39 Mx ± CT)	Non-randomised Retrospective follow up	2 yrs post-surgery	No significant differences in body image between groups. BC group had less illness-related stress.
Ganz, Schag, Lee et al (1992). <i>Cancer</i> .	109 (52 BC + RT ± CT; 57 Mx ± RT ± CT)	Randomised.	1mth + 4 + 7 + 13 mths post-surgery	No group differences in quality of life, psychosocial adjustment or mood. Better body image in BC group.
Goldberg, Scott, Davidson et al (1992). <i>Euro. J. Surg. Oncol.</i>	322 (73 BC ± RT ± CT; 93 M ± RT ± CT; 156 Benign Breast Biopsy)	Non-randomised. Prospective	Pre-surgery; 6 + 12 mths post-surgery	No difference between groups on scores for anxiety/depression, body image and sexual problems pre-operatively or at 6 + 12 mths.
Levy, Haynes, Herberman et al (1992). <i>Health</i>	129 (90 BC + RT ± CT; 39 M ± CT)	Non-randomised Prospective	5 days + 3 + 15 mths post-	BC group more distressed and experienced less emotional support

<i>Psychol.</i> (Follow up of Levy et al, 1989)	CT)		surgery	at 3 mths.
Lee, Love, Mitchell et al (1992). <i>Euro. J. Cancer.</i>	197 (100 BC + RT ± CT; 97 MX ± CT)	Randomised Prospective	Presurgery; 6 + 12 mths post-surgery	No difference between groups in overall adjustment. More in MX group reported body image dissatisfaction and loss sexual interest.
Maraste, Brandt, Olsson & Ryde-Brandt (1992). <i>Acta Oncol.</i>	133 (79 BC ; 54 M)	Non-randomised.	<2 mths post-surgery	No significant difference between groups for anxiety. For patients aged 50-59 anxiety highest in M group.
Omne-Ponten, Holmberg, Burns et al (1992). <i>Euro. J. Cancer.</i>	99 (37 BC ± RT; 62 M ± RT ± CT)	Non-randomised.	4 + 13 mths post-surgery	Better psychosocial adjustment and less depression in BC group at 4 + 13 mths. Fewer sexual problems in BC group by 13 mths
Pozo, Carver, Noriega et al (1992). <i>J. Clin. Oncol.</i>	63 (15 BC ± RT ± CT -choice; 48 M ± RT ± CT - 50% choice)	Non-randomised. Prospective	1 day pre-surgery; 10 days, 3 + 6 + 12 mths post-surgery	No significant differences between groups for emotional adjustment in first year post-surgery. BC group reported more enjoyment of sexual relationships at 6 + 12 mths.
Hughes (1993). <i>Cancer Nursing.</i>	71 (46 BC + RT; 25 MX)	Non-randomised. Prospective	At time of diagnosis + 8 wks post-surgery	No group difference in distress about cancer diagnosis, uncertainty or quality of life.
Mock (1993). <i>Nursing Res.</i>	257 (90 BC; 62 M; 58 M + RC - immediate; 47	Non-randomised Retrospective follow up	2 mths - 2 yrs post-surgery	No difference between groups in body image using one measure; with

	M RC + delayed)			another measure BC group more satisfied with body image than M or M + RC (immediate) groups.
Noguchi, Kitawaga, Kinoshita et al (1993). <i>J. Surg. Oncol.</i>	90 (42 BC + RT + CT; 48 Mx + RC (immediate) + CT.	Non-randomised. Choice of treatment	< 1 yr post- surgery	No group difference in fear of cancer recurrence or sexual adjustment. Body image satisfaction better in BC group.
Noguchi, Saito, Nishijima et al (1993). <i>Jap. J. Surg.</i>	102 (31 BC + RT + CT, 71 Mx + RT). Choice of treatment.	Non-randomised. Retrospective	> 6mths post- surgery	More of Mx group concerned about body image. No group difference for satisfaction operative results, fear of recurrence or sexual adjustment.
Omne-Ponten, Holmberg & Sojden (1994). <i>J. Clin. Oncol.</i> (follow-up of Omne-Ponten et al, 1992)	66 (26 BC ± RT ± CT; 40 Mx ± RT ± CT)	Non-randomised Retrospective follow up of consecutive cases	6 yrs post- surgery	Mx group slightly less satisfied with body image. No difference overall adjustment.
Schain, d'Angelo, Dunn et al (1994). <i>Cancer.</i>	136 (76 BC + RT; 60 Mx ± RT)	Randomised. Prospective	Pre- operatively, 6+ 12+ 24 mths post- surgery	Mx group reported less control. More sexual difficulties at 6 mths, more body image distress at 6 +12 mths.
Yilmazer, Aydiner, Ozkan et al (1994). <i>Supportive Care in Cancer.</i>	80 (40 BC ± RT ± CT; 40 Mx ± RT ± CT).	Non-randomised. Retrospective.	10-48 mths post- surgery	Better body image satisfaction in BC group. No group differences self- esteem.
Schover, Yetman, Tuason	218 (72 BC ± RT/HT/CT/HT;	Non-randomised. Prospective	4 yrs post- surgery	Type of surgical treatment had little impact on psychosexual

et al (1995). <i>Cancer</i>	146 Mx + RC ± RT/CT/HT)			function or distress. CT associated with greater long-term impact on QOL.
Tjemsland, Soreide & Malt (1997). <i>Psycho- oncol.</i>	106 (30 BC + RT; 76 MX ± CT ± HT)	Non-randomised. Prospective. Choice of Treatment	Presurgery; 6 wks post- surgery	No difference between groups on levels of intrusive anxiety post-op.
Stanton, Cameron, Danoff-Burg et al (1998). <i>J. Consult. Clin. Psychol.</i>	76 (BC= 48; Mx =28;no info on RT/CT/HT)	Randomised. Retrospective follow up of consecutive cases	Pre- surgery; 3 + 12 mths post- surgery	No difference between groups on adjustment apart from BC group rated treatment had less effect on appearance. Age and expectations of treatment more important.
Yurek, Farrar & Andersen (2000) <i>J. Consult. Clin. Psychol.</i>	186 (78 BC; 29 Mx + immediate RC; 79 Mx)	Non-randomised. Prospective	1-2 mths post- surgery	No significant differences between groups in post-operative sexual functioning. Less body change stress in BC group.
Nissen, Swenson, Ritz et al (2001). <i>Cancer.</i>	198 (BC=103; Mx =55; Mx + RC = 40)	Randomised. Prospective.	Pre- surgery; 1+3 +6+12+18 mths post- surgery	Aspects of quality of life other than body image not better for BC + MX + RC groups versus Mx alone. Greater distress at 18 mths in Mx + RC group.

(BC= Breast-conserving surgery; Mx = Mastectomy; RC= Breast Reconstruction; RT = Radiotherapy; CT = Chemotherapy; HT = Hormone therapy; QOL = Quality of Life)

1.6 Psychological Distress and Adjuvant Therapies

Treatment of disease involving adjuvant treatments such as radiotherapy, chemotherapy or hormone therapy often has a major impact on perceived body image and sexuality, as well as having implications for fertility in younger patients (Irvine, Brown, Crooks et al, 1991) and present considerable physical and psychosocial challenges (Moyer & Salovey, 1997).

Radiotherapy

During the first year post-surgery, adjuvant radiation that more often accompanies breast-conserving procedures or the combination of surgery and radiation, may be a source of psychological distress (Levy, Haynes, Herberman et al 1992; Steinberg, Julian & Wise, 1985). Longer-term assessments may therefore be more sensitive to potential advantages for breast-conserving surgery. This may explain why no substantial benefits have been found for BCT versus mastectomy. Radiation therapy usually follows a rigid schedule of treatment for several weeks. Most women do not experience serious side effects, but itching, swelling, skin changes, and especially fatigue may result (Seltzer, 1987). Difficulties with this treatment are reported to include fear of radiation exposure and indelible marks on the body to indicate where to focus radiation (Greenberg, 1988).

Chemotherapy and Hormone Therapy

The symptoms resulting from chemotherapy and hormone therapy can lead to depression, low self esteem, disruption to family function, sexual inhibitions or loss of

interest in sex, and fear of losing a partner (Myerowitz, Sparks & Spears, 1979; Seltzer, 1987).

Chemotherapy

Chemotherapy uses cytotoxic drugs to destroy cancerous cells throughout the body. Chemotherapy is often administered over a period of six months to a year, and can make patients physically ill in the days after each treatment (Hughson, Cooper, McArdle & Smith, 1986). There are many chemotherapy agents available. Combination chemotherapy has been shown to be the most effective as adjuvant therapy, and is typically administered in six cycles over a six month period. Benefits of chemotherapy appear to be higher for premenopausal than postmenopausal women. Anticipatory anxiety is problematic for some women especially before the first chemotherapy treatment (Jacobsen, Bovbjerg & Redd, 1993). Symptoms that can occur during treatment include chronic fatigue, hair loss, weight fluctuation, infections, mouth sores, altered taste sensations, anticipatory nausea and vomiting (Carey & Burish, 1988; Nerenz, Leventhal, Love & Ringler, 1984). Kiebert, Hanneke, de Haes et al (1990) studied the effect of chemotherapy on perceived quality of life in two groups of women with early stage breast cancer, one of which received peri-operative chemotherapy. Women were interviewed at 2 and 12 months post-surgery. At two months, the group who had received chemotherapy reported reduced quality of life due to side effects of fatigue and hair loss. No differences were found at 12 months. For younger women chemotherapy may have implications for fertility, and longer term emotional consequences of adjuvant treatment may therefore result from the risk of becoming permanently sterile or at the very least having to wait several years before becoming

pregnant because of the threat of cancer recurrence and risk of birth defects (Greenberg, 1988).

Depression and Acceptance of Adjuvant Treatment

Detection of depression amongst breast cancer patients may be particularly important, since depression in this population has been associated with a tendency to be less proactive in obtaining healthcare (Watson, Haviland, Greer, Davidson & Bliss, 1999). Depression is also suggested to be associated with reduced acceptance of adjuvant chemotherapy following surgery. Colleoni, Mandala, Peruzzotti, Robertson, Bredart & Goldhirsch (2000) report findings of a study comparing acceptance of adjuvant cytotoxic drugs in 39 breast cancer patients who were identified as needing psychological support and who met the DSM-IV criteria for depression, with a control group of non-depressed patients ($N = 78$) matched for age and on tumour prognostic status (primary tumour size, number of involved lymph nodes, oestrogen and progesterone receptor status, histological grade) and treatment details (type of surgery). Only 51% of the depressed group accepted adjuvant treatment, compared with 92% of the control group. Psychological support and treatment for depression thus may increase acceptance of chemotherapy, therefore improve prognosis for these patients.

Palliative Chemotherapy in Advanced Disease

In advanced disease, palliative chemotherapy may be administered. The major side effects of such treatment are fatigue, gastrointestinal symptoms and pain (Payne, 1992). Quality of life for patients undergoing palliative chemotherapy appears to be enhanced by administration at home rather than in hospital (Payne, 1992).

Hormone therapy

Hormonal therapy, which affects secretions of endocrine glands, may be prescribed for tumours influenced by hormones (Goodman, 1991; Rubenstein & Cirillo, 1985). Due to hormonal suppression of oestrogen, hot flushes, amenorrhoea, and reduced vaginal lubrication may result. Tamoxifen is the most widely used hormonal treatment for breast cancer. Tamoxifen is a synthetic partial oestrogen agonist which acts primarily by binding to the oestrogen receptor. Tamoxifen appears to produce benefits in pre and post menopausal women, but these benefits are higher in post menopausal women. The optimal duration of tamoxifen in women over 50 has been shown to be 5 years (Early Breast Trialists Collaborative Group, 1992). The production of oestrogen requires the presence and activity of the aromatase enzyme. Aromatase inhibitors have found to be effective in treating breast cancer which no longer responds to Tamoxifen, and shows survival advantages over progestogens which are currently the second line hormonal agents (Dixon & Sainsbury, 1998).

Neoadjuvant Treatment

Primary medical therapy is increasingly being used for larger operable breast cancers. Tumours will usually show either a useful response or progression within 12 weeks of primary medical treatment. Induction (neoadjuvant) chemotherapy has been shown to shrink large T2 and T3 tumours thus permitting quadrantectomy rather than mastectomy, with post-operative consolidation therapy usually given (Dixon & Sainsbury, 1998). Tamoxifen has been used as an adjuvant and as therapy for metastatic breast cancer in premenopausal women. Recent trials have investigated the

primary therapy using the new aromatase inhibitors (anastrozole, letrozole, and vorozole).

1.7 Individual Patient Factors Influencing Psychosocial Outcome

Burton & Watson (1998) identify several key characteristics of patients at risk of psychological problems (Table 1.6).

Table 1.6: Patients at risk of psychological problems (Burton & Watson, 1998)

- | |
|--|
| <ul style="list-style-type: none">• Previous psychiatric history• Lack of support from family and friends• Inability to accept the physical changes associated with the disease and its treatment• Lack of involvement in satisfying activities• Prior adverse experience of cancer in the family• Low expectations regarding the effectiveness of treatment• Pre-existing marital problems• Younger age at diagnosis |
|--|

Age at Diagnosis

Age is believed to have an important influence on women's reactions to breast cancer (Rowland & Holland, 1989; Derogatis, 1980). Younger women are more distressed than older women by the impact on body image and sexuality, whereas older women may react more to the threat to life, perhaps especially if they have experienced losses such as the death of their partner (Holland & Rowland, 1989; Jamison, Wellisch & Pasnau, 1978). It cannot be assumed, however, that issues of body image are unimportant to older women (Frank, Dunnington & Fitzgibbons, 1991). The developmental stage in women's life at which breast cancer occurs may be relevant to the particular challenges this presents. In a study of the issues facing women who are dealing with breast cancer in their twenties, thirties, mid-life and later life, Oktay & Walter (1991) illustrate how at different points, fertility, developing relationships, personal growth,

career, children, ageing, maintaining a mature relationship, and dealing with multiple losses are threatened and complicated by breast cancer. Age and developmental stage are considered as factors that warrant further attention in breast cancer research in relation to the amount and type of information required by patients, the optimal type of surgical treatment, and the types of coping and support that are most beneficial (Moyer & Salovey, 1997). Age may have an important influence on treatment choice, with older women more likely to choose mastectomy and rating maintenance of attractiveness, femininity and sexuality as less important in considering their treatment options than did younger women (Satariano, Swanson & Moll, 1992; Stanton, Cameron, Danoff-Burg et al, 2000). Older women also may be less strongly recommended BCT because comorbidities can contra-indicate radiation (Satariano, Swanson & Moll, 1992). Younger patients may be more likely to be offered breast-conserving procedures (Maunsell, Brisson & Deschenes, 1989; Wellisch, Di Matteo, Silverstein et al, 1989). Older and younger patients may have a different psychosocial response to surgical treatments, and react more negatively to breast removal (Moyer, 1997). Younger breast cancer patients may be more distressed generally (Holland & Rowland, 1989). Maunsell, Brisson & Deschenes (1989) found that for women under 40 years old, breast-conserving treatment was protective against psychological distress. Amongst women aged 50-59 years old, breast-conserving treatment associated with more distress, and in women aged over 70 years old there was no relationship between type of surgery and level of distress. In at least one other study, women age 50-59 receiving breast-conserving surgery have been reported to show less anxiety than those treated with mastectomy (Maraste et al, 1992).

Premorbid Adjustment

Stressful life events in the year before diagnosis and prior history of depression are strong indicators for psychological distress after treatment for breast cancer (Maunsell, Brisson & Deschenes, 1989). Psychological adjustment prior to diagnosis has also been found to predict adjustment to the disease one year after surgery (Royak-Schaler, 1991).

Personality

The earliest observation of psychological aspects of cancer were documented by Galen (200 A.D.), who noted that 'melancholic' women were at greater risk for depression than 'sanguine' women (Goldfarb, Driessen & Cole, 1967). Throughout the eighteenth and nineteenth centuries, many observers commented on this relationship. Gendron (1701) noted that anxious and depressed women were cancer prone, and Guy (1759) suggested that women with hysteria and nervous difficulties, especially those of 'phlegmatic and melancholic' character were more likely to develop cancer. Walshe (1846) implicated a state of 'defective innervation' (resulting from the stresses of a difficult life) in cancer pathogenesis. In the 1960's theories of psychogenic origin for cancer were proposed by several investigators. LeShan (1966) associated unresolved loss, inability to express frustration and anger, and tenuous affective relationships with cancer patients. Schmale & Iker (1964) similarly identified a pattern of separation and loss, depression, and sense of helplessness-hopelessness with cancer. Based on his research with lung cancer patients, Kissen (1966) observed a personality pattern in his exclusively male patient sample that was associated with few outlets for emotional

expression. The most complete psychological etiologic model for cancer at this time was probably the theory of 'psychophysiological complementarity' described by Bahnson & Bahnson (1966). This concept associated the development of cancer with repressed emotional conflicts related to loss. During the last two decades, the role of personality and mental state and other psychosocial variables influencing induction of malignancy and tumour progression has received increased empirical attention (Cooper & Watson, 1991). There are many methodological problems in examining the role of psychological factors, including effects on psychological functioning of malignancy present prior to diagnosis, and the impact of the diagnosis itself (Walker & Eremin, 1995). There does, however, appear to be some evidence for a type C or 'cancer prone' personality. For example, there is evidence that some cancer patients score highly on the L-scale of the Eysenck Personality Inventory (originally designed to detect patients who are 'faking good') and associated with suppression of certain feelings such as anger, passive coping with stressful events, and a strong need to conform (Eysenck, 1994). In patients with lymphoma, L-scores assessed immediately following diagnosis have been found to be an independent prognostic factor for survival, as was depressed mood (Ratcliff, Dawson & Walker, 1995).

Coping Styles

Morris, Greer & White (1977) identify 5 categories of response to diagnosis of breast cancer. These are: denial; fighting spirit; stoic acceptance; anxious/depressed acceptance; and helplessness/hopelessness. Greer, Morris, Pettingale & Haybittle (1990) reports that fighting spirit and denial are better responses than stoic acceptance, anxiousness or helplessness. Friedman et al (1990) report on a partial replication of a

previous study of coping and adjustment to breast cancer. Coping styles were assessed in 49 women. The results indicated that fighting spirit was related to better psychological adjustment, and that coping by avoidance was related to poorer adjustment. Denial as a coping strategy was unrelated to adjustment. Orr & Meyer (1990) investigated minimising threat as a coping strategy in 49 breast cancer patients compared with a comparison group of 57 healthy women. It was found that healthy subjects were more negative about cancer outcome than breast cancer patients, who appeared to reappraise the threat more positively after diagnosis and treatment. The authors conclude that 'diminished threat appraisal' is therefore an effective coping strategy for breast cancer patients. Similarly, Dunkell-Schetter, Feinstein, Taylor & Falke, (1992) examined coping patterns amongst a sample of 603 cancer patients (78% women and 22% men), of whom 42% had breast cancer. Five coping patterns were identified: seeking or using social support; focusing on the positive; distancing; cognitive escape-avoidance; and behavioural escape-avoidance. Studies of what patients can do to successfully cope with diagnosis and treatment for breast cancer have, however, so far failed to provide evidence of which coping strategies are particularly helpful (Irvine et al, 1991). Recent findings suggest that emotionally expressive coping, which involves actively processing and expressing emotions, may be a key predictor of psychological and physical adjustment to breast cancer, and is related to enhanced perceived quality of life (Stanton, Danoff-Burg, Cameron, et al 2000).

1. 8 Issues of Treatment Decision Making and Choice

Advances in cancer medicine including development of new drug treatments means that there are now an increasing range of treatment options available. Whilst these advances bring many positive benefits, they present new challenges regarding treatment decision making and choice. The majority of cancer patients want to have an active and collaborative role in decision making and to have information regarding the disease and its treatment (Blanchard, Labreque, Ruckdeschel & Blanchard, 1988; Hack, Degner & Dyck, 1994). Doctors play an important role in women's decision making, and variability in physicians opinions regarding appropriate treatments for breast cancer has been documented (McFall, Warnecke, Kaluzny et al, 1994). The need for studies addressing these important issues has been highlighted by several influential researchers (e.g. Fallowfield, 1990; Holland & Rowland, 1990). Perhaps surprisingly, relatively few studies (Ashcroft, Leinster & Slade, 1985; Kasper, 1995; Margolis & Goodman, 1984; Morris & Ingham, 1988; Owens, Ashcroft, Leinster & Slade, 1987; Siminoff & Fetting, 1991; Ward, Heidrich & Wolberg, 1989) have been carried out investigating the process of women's treatment decision making on adjustment. Those studies which have been reported have tended to use small samples (e.g. $N < 30$), have used unsystematic clinical interviews to assess decision making, or are based entirely on retrospective reports obtained from patients post-surgery. Only one prospective, longitudinal study is known to have been carried out (Stanton, Cameron, Danoff-Burg et al, 1998). The study monitored 76 women with breast cancer from diagnosis through to one year and examined the influence of women's expectations of treatment before surgery on treatment choice and subsequent adjustment. Women's expected consequences of surgical options, assessed before a

final decision making appointment with their physician, successfully predicted those patients electing BCT versus mastectomy. The elected treatment itself made little difference in presurgery and outcome perceptions or adjustment. An important exception to this was that patients electing BCT rated their physicians agreement as more important than did mastectomy patients before surgery. The authors suggest that one reason for this may be that only those who believed that their surgeons strongly support the BCT option may choose it. As this sample are likely to have seen the evolution of less invasive surgery for breast cancer, it is suggested that they may seek reassurance from their physician that it is no longer an experimental procedure. At one year, BCT patients also rated avoiding additional treatment as more important, possibly due to the longer initial treatment associated with this procedure. No group differences were revealed with regard to perceptions of outcome in relation to appearance, femininity, and sexuality. BCT patients in fact reported greater satisfaction with treatment outcome on only a single item concerning the effect of treatment on appearance. The finding that discrepancies between women's expectancy over actual outcome of treatment were associated with more distress at 3 months and at one year held up even controlling for age and presurgery adjustment. Several studies have been reported where patients (or a proportion of the sample) have been given a choice of treatment (e.g. Fallowfield, Hall, Maguire & Baum, 1990; Noguchi, Kitawaga, Kinoshita et al 1993; Pozo, Carver, Noriega et al 1992; Steinberg, Juliano & Wise, 1985). These studies suggest that offering patients choice of treatment and involvement in decision making may improve psychological outcome irrespective of type of procedure chosen. This control may be especially important in the context of a disease that often makes patients feel a lost sense of control (Moyer, 1997). Although some investigators argue that the majority of patients wish to be involved in the decision making process (e.g.

Ward et al , 1989), others have suggested that decision making may be an additional burden for patients during a time of already high anxiety, and may lead to patients feeling responsible if treatment is unsuccessful (Morris & Ingham, 1988). In one study of recently diagnosed breast cancer patients, it is reported that 52% of patients preferred that their surgeon made the decision for them (Luker, Leinster, Owens et al - cited in Fallowfield, Hall, Maguire et al, 1994).

In their study on treatment decision making amongst women offered a choice of breast conserving treatment or mastectomy, Stanton, Cameron, Danoff-Burg et al (2000) reported that in general women reported positive expectancies of their treatment, which were maintained during treatment. At one year after diagnosis though, women were less likely to believe that treatment would prevent recurrence than they were before surgery. This occurred despite none of the women actually experiencing recurrence, highlighting the importance of such concerns in terms of quality of life for cancer patients, as noted in earlier studies with patients who had undergone mastectomy (Northouse, 1981). Expectancies regarding positive outcome were different for the two types of treatment (i.e. women choosing mastectomy did not believe that BCT would be curative) rather than related to more generalised optimism in this sample. Although dispositional optimism has been reported to be associated with lower distress in breast cancer patients (Carver, Pozo, Harris et al 1993), the results of this study suggest that discrepancies between expected and perceived outcomes rather than positive expectancies by themselves that influence adjustment.

1.9 Aims and Objectives of Current Investigation

Aim: The aim of this study was to examine short-term psychological adjustment amongst patients undergoing breast cancer surgery.

Objectives:

1. To investigate the psychological impact of diagnosis in relation to evidence of acute stress response, and to assess changes in this response between diagnosis and follow up one month after surgery.
2. To compare psychosocial outcome of surgery for patients who received breast-conserving surgery versus mastectomy. Psychosocial outcome was assessed at baseline and at follow up one month after surgery in terms of several key indicators of psychological adjustment: levels of psychological distress (anxiety/depression); coping response; and body image satisfaction.
3. To examine the relationship between control and expression of negative emotion and other psychosocial outcome measures.

1.10 Hypotheses

Hypothesis 1: *It was hypothesised that psychological reactions to diagnosis of breast cancer would be associated with an acute stress response, with levels of intrusive distress and avoidance predicted to be higher amongst patients assessed soon after diagnosis than at follow up one month post surgery.*

Hypothesis 2: *It was hypothesised that breast-conserving (BC) surgery versus mastectomy would result in better short-term psychological adjustment, as indicated by levels of psychological distress, coping response to diagnosis, and satisfaction with body image at follow up one month after surgery.*

Hypothesis 3: *It was hypothesised that suppression of negative emotion amongst patients diagnosed with breast cancer would predict poorer psychosocial outcome, indicated by greater psychological distress, less adaptive coping responses, and greater dissatisfaction with body image.*

2. Method

2.1 Design

Study Design

Short-term psychological adjustment was investigated in a longitudinal study of patients with early stage breast cancer. Patients were assessed pre and post surgery using psychological measures to assess evidence of acute stress response and adjustment over time. Psychosocial outcome (levels of psychological distress, coping responses and satisfaction with body image) were compared for patients who had undergone breast-conserving surgery versus mastectomy.

Calculation of Statistical Power/Expected Effect Size

A minimum of 50 patients were calculated as being required for the study in order to achieve sufficient statistical power to demonstrate moderate effects sizes (ES) at the 0.8 level (Cohen, 1988). Fewer numbers of participants were recruited than was anticipated due to timescale constraints of this study.

Sample

The original sample comprised 29 patients newly diagnosed with early stage (operable) breast cancer, assessed soon after diagnosis. Follow-up data were available for 25 patients. In two cases, patients subsequently entered a neoadjuvant treatment trial (Impact Study), therefore the date of surgery was delayed. Two patients who were contacted for follow up indicated that they wished to withdraw from the study, in both

cases as their pathology results following surgery were worse than they had expected. Information obtained from medical records on patient demographics (age, marital and employment status), type of disease and treatment related variables for the remaining 25 patients who represented the study sample is shown in Table 3.1. The mean age of patients was 58.13 years (S.D.= 11.37), with an age range from 38-85 years. Two-thirds of the sample (N= 16) received breast conserving (BC) surgery, involving wide local excision (WLE) and axillary node sampling/clearance. Of the 9 patients who received a mastectomy, only one patient is known to have opted for immediate reconstruction.

	BC	Mx	Total		BC	Mx	Total
<u>CLINIC:</u>				<u>SCREEN DETECTED:</u>			
QMH	9	5	14	YES	7	5	11
WGH	7	4	11	<u>DISEASE TYPE:</u>			
TOTAL	16	9	25	DCIS	3	0	3
<u>PATIENT DEMOGRAPHICS:</u>				INV-NST	9	8	17
AGE				INV-LOB	1	1	2
Mean	53.43	65.44	58.13	INV-TUB	3	0	3
S.D.	10.43	8.93	11.37	<u>ADJUVANT THERAPY:</u>			
(Range = 38-78 yrs)				RT	16	2	18
MARITAL STATUS				CT	5	1	6
Married	12	5	17	HT	13	6	19
Other/not known	4	4	8				
EMPLOYED	11	2	13				

Table 2.1: Patient demographic details and information on disease/treatment variables

2.2 Procedure

Patient Ethics

Ethical approval was obtained prior to the study commencing. Approval was sought from Fife Health Board Ethics Committee in October 2000, which was granted in November 2000. Recruitment of Fife patients began at the end of January 2001. Due to fewer numbers of participants being recruited than was originally anticipated, permission was sought to extend the study to Lothian Health Board in April 2001. Recruitment of Lothian patients began in May 2001.

Patient Recruitment

Patients were recruited from a consecutive sample of patients attending two Specialist Breast Care Units - (1) Queen Margaret Hospital (QMH), Dunfermline, (2) Western General Hospital (WGH), Edinburgh. These units have close medical links through the Consultant Breast Surgeons and the clinical team, and post-operative radiotherapy is provided for patients from the QMH at the WGH. Patients were recruited for the study shortly after undergoing investigation for breast cancer and having a diagnosis confirmed. In almost all cases diagnosis was confirmed by triple assessment (clinical examination, mammography and fine needle aspiration (FNA) cytology). Patients at QMH receive their diagnosis the same day as their first appointment ('one-stop' assessment). At the WGH, patients receive their diagnosis at their second appointment. Patients were introduced to the study by their Specialist Breast Care Nurses. An information sheet about the study (see Appendix 1) was given to patients during their clinic appointment at which diagnosis was confirmed. Patients were then asked whether

or not they wished to take part in the study when they returned to the clinic the following week for their final staging appointment.

Study Inclusion/Exclusion Criteria

Patients were identified for study inclusion by the Specialist Breast Care Nurses at each unit. All patients with newly diagnosed, early stage (operable) breast cancer were considered for study inclusion. There was no upper age limit on study inclusion. Patients with known evidence of neurological impairment/dementia, or serious mental illness were excluded from the study.

Patient Consent

Written, informed consent was obtained prior to patients entering the study. Patients were advised that their decision whether or not to participate in the research would not affect their treatment in any way, and that they were free to withdraw from the study at any time. Patients were given 5 days to consider whether they wished to take part in the study after receiving the patient information sheet (see appendix).

Protocol

Assessment interviews lasted approximately 45 minutes. Patients were given the opportunity to have their relatives or a friend present during interviews.

Pre-surgery: Patients were interviewed at the breast unit within one week of diagnosis. Patients were seen on the same day as attending their clinic appointment during which final staging results were discussed and they were given a date for surgery.

Post-surgery: Follow-up appointments were arranged within the first month after patients had received the results of their surgery from the clinic (results of surgery were available within 10 days to two weeks of the operation). Follow up was planned for within this timescale to try to avoid possible confounding of results with effects of adjuvant therapy. As patients were not usually due to return to the clinic within this time period, follow up appointments were arranged to take place at the patients home. Follow up appointments were carried out throughout Fife and Lothian regions.

2.3 Psychological Measures

Copies of all measures used are included in Appendix 2.

Anxiety and Depression : *HAD*

The Hospital Anxiety and Depression Scale (HAD, Zigmond & Snaith, 1983) is a brief, 14-item scale measuring anxiety and depression. The HAD is a well-validated clinical research scale, designed for use in out-patient medical settings which does not include items that may be confused with physical symptoms related to illness. Anxiety and depression are measured on two separate subscales, with each item scored from 0 to 3, so that the total scores for each subscale range from 0 to 21. The cut-off score for clinical 'caseness' for anxiety or depression is a subscale score of more than 11. Mean anxiety and depression subscale scores have been reported for a clinical population of 573 patients with cancer at the time of initial diagnosis or first recurrence (Moorey, Greer, Watson et al 1991).

Acute Stress Response: *IES*

The Revised Impact of Events Scale (IES, Horowitz, 1979) is designed to measure symptoms associated with traumatic stress response, and is widely reported in the literature on traumatic stress. The IES is a 15 item questionnaire that provides two subscale scores for intrusive distress ('I thought about it when I didn't mean to', 'Pictures about it popped into my mind', ' Any reminder brought back feelings about it') and symptoms of avoidance/emotional numbing ('I tried not to talk about it', 'My feelings about it were kind of numb'). Items are scored on a 4 point scale based on the frequency with which patients rate each statement as being true for them during the

past 7 days (0 = not at all, 1 = rarely, 3 = sometimes, 5 = often). For the purpose of this study, patients were instead asked to rate how often each statement was true for them *since their diagnosis* (pre-surgery assessment), and *since their operation* (post-surgery assessment). Satisfactory reliability is reported for the IES by Horowitz (1979) based on a sample of 66 patients who had experienced traumatic events including bereavement and serious personal injury. Mean scores on the IES subscales for this sample were reported for intrusion (mean = 21.4, S.D. 9.6) and for avoidance (mean = 18.2, S.D. = 10.8). Reliability of the IES has since been confirmed in subsequent studies, and its validity demonstrated for use with a range of clinical populations (Turner & Lee, 1998). Scores on the IES have been found to be highly correlated with traumatic stress responses as assessed by formal interview based on DSM criteria. The IES has been used to assess acute stress response in one other study of breast cancer patients (Tjemsland, Soriede & Malt, 1996). IES scores were reported in this study for patients who were assessed pre- surgery (intrusion: mean = 17.2, S.D = 9.0; avoidance mean = 15.0, S.D. = 8.5) and 6 weeks post-surgery (intrusion: mean = 15.0, S.D. = 8.5; avoidance = 10.1, S.D. = 7.5).

Coping responses: MAC

The Mental Adjustment to Cancer Scale (MAC, Watson et al 1988) is a 40-item scale designed to assess adjustment or response to cancer diagnosis. It is used as a measure of the coping styles adopted by cancer patients.

The MAC incorporates 5 subscales:

- Fighting spirit (FS)
- Helplessness/hopelessness (HH)
- Anxious preoccupation (AP)
- Fatalistic (FA)
- Avoidance (AV)

The scale was developed based on earlier work (Greer et al 1979; Morris et al 1985; 1992; Pettingale et al 1985) using clinical interviews which reported that coping styles of fighting spirit and denial tend to be associated with better outcomes in terms of psychological morbidity, and possibly overall survival and recurrence-free survival (although these findings are more tentative). Reliability and validity data for the MAC is reported based on a study of 235 patients with various stages and types of cancer (Watson et al, 1988). Acceptable internal reliability is reported. High levels of internal validity were reported for correlations between respondents self-ratings and ratings by their partners. Highly significant correlations are reported between anxious preoccupation and HADS anxiety, and between HADS depression and hopelessness/helplessness and fatalistic responses. Raw scores on each of the 5 subscales are converted to T-scores providing a coping-styles profile for three subscales: 'fighting spirit' versus 'hopelessness' (FSH), 'anxious preoccupation' (AP) and 'fatalistic' (FA). The avoidance subscale, which contains just one item ('I don't really believe I had cancer') is not included in this profile. Mean T-scores of 50 are reported for responses on each of these three scales based on the Watson et al (1998) sample.

Body Image Satisfaction: *BIS*

Body image was examined using the 10-item Body Image Scale (BIS; Hopwood, Fletcher, Lee & Ghazal, 2001) designed to assess body image as a psychosocial outcome measure in clinical treatment trials. The Body Image Scale (BIS) was used to provide a measure of body image satisfaction at baseline (pre-surgery) and to assess any changes as a result of treatment. Responses to each item on the scale are rated on a 4 point Likert scale (0 = not at all, 1 = a little, 2 = quite a bit, 3= very much). The BIS was designed for use with any cancer patient group likely to experience body image concerns as a result of their disease or its treatment. The BIS has been validated on a sample of 276 cancer patients, that included a subsample of 160 breast cancer patients. Reliability and validity data are reported for this measure by Hopwood, Fletcher, Lee & Ghazal (2001).

Suppression of Negative Emotion: *BES*

An adapted, short-version of the Basic Emotion Scale (BES, Power, 2001) was administered. This scale assesses a number of core emotions, providing both state (how often have you experienced these feelings during the last 7 days?) and trait (how often do you usually experience these emotions?) responses. Patients are also asked to rate their perceived control of emotions that they experience. The BES is a recently developed measure, and has so far been validated for a sample of depressed patients and for controls.

3. Results

Statistical Analysis of Results

Data were analysed using SPSS for windows, PC version, release 10.0. Data obtained for continuous variables were normally distributed. Statistical tests used to examine each of the hypotheses are described below. Statistical significance was accepted at the 0.05 level.

Testing of Hypotheses 1 and 2

To test hypotheses 1 and 2, a mixed within and between subjects repeated measures ANOVA was used. The main effect examined for within subjects comparisons was time of assessment (pre or post surgery). The interaction of type of surgery - breast conserving (BC) surgery versus mastectomy (Mx) - with time of assessment was examined.

3.1 Hypothesis 1

***Hypothesis 1:** It was hypothesised that psychological reactions to diagnosis of breast cancer would be associated with an acute stress response, with levels of intrusive distress and avoidance predicted to be higher amongst patients assessed soon after diagnosis than at follow up one month post surgery.*

Evidence of Acute Stress Response

One quarter of the sample ($N=7$) assessed soon after diagnosis scored highly (IES subscale scores >19) for intrusive distress and avoidance. At follow up one month after surgery, four patients (17% of sample) scored highly on intrusion and avoidance. Mean scores obtained on IES measures of intrusion and avoidance before and after surgery, and results of the repeated measures ANOVA are presented in Tables 3.1 to 3.3. Significantly higher scores were found pre-surgery for total IES total scores ($F(1,23) = 13.375, p < 0.05$), and on scores for intrusive distress ($F(1,23) = 9.452, p < 0.05$) and avoidance ($F(1,23) = 8.091, p < 0.05$). No significant differences were found for the interaction of type of surgery and time assessed on IES total or intrusion/avoidance subscale scores.

IES:TOTAL INTRUSION AND AVOIDANCE						
TYPE OF SURGERY	MEAN SCORES (S.D)		WITHIN SUBJECT EFFECT (TIME ASSESSED)		BETWEEN SUBJECT EFFECT (TYPE OF SURGERY)	
			F(df=1,23) SIG (*p<0.05)		F(df=1,23) SIG (*p<0.05)	
BC (N=18)	PRE	28.44 (16.83)	13.735	.001 *	.671	.421 NS
	POST	22.19 (17.08)				
Mx (N=9)	PRE	27.11 (15.14)				
	POST	13.67 (11.09)				
SAMPLE (N=25)	PRE	27.96 (15.94)				
	POST	8.32 (7.71)				

Table 3.1: Mean IES total scores pre/post surgery and results of repeated measures ANOVA

IES:INTRUSION SUBSCALE						
TYPE OF SURGERY	MEAN SCORES (S.D)		WITHIN SUBJECT EFFECT (TIME ASSESSED)		BETWEEN SUBJECT EFFECT (TYPE OF SURGERY)	
			F(df=1,23) SIG (*p<0.05)		F(df=1,23) SIG (*p<0.05)	
BC (N=18)	PRE	13.81 (10.23)	9.452	.005 *	1.470	.238 NS
	POST	10.13 (8.35)				
Mx (N=9)	PRE	11.11 (7.83)				
	POST	5.11 (5.42)				
SAMPLE (N=25)	PRE	12.84 (9.36)				
	POST	8.32 (7.71)				

Table 3.2: Mean IES intrusion scores pre/post surgery and results of repeated measures ANOVA

IES:AVOIDANCE SUBSCALE						
TYPE OF SURGERY	MEAN SCORES (S D)		WITHIN SUBJECT EFFECT (TIME ASSESSED)		BETWEEN SUBJECT EFFECT (TYPE OF SURGERY)	
			F(df=1,23) SIG (*p<0.05)		F(df=1,23) SIG (*p<0.05)	
BC (N=18)	PRE	14.62 (8.66)	8.091	.009 *	.091	.765 NS
	POST	12.06 (10.05)				
Mx (N=9)	PRE	16.11 (9.84)				
	POST	8.56 (6.91)				
SAMPLE (N=25)	PRE	15.16 (8.92)				
	POST	10.80 (9.06)				

Table 3.x: Mean IES avoidance scores pre/post surgery and results of repeated measures ANOVA

3.2 Hypothesis 2

Hypothesis 2: *It was hypothesised that breast-conserving (BC) surgery versus mastectomy would result in better short-term psychological adjustment, as indicated by levels of psychological distress, coping response to diagnosis, and satisfaction with body image at follow up one month after surgery.*

Psychosocial Outcome of BC Surgery versus Mastectomy

(i) Anxiety and Depression

Amongst women assessed shortly after diagnosis, clinically significant levels of distress (HAD scores > 11) were found for anxiety in eight cases (one third of sample) and for depression in just one case (< 5% of sample). None of the patients assessed at follow up one month after surgery achieved clinically significant scores on HAD subscales for anxiety or depression. Mean scores obtained on HAD measures of anxiety and depression before and after surgery, and results of the repeated measures ANOVA are shown in Tables 3.4 to 3.6. Significantly higher HAD total scores were found for assessment pre versus post surgery ($F(1,23) = 19.442, p < 0.05$). HAD subscale scores were significantly higher before surgery for anxiety ($F(1,23) = 47.384, p < 0.05$), but not for depression. No significant differences were found for the interaction of type of surgery and time assessed on anxiety or depression.

HAD:TOTAL ANXIETY AND DEPRESSION						
TYPE OF SURGERY	MEAN SCORES (S.D)		WITHIN SUBJECT EFFECT (TIME ASSESSED)		BETWEEN SUBJECT EFFECT (TYPE OF SURGERY)	
			F(df=1,23) SIG (*p<0.05)		F(df=1,23) SIG (*p<0.05)	
BC (N=18)	PRE	12.56 (7.08)	19.442	.000 *	.215	
	POST	6.94 (3.94)				
Mx (N=9)	PRE	11.00 (5.363)				
	POST	6.67 (4.44)				
SAMPLE (N=25)	PRE	12.00 (6.44)				.647 NS
	POST	6.84 (4.04)				

Table 3.4: Mean HAD total scores pre/post surgery and results of repeated measures ANOVA

HAD:ANXIETY SUBSCALE						
TYPE OF SURGERY	MEAN SCORES (S.D)		WITHIN SUBJECT EFFECT (TIME ASSESSED)		BETWEEN SUBJECT EFFECT (TYPE OF SURGERY)	
			F(df=1,23) SIG (*p<0.05)		F(df=1,23) SIG (*p<0.05)	
BC (N=18)	PRE	9.44 (4.30)	47.384	.000 *	1.591	
	POST	4.50 (2.56)				
Mx (N=9)	PRE	8.11 (3.55)				
	POST	2.78 (2.68)				
SAMPLE (N=25)	PRE	8.96 (4.03)				.220 NS
	POST	3.88 (2.68)				

Table 3.5: Mean HAD anxiety scores pre/post surgery and results of repeated measures ANOVA

HAD:DEPRESSION SUBSCALE						
TYPE OF SURGERY	MEAN SCORES (S.D)		WITHIN SUBJECT EFFECT (TIME ASSESSED)		BETWEEN SUBJECT EFFECT (TYPE OF SURGERY)	
			F(df=1,23) SIG (*p<0.05)		F(df=1,23) SIG (*p<0.05)	
BC (N=18)	PRE	3.13 (3.88)	.097	.758 NS	.279	
	POST	2.44 (2.31)				
Mx (N=9)	PRE	2.89 (2.62)				
	POST	3.89 (2.67)				
SAMPLE (N=25)	PRE	3.04 (3.42)				.602 NS
	POST	2.96 (2.49)				

Table 3.6: Mean HAD depression scores pre/post surgery and results of repeated measures ANOVA

(ii) Coping

Mean scores for coping responses assessed using the MAC (FSH = Fighting Spirit versus Hopelessness; AP = Anxious Preoccupation; FA =Fatalistic) and results of the repeated measures ANOVA are presented in Tables 3.7 to 3.9. Patients scores for fatalistic coping responses were higher soon after diagnosis than at follow up after surgery ($F(1,23) = 7.387, p < 0.05$). No significant differences were found between scores on AP or FSH coping responses assessed before and after surgery. There were no significant differences between groups (BC v Mx) on any of the coping responses at either time assessed.

MAC:FIGHTING SPIRIT-HELPLESSNESS (FSH)						
TYPE OF SURGERY	MEAN SCORES (S.D)		WITHIN SUBJECT EFFECT (TIME ASSESSED)		BETWEEN SUBJECT EFFECT (TYPE OF SURGERY)	
			F(df=1,23) SIG (*p<0.05)		F(df=1,23) SIG (*p<0.05)	
BC (N=18)	PRE	50.63 (8.16)	1.63	.690 NS	.001	.972 NS
	POST	50.94 (10.60)				
Mx (N=9)	PRE	51.89 (10.94)				
	POST	49.44 (11.29)				
SAMPLE (N=25)	PRE	51.08 (9.05)				
	POST	50.40 (10.65)				

Table 3.7: Mean MAC FS-H scores pre/post surgery and results of repeated measures ANOVA

MAC:ANXIOUS PREOCCUPATION (AP)						
TYPE OF SURGERY	MEAN SCORES (S.D)		WITHIN SUBJECT EFFECT (TIME ASSESSED)		BETWEEN SUBJECT EFFECT (TYPE OF SURGERY)	
			F(df=1,23) SIG (*p<0.05)		F df=1,23) SIG (*p<0.05)	
BC (N=18)	PRE	56.56 (10.42)	.289	.596 NS	2.598	.121 NS
	POST	52.38 (11.14)				
Mx (N=9)	PRE	48.67 (14.15)				
	POST	49.44 (8.38)				
SAMPLE (N=25)	PRE	53.72 (12.23)				
	POST	51.32 (10.15)				

Table 3.8: Mean MAC AP scores pre/post surgery and results of repeated measures ANOVA

MAC:FATALISTIC (FA)						
TYPE OF SURGERY	MEAN SCORES (S.D)		WITHIN SUBJECT EFFECT (TIME ASSESSED)		BETWEEN SUBJECT EFFECT (TYPE OF SURGERY)	
			F(df=1,23) SIG (*p<0.05)		F(df=1,23) SIG (*p<0.05)	
BC (N=18)	PRE	51.13 (11.06)	.7.387	.012*	.690	.415 NS
	POST	48.81 (10.63)				
Mx (N=9)	PRE	59.78 (14.80)				
	POST	47.33 (14.18)				
SAMPLE (N=25)	PRE	54.24 (12.94)				
	POST	48.28 (11.75)				

Table 3.9: Mean MAC FA scores pre/post surgery and results of repeated measures ANOVA

(iii) Body Image Satisfaction

Mean Body Image Scale (BIS) scores obtained pre and post surgery, and results of the repeated measures ANOVA are reported in Table 3.10. Patients in both groups rated their level of dissatisfaction with body image significantly higher post surgery ($F(1,23) = 6.98, p < 0.05$), with no effect found for type of surgery (BC v Mx).

BODY IMAGE SCALE (BIS) SCORES								
TYPE OF SURGERY	MEAN SCORES (S.D)		WITHIN SUBJECT EFFECT (TIME ASSESSED)		BETWEEN SUBJECT EFFECT (TYPE OF SURGERY)			
			F(df=1,23) SIG (*p<0.05)		F(df=1,23) SIG (*p<0.05)			
BC (N=18)	PRE	0.87 (1.50)	9.7187	.005*	.016			
	POST	2.37 (3.22)						
Mx (N=9)	PRE	0.44 (0.73)						
	POST	3.00 (3.08)						
SAMPLE (N=25)	PRE	0.72 (1.27)						.901 NS
	POST	2.66 (3.12)						

Table 3.10: Mean BIS scores pre/post surgery and results of repeated measures ANOVA

Influence of other factors on adjustment

Age and Screening

Patients who received breast conserving surgery were significantly younger than those who underwent mastectomy, with a mean age difference of 12.02 years ($t= 2.845, df=23, p<0.05$). Patient age was entered as a covariate within the repeated measures design. Whether or not cancer was screen detected was entered as another factor, since patients identified through screening were those with DCIS. Data were re-analysed for scores obtained on each of the measures pre and post surgery for both surgical groups. Significant covariate effects were found between groups for age on HAD anxiety subscale scores ($F (1,23) = 4.488, p < 0.05$), IES total scores ($F (1,23) =$

5.305, $p < 0.05$) and IES intrusion scores ($F(1,23) = 4.868$, $p < 0.05$). No significant covariate effects were found for screening on any of the psychological measures.

3.3 Hypothesis 3

Hypothesis 3: *It was hypothesised that suppression of negative emotion amongst patients diagnosed with breast cancer would predict poorer psychosocial outcome, indicated by greater psychological distress, less adaptive coping responses, and greater dissatisfaction with body image.*

Influence of Emotional Suppression on Adjustment

Backward multiple linear regression analyses were performed to investigate whether expression of negative emotion and negative emotional control predicted outcome in terms of measures of psychological adjustment. Results of the analyses demonstrated that significant contributions were made by expression of negative emotion (state) and negative emotional control assessed soon after diagnosis using the BES, to the determination of IES total scores ($F_{2,22} = 6.24, p < 0.05, R^2 = .36$) as well as IES subscale scores for intrusive distress ($F_{2,22} = 4.66, p < 0.05, R^2 = .29$) and avoidance ($F_{2,22} = 5.24, p < 0.05, R^2 = .32$). Backward linear regression analysis on levels of body image satisfaction post-surgery (assessed using the BIS) further demonstrated a significant contribution of negative emotional control to scores obtained on this measure ($F_{2,22} = 7.74, p < 0.05, R^2 = .25$). Due to the small sample, findings must be interpreted with caution, but suggest that higher levels of negative emotion together with greater attempt to control, or suppress negative emotion in response to diagnosis is predictive of symptoms of acute stress response (intrusion and avoidance), and greater dissatisfaction with the outcome of treatment in terms of body image one month after surgery. As the questionnaires used to measure these concepts have not yet been validated for this population this is presented as an exploratory model.

4. Discussion

Overview

Short-term psychological adjustment was investigated in a longitudinal study of patients with early stage (operable) breast cancer. Twenty-nine patients completed baseline psychological measures. Follow up data one month after surgery was available for 25 patients. The study attempted to address a number of specific research questions relating to the psychological impact of diagnosis, and the effects of surgery on aspects of psychological adjustment, namely: (1) 'Is diagnosis of breast cancer associated with evidence of an acute stress response?' (2) 'Is psychosocial outcome at one month after surgery better for patients who have undergone breast-conserving surgery versus mastectomy?', and (3) 'Are emotional control and suppression of negative emotion associated with poorer psychological adjustment?' Results of the study are reported in this section, and findings compared with those previously reported in the literature. Methodological limitations of the present study are highlighted. Implications of the results for psychosocial care of breast cancer patients are discussed. Finally, conclusions are drawn and directions for future research identified.

4.1 Summary of Main Findings

Evidence of Acute Stress Response

Previous studies have suggested that diagnosis of cancer (Andrykowski, Griener, Altmaier et al, 1995; Lepore & Helgeson, 1998; Tjemsland et al 1996) or recurrence (Cella, Mahon & Donovan, 1990) may be associated with acute stress reactions. Such responses are characterised by alternation between intrusive distress (thoughts or images about cancer or its treatment) and behavioural avoidance (avoidance of reminders, numbing of emotional response). Diagnosis of breast cancer was associated with an acute stress response for 28% of patients in this sample ($N=7$) who scored above clinical caseness levels for intrusion and avoidance on the IES soon after diagnosis. This level is slightly lower than that reported in Tjemsland et al's (1996) study of 106 breast cancer patients, among whom acute stress response in described in one-third of the sample. At follow up one month after their operation, levels of intrusive distress and avoidance were significantly lower ($p < 0.05$) compared with levels assessed shortly after diagnosis for patients in this sample. However, in a proportion of cases ($N= 4$), patients continued to score above the level for clinical significance for intrusion and avoidance, representing 17% of the sample. It is possible that these patients may be at higher risk for poorer adjustment, since assessment of distress at 4-6 weeks after exposure to a stressor has been found to predict reliably subsequent adjustment problems in the trauma literature (Budin, 1998). This level is higher than previously reported by Tjemsland et al (1996), who report that at follow up 6 weeks post surgery only 8% of patients in their sample continued to experience clinically significant levels of traumatic distress. Differences in levels of intrusive distress and avoidance at

follow up may be a factor of variations between studies in the stage of treatment at which patients were re-assessed. In the Tjemslund et al (1996) study, for example, almost all patients allocated to adjuvant therapies had commenced treatment by follow up. For patients in this sample, intrusive thoughts at follow up post surgery were related to apprehension regarding starting radiotherapy or chemotherapy especially. Monitoring of stress response in breast cancer patients is of potential clinical importance, since patients who demonstrate high levels of traumatic stress may need help in coping with the situation in order to moderate distress and to improve their coping with normal daily life (Cordova et al, 1995). Further follow up of a larger sample of patients during treatment is therefore required to assess changes in levels of traumatic distress over time.

Psychosocial Outcome of BC Surgery versus Mastectomy

Psychosocial outcome of breast conserving (BC) surgery versus mastectomy (Mx) was examined by comparing baseline measures of psychological distress, stress response, adjustment and coping, and body image satisfaction with those obtained at one month after patients' operations. No significant differences were found between patients in each of the surgical groups on any of the measures used. These findings are broadly consistent with the results of several recent studies using much larger samples (e.g. Stanton et al, 2000; Nissen, 2001), and with the results of a well-designed meta-analysis of over 40 studies in this field, that have assessed patients at various times since diagnosis (Moyer, 1997). The exception to this was the lack of observed effect for differences in body image between groups, discussed below.

Body image

In this sample, no difference was found between patients who had undergone either breast conserving surgery or mastectomy in relation to body image. Patients in both groups, however, were less satisfied with body image after surgery. Relatively few previous studies have included baseline measures of body image satisfaction. Of the results of over 40 studies now published comparing psychosocial outcome of BC with mastectomy (see Table 1.5 in introduction), pre-surgery measures of body image satisfaction were included in just six studies. Results of earlier studies, using relatively small samples of up to 51 patients (e.g. Ashcroft et al, 1985; Wellisch et al, 1989) report better body image satisfaction in BC versus mastectomy patients assessed a few months to one to three years post surgery. Length of time assessed after surgery has been suggested as an important factor (Moyer & Salovey, 1997), as it is assumed that body image issues may become more important to patients at the end of treatment, since during treatment more immediate concerns associated with diagnosis of life-threatening illness and managing the effects of treatment may be a priority. Subsequent studies (e.g. Goldberg et al, 1992; Lee et al, 1992) in which baseline measures of body image satisfaction were completed using much larger samples (> 100 patients) failed to replicate this effect. More recent prospective studies (Stanton et al, 2000; Nissen et al, 2001), using samples of 186 and 198 patients respectively, have highlighted the complexity of issues surrounding evaluation of body image satisfaction and other aspects of psychosocial outcome after treatment. For example, patients who are given a choice of treatment appear to do better psychologically irrespective of the type of

treatment chosen (Fallowfield et al, 1990). Choice of treatment is not possible for all patients, however. In the Nissen et al (2001) study, women who underwent mastectomy with reconstruction ($N = 40$) were likely to be younger, require more extensive surgery, and be more likely to receive adjuvant cytotoxic drug treatment than women who received breast conserving surgery ($N=103$). Mastectomy may be recommended in cases where the cosmetic outcome of breast-conserving surgery will be unsatisfactory, or where the tumour is large compared to the size of the woman's breast (Dixon & Sainsbury, 1998). For patients who are given a choice of treatment, decisions regarding whether or not to elect breast conserving treatments rather than mastectomy may be influenced by the need for adjuvant radiotherapy, which more often accompanies breast conserving treatments. Several reports have suggested that for some women, mastectomy may be preferred, essentially to get the treatment over with, or as women may believe that the mastectomy is more likely to get rid of the cancer (Fallowfield & Clark, 1992). Many of the women seen in this study expressed having sought reassurance from their doctors that the cancer had been 'removed' by their operation.

Cancer related fears and concerns

Receiving a diagnosis of breast cancer it thought to be the primary cause of distress, which may supercede more cosmetic concerns regarding appearance after surgery (Fallowfield & Clark, 1992). For patients included in this sample, significantly greater levels of psychological distress (anxiety and depression), and traumatic stress were found at baseline assessment soon after diagnosis than at follow up one month after surgery ($p<0.05$). For example, clinically significant levels of psychological distress were present in one third of the sample assessed soon after diagnosis. By follow up one

month after surgery, none of the patients in this sample scored above clinical 'caseness' for anxiety or depression on the HAD scale, suggesting that it was receiving a diagnosis of breast cancer itself rather than the effects of surgery that were associated with greatest distress in this sample. Assessments of cancer patients made at time of diagnosis show higher morbidity rates than those made 3 to 12 months after diagnosis, suggesting that these tend to be transient reactions which have usually remitted by the end treatment (Derogatis, Morrow, Fetting et al 1983). Identifying those patients who experience substantial levels of psychological distress during treatment and beyond is important in order that appropriate support can be provided or specialist referral made where necessary.

Coping and Adjustment

Coping responses to cancer diagnosis were similar for patients assessed pre and post surgery. Response profiles for each of the coping strategies assessed were similar, with patients in this sample scoring in the average range compared with scores obtained for other groups of cancer patients (Watson et al, 1988) on MAC subscales assessing fighting spirit ('I try to keep a very positive attitude', 'I have plans for the future', 'I think of other people who are worse off') versus hopelessness ('I feel like giving up'); anxious preoccupation ('I worry about the cancer returning or getting worse'); and fatalistic attitudes ('I've put myself in the hands of God', 'I feel that I can't control what is happening'). There was no difference between surgical groups in the type of coping responses used by women in this sample. Patients in this sample appeared to have mobilised a range of coping responses soon after diagnosis. Levels of fighting spirit, which has been associated with good psychological adjustment in women with breast

cancer (Friedman et al, 1990), were no different at baseline than when patients were re-assessed one month after their operation. Anxious preoccupation was also more common before surgery than after, with the only difference in coping responses before and after surgery observed for items indicating fatalistic attitudes, which were more frequently endorsed in patients assessed soon after diagnosis ($p < 0.05$). Patients' responses at both of these times would appear to be adaptive, since levels of distress had decreased by assessment one month after surgery. It is possible that the similar coping response profile for patients assessed pre and post surgery may reflect the relatively short time period involved between diagnosis and follow up in which processing of the experience was able to occur. Long term follow up of the sample might therefore have resulted in changes in coping responses used at various times during treatment. Alternatively, patients who have mobilised effective coping strategies in response to diagnosis may have been more likely to have agreed to participate in this kind of research study, possibly reflecting sample bias.

Influence of Other Factors on Psychosocial Outcome

Age

Age has been identified as one factor that may be related to psychosocial outcome of breast cancer surgery. Younger women are thought to show evidence of greater psychological distress in relation to diagnosis, and to express more concern regarding the effect of treatment, including surgery, on body image and sexuality than older women (Moyer & Salovey, 1997). The findings of this study confirm that patients who

are younger and who receive more extensive surgery show greater levels of overall psychological distress and intrusive distress ($p < 0.05$).

Screen Detected Cancer

It has been suggested (Farmer, Payne & Royle, 1995) that patients with screen detected cancers may experience less psychological distress, since these cancers may usually be detected earlier and a model of early disease and favourable outcome may be presented. Perhaps surprisingly, patients who had screen detected cancers in this sample ($N=12$) were not found to experience any less distress than women who had presented symptomatically. Again, this may have been a feature of small sample size. Alternatively, it may be that there were few differences between women with screen detected cancer and those who had presented with breast lumps in this sample.

Relationship Between Emotional Suppression and Adjustment

It was predicted that higher control of negative emotions such as anger, fear, sadness and guilt would be associated with poorer adjustment to cancer diagnosis. In this sample, higher scores for expression of negative emotions (state) and for emotional control (suppression) assessed soon after diagnosis, were predictive of greater levels of intrusive distress and avoidance one month after surgery ($p < 0.05$). Patients rating of 'trait' levels of negative emotional expression were not found to be predictive of stress response assessed using the IES. Previously it has been suggested that suppression of negative emotion is linked to a type 'C', or cancer-prone personality (Eysenck, 1994). An alternative explanation is presented in relation to models of understanding individuals responses to traumatic distress (see Joseph, Yule & Williams, 1997), which

suggest that attempts to control expression of emotions may be related to attempts to contain emotional distress. Findings of the present study suggest that those patients who experience high levels of emotional distress at the time of diagnosis, but who attempt to suppress those feelings, may be those most likely to continue to show evidence of symptoms of intrusive distress and of avoidance/emotional numbing associated with traumatic stress response one month after surgery. There is strong evidence from the trauma literature that for recovery from exposure to a traumatic event to occur, the experience must be assimilated within existing mental frameworks or schemata. Patients who suppress their expression of negative emotions may therefore be finding it more difficult to come to terms with breast cancer diagnosis or the effects of treatment. Consistent with this was the finding that self-report of attempts to suppress negative emotion among patients assessed one week after diagnosis predicted higher levels of dissatisfaction with outcome of treatment after surgery in relation to body image ($p < 0.05$). This finding appears to be independent of extent of surgery, since no difference was found between BC and mastectomy patients in relation to levels of body image satisfaction post-surgery (see earlier discussion under Body Image heading). Facilitating expression of emotion is recognised as a key component of psychosocial interventions (Stanton et al, 2000). Women who are helped to express their feelings, especially those experiencing higher levels of distress surrounding diagnosis, may therefore do better in terms of psychological adjustment, although longer term follow up is required to clarify the relationships between emotional expression and emotional control and adjustment processes.

4.2 Methodological Limitations of the Present Study

Sample

Sample size

The principal limitation of the present study was the relatively small sample size ($N=25$). Despite the small sample, evidence of an acute stress response was demonstrated amongst patients recently diagnosed with early stage breast cancer in this study, consistent with reports from at least one other study using a much larger sample (Tjemsland et al 1996). The findings of the present study failed to support any evidence of better psychosocial outcome for patients who had undergone breast cancer surgery versus mastectomy. This finding is consistent with those reported elsewhere in the literature (see Moyer, 1997).

Representativeness of sample

The sample comprised consecutive cases of women attending two specialist breast units. All patients who met the inclusion criteria were asked to take part in the study. Information obtained for the study sample on patient demographic variables in terms of disease and treatment related variables would suggest that the sample were representative of this patient population. The proportion of women in the sample who had presented to the clinic through screening (40%) is similar to the proportion of women amongst whom breast cancers are currently detected. The majority of patients in this study had invasive cancers ($N = 22$), of which 17 were of NST and five of which were special types (lobular $N = 2$, tubular $N = 3$). DCIS was recorded in 3 cases. The

proportion of patients in each group are thus comparable with those routinely presenting at specialist breast clinics (Dixon & Sainsbury, 1998). The mean age of patients in this sample was 58 years, consistent with peak incidence of breast cancer in women aged 55-60 years (Watson, 1991).

Timescale

Fewer patients than initially anticipated were recruited for the study. One reason for this was that at the time when the study was planned, a screening programme had just ended and it was expected that a high numbers of new patients would be attending the clinic at QMH. Unfortunately the study was unable to start until several months after this time due to requirements for Fife Health Board ethics submissions. The number of new patients routinely presenting at this clinic each week is variable, and not all of those who were suitable for study inclusion agreed to take part. For this reason the study was extended to Lothian Health Board in order to try to recruit additional number of patients attending the WGH clinic, which has a larger clinic with a higher number of routine referrals per year. Although the recruitment problem was identified a few weeks after the study commencing at QMH in late January, the process of extending the study to another area took several months, again due to requirements for ethical approval which was sought before approaching the hospital and requesting permission from the Consultants and Breast Care Nurses at the WGH to access their patients. Recruitment of Lothian patients therefore did not begin until May 2001.

Rates of Participation in Study

Data from previous studies investigating psychosocial outcome of breast cancer have tended to include psychosocial measures within larger, controlled treatment trials, therefore have achieved high rates of participation. Previous research has demonstrated that there are few differences in characteristics of breast cancer patients who participate and those who refuse to participate in clinical trials (Brewin & Bradley, 1989). In relation to the present study, it is possible that the type of study (i.e. investigating psychological aspects of cancer) may have resulted in sample bias. Patients who were more distressed by diagnosis may have been more likely to take part in this kind of study. On the other hand, those patients who considered that they were coping well may have been more likely to agree take part. Several patients mentioned that feeling they were able to help others in some way or to contribute to research actually increased their feelings of control. Attention has previously been drawn to the feelings of lack of control evoked by cancer diagnosis (Ell et al, 1989). The two patients who withdrew from the study after receiving their results of surgery were extremely distressed by the results and the implications for their prognosis and treatment. Stanton et al (2000) suggest that patients expectations of treatment are a crucial factor in determining outcome.

In retrospect, additional numbers of patients may have been recruited for this study if patients had been introduced to the study after attending their final staging appointment at the clinic, for example, if it had been possible to assess patients on the ward the day before surgery. Patients attending the clinic on the day of that their final staging results were generally very anxious, and it is likely that in the previous week concerns were predominated by awaiting the results of their treatment.

Critique of Measures Used

The measures used in this study are discussed in relation to their potential clinical use in routine monitoring of psychological adjustment of breast cancer patients, and in terms of further work required to validate their use as research measures.

HAD

The HAD has been widely used in out-patient medical populations, and provides a brief measure of anxiety and depression which may be useful for screening or monitoring of psychological distress. The HAD is already in routine use in Breast Care Units for monitoring patients levels of psychological distress over the course of treatment.

IES

The IES has proved to be a sensitive measure for detecting psychological stress responses in cancer patients (Kaasa et al, 1993). The IES is a brief measure, and results of this study suggest that it may be useful to include this in routine assessment of breast cancer patients in order to identify those patients who are experiencing significant levels of traumatic stress. Further research including longer term follow up using larger samples is required to validate its clinical use with this population however.

BIS

The BIS is a brief, 10 item questionnaire. The results of this study suggest that it would be useful to use to obtain baseline levels of body image satisfaction if using the BIS in treatment trials.

MAC

The MAC is widely used a research tool to assess coping responses of cancer patients. As the MAC is a 40-item scale it is fairly lengthy to complete and to score. Patients in this sample found some items difficult to rate using the rating key provided. Patients assessed soon after diagnosis may have already had fairly lengthy clinic appointments during which their levels of anxiety were quite high whilst waiting for their results. It was therefore sometimes difficult for them to concentrate on this questionnaire. Studies have shown that responses assessed using the MAC are similar to assessment of coping conducted through clinical interview (Greer et al, 1989). It is likely that in routine clinical practice it may be more helpful to ask patients for information about their beliefs and attitudes towards cancer, and their coping responses than to use this kind of scale, which has been designed mainly for research purposes. Items assessing hopelessness on this scale may be useful to incorporate into clinical interview however, given that these items have been associated with evidence of poorer adjustment, in particular depression (Watson et al, 1988b).

BES

The BES is a recently developed measure designed for research with both normal and psychiatric populations. It has been noted that measures devised for use with psychiatric populations often do not translate well to research with non-psychiatric populations (Watson, 1991). Further research is required to validate the use of this scale with cancer patients.

4.3. Implications of Findings for Psychosocial Care of Breast Cancer Patients

Patients in this study generally reported that they felt their doctors had taken time to explain their results and to discuss their treatment with them, and appreciated the opportunity to have their relative or friend present during the consultation with the doctor. Partners and family members also appreciated this, as it helped them to feel more involved to understand aspects of the disease and its treatment better, therefore offer more support. Several previous studies have highlighted that partners and families can often feel 'helpless' at this time, therefore this is an important aspect of patient psychosocial care. Patients and their relatives also appreciated making contact with a specialist breast care nurse whom they were able to contact by telephone.

The delivery of information in a caring and sensitive manner may provide one of the most important sources of emotional support for patients. It is therefore vital that doctors are trained in the necessary communication skills to elicit patients needs for support and to respond appropriately to them (Fallowfield & Clark, 1991). Doctors and medical staff have a key role in establishing good communication and offering support to women around the time of diagnosis, which may help to alleviate distress surrounding diagnosis, and may have been associated with lower distress at follow up after surgery found in this sample.

The preliminary results of this study suggest that expression of negative emotion may reduce anxiety or psychological distress. Helping patients to express negative emotions is a key component of most psychosocial interventions. The form in which these interventions may be appropriate for different patients may vary, but it is important that

all patients have access to a range of resources. The importance of patients understanding what has happened to them and being supported and reassured by others that their reactions are normal or otherwise has been emphasised (Wortman & Conway, 1985). Patients who receive strong and consistent emotional support are thought to adjust more successfully over time (Dinkel-Schetter, 1984). Different sources of support such as family and friends, or doctors often provide different types of support (Rowland, 1990). By allowing patients to express their concerns, family and friends can acknowledge and help patients to manage fears (Slevin, Nichols, Downer et al, 1996). In one study which looked at 'helpful' and 'unhelpful' responses to cancer patients (Dunkel-Schetter, 1984), 'help' most often meant emotional support, and was perceived as most supportive when given as a combination of information and direct help. Blanchard et al (1990) have shown that information giving by physicians is an important predictor of satisfactory emotional support in cancer patients. Results of a study that included 431 cancer patients attending out-patient oncology, radiotherapy and haematology clinics (Slevin, Nichols, Downer et al, 1996) found that the majority of patients (86%) were satisfied with emotional support provided by their doctors and nurses. Patients who expressed dissatisfaction with their emotional support were more likely to be anxious or depressed.

Many patients assessed soon after diagnosis and following surgery commented on the excellent levels of support provided by the clinic team, and by the nursing staff whilst they were in hospital for their operations. Patients who were assessed at follow up one month after surgery were generally less distressed than when seen at the clinic, but continued to express concerns about aspects of treatment, including worries about

effects of adjuvant treatment and fears of recurrence. It is likely that the concerns experienced by women at different stages of treatment may change, and it is important that women have access to information and sources of support during this time. Specialist Breast Care Nurses therefore have a crucial role in monitoring distress and providing support to improve the psychosocial outcome of the disease (Carroll, 1998).

4.4 Conclusions and Directions for Future Research

Patients in this sample showed evidence of acute stress response associated with diagnosis. The results of the study indicate that diagnosis of life-threatening disease is associated with considerable distress, but that in most cases this distress tends to be transient. At follow up one month after surgery, none of the patients in this sample experienced clinically significant levels of depression or anxiety. Evidence of stress response continued to be shown in a proportion of patients, however. Further follow up of these patients is required to monitor the course of stress response in this population. Several studies have indicated that substantial distress may be associated with effects of adjuvant treatment, therefore it may be especially important to monitor patients psychological reactions more frequently during the first year after diagnosis.

To date only one other longitudinal study has investigated acute stress response in breast cancer patients. Stress response may be an important predictor of adjustment, but as yet insufficient information is available regarding changes in stress response patterns throughout treatment. Intrusive thoughts and avoidance have been conceptualised as mechanisms by which stress associated with diagnosis or treatment can have a continuing impact of levels on psychological distress experienced by cancer patients, and may occur even long after treatment has ended (Baum, Cohen & Hall, 1993; Greenberg, Kornblith, Herndon et al, 1997). A relationship between stress response measured with the IES and psychological distress amongst cancer patients has been reported amongst patients with varying diagnoses and disease stages (Epping-Jordan, Compas & Howell, 1994), including breast cancer patients (Baider & DeNour, 1997; Vickberg, Bovbjerg, DuHamel et al, 2000). Improved understanding of possible phase specific responses is of potential clinical importance, in order to ensure

that additional resources are targeted effectively towards patients at these stages of treatment. Longer term follow up using larger samples of patients are required to further assess the relationship between stress response and psychological adjustment to breast cancer.

Given the high levels of anxiety and traumatic stress associated with investigation of breast cancer, it is important that ways to reduce distress for patients at this time are identified. The time waiting for results of investigations and for surgery was described as one of the most stressful aspects of the experience by patients assessed before and after surgery. Several patients at one of the clinics mentioned waiting times for their appointment as a source of considerable distress, especially once diagnosis was confirmed which resulted in worries that cancer may have 'got worse' during the time between finding a lump and having their investigations carried out. This is clearly an unacceptable cause of additional anxiety amongst breast cancer patients. Waiting times for clinic appointments vary nationally and regionally. In response to issues of waiting time for cancer referrals, the Government last year introduced a two week rule for GP referrals. Due to resource constraints, it has been impossible for specialist cancer units in many areas to meet this demand (Jones, Rubin & Hungin, 2001). Although there is a view that this goes beyond the evidence base, delays of to 3-6 months in breast cancer patients are associated with reduced survival (Richards, Westcome, Love, et al, 1999). Increasing demand for patients to be seen earlier, and for results to be available more quickly means that additional resources are required to be in place. It is likely that these issues have a major impact of aspects in relation to levels of patient distress.

With regard to studies comparing the psychosocial outcome of breast cancer surgery, relatively few studies to date have provided baseline data by which to assess specific

treatment effects on aspects of body image satisfaction or in relation to other measures of psychological adjustment. The results of this study highlight the importance of obtaining baseline measures. As previously concluded by other reviewers (Carlsson & Hamrin, 1994; Fallowfield & Clark, 1992; Moyer & Salovey, 1997) failure to demonstrate significant differences in levels of psychological distress between patients undergoing BC surgery and mastectomy underlined the need for psychosocial support to be available to all breast cancer patients. It is hoped that in the future, outcome of breast cancer treatment will be improved through the advent of newer, less aversive treatments (Fallowfield & Clark, 1992). The advent of potential new drug treatments for breast cancer continues to receive substantial media attention (Tait, 1996), and breast cancer remains an emotive topic. Whilst new treatments offer many more possibilities for breast cancer treatment in the future (see recent copy of recent newspaper article included in Appendix 3), new challenges are raised regarding involvement of patients in aspects of treatment decision-making and choice, and regarding expectations of treatment. Given the high levels of distress associated with diagnosis of breast cancer, concerns have been expressed regarding patients' reduced capacity for information processing and decision making at this time. Provision of balanced information given in a sensitive manner, and time allocated to discuss various options with patients is therefore crucial, given that various treatments available may be associated with a range of different temporary or permanent effects, and there may be variations in the duration of treatments. Recent studies comparing effects of breast cancer treatments including surgery (Stanton et al, 2000; Nissen et al, 2001) have highlighted the many individual factors that need to be taken into account in relation to issues of optimal patient matching with appropriate treatment based on medical criteria and taking into account the patients wishes.

5. References

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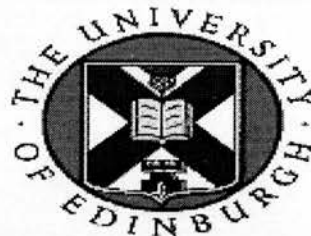
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References marked with an asterisk indicate studies cited in Table 1.5.

Appendices

Appendix 1

The University of Edinburgh



RESEARCH STUDY

**“PSYCHOLOGICAL IMPACT OF DIAGNOSIS AND SURGERY
IN THE TREATMENT OF EARLY STAGE BREAST CANCER”**

BREAST UNIT, WESTERN GENERAL HOSPITAL, EDINBURGH

PATIENT INFORMATION SHEET

This leaflet tells you about the study which you have been asked to take part in. Please read this carefully before deciding whether or not you wish to take part. Remember to take the information sheet with you when you leave today.

What is the study about?

We are keen to find out more about the psychological impact of diagnosis and of surgery in the treatment of early stage breast cancer. To help us with this, we would like to speak to women who have recently been diagnosed with breast cancer, to ask about their feelings about diagnosis and about how they are coping with this experience. We will then follow up patients who are seen at this stage a few weeks after their surgery. As part of the study, we would also like to ask patients about the support available to them at this stage of their investigations and treatment.

Who is carrying out the study?

The study is being carried out by **Elaine Johnston**, who is a final year trainee on the doctoral training course in Clinical Psychology at the University of Edinburgh. The study is being carried out as part of a doctoral thesis.

Who is being asked to take part?

Patients attending the clinic who are being considered for surgery will be invited to take part in the study.

Do I have to take part?

No. Participation in the study is entirely voluntary. If you decide not to take part, this will not affect your treatment in any way.

What will the study involve?

If you agree to take part in the study, you will be seen for a brief appointment when you come back to the clinic on Tuesday next week, in order to complete a few short questionnaires. This should take no more than 20-30 minutes, and will be arranged to take place at some point during the morning while you are waiting to see the doctors and nurses at the clinic.

You will be contacted to arrange a follow-up appointment a few weeks after your operation, which can be arranged to take place either at the clinic, or at your home if you prefer. The follow up appointment will again involve a short interview and completing a few questionnaires.

Will my information be confidential?

Yes. The information you provide will be treated as strictly confidential, and will not be passed on to anyone without your prior consent. This means that the hospital staff will not have access to this information, and it will not be used to inform any decisions about your treatment. The results of the study will be reported anonymously, so that it will not be possible to identify individual patients.

Patient Ethics

This study has been approved by the Ethics Committee of Lothian Health Board. The local independent advisor for the project is Dr. Aileen Thomson, Chartered Clinical Psychologist, who can be contacted at the Astley Ainslie Hospital on 0131 537 9125 in case of any queries or complaints which you do not feel have been addressed by the researcher.

Further questions?

If you have any other questions about the study before deciding whether you wish to take part, or would like to discuss the study informally, please ask to speak to **Elaine Johnston**, who will be available at the clinic on Tuesday, or can be contacted at the University of Edinburgh on **0131 537 6279** (please leave message with secretary).

Thank you for taking the time to read this leaflet !

You will be asked whether or not you wish to take part in this study when you attend your appointment at the clinic on Tuesday. It would help the researcher if you could let us know if you are interested by handing in the attached form when you arrive at reception, but don't worry if you forget to bring this!

RESEARCH STUDY

**“PSYCHOLOGICAL IMPACT OF DIAGNOSIS AND SURGERY
IN THE TREATMENT OF EARLY STAGE BREAST CANCER”**

BREAST UNIT, WESTERN GENERAL HOSPITAL, EDINBURGH

I am / am not * interested in taking part in this study.

(*please delete as appropriate)

Name: _____

Appendix 2

IMPACT OF EVENT SCALE

MARDI HOROWITZ et al.

Name _____ Date Completed _____

Therapist/Interviewer _____

On _____ (date) you experienced _____ (life event)

Below is a list of comments made by people after stressful life events. Please check each item, indicating how frequently these comments were true for you DURING THE PAST SEVEN DAYS. If they did not occur during that time, please mark the "not at all" column.

FREQUENCY

Not at All Rarely Sometimes Often

1. I thought about it when I didn't mean to.				
2. I avoided letting myself get upset when I thought about it or was reminded of it.				
3. I tried to remove it from my memory.				
4. I had trouble falling asleep or staying asleep, because of pictures or thoughts about it that came into my mind.				
5. I had waves of strong feelings about it.				
6. I had dreams about it.				
7. I stayed away from reminders of it.				
8. I felt as if it hadn't happened or it wasn't real.				
9. I tried not to talk about it.				
10. Pictures about it popped into my mind.				
11. Other things kept making me think about it.				
12. I was aware that I still had a lot of feelings about it, but I didn't deal with them.				
13. I tried not to think about it.				
14. Any reminder brought back feelings about it.				
15. My feelings about it were kind of numb.				

Below to be completed by therapist:

Intrusion subset = 1, 4, 5, 6, 10, 11, 14. Avoidance subset = 2, 3, 7, 8, 9, 12, 13, 15.

TOTAL = _____

TOTAL = _____

OVERALL
TOTAL = _____

MENTAL ADJUSTMENT TO CANCER SCALE (MAC)

Name:

Date: Record Number:

INSTRUCTIONS: A number of statements are given below which describe people's reactions to having cancer. Please circle the appropriate number to the right of each statement, indicating how far it applies to you at present. For example, if the statement definitely does **not** apply to you, then you should circle 1 in the first column.

	<i>Definitely does not apply to me</i>	<i>Does not apply to me</i>	<i>Applies to me</i>	<i>Definitely applies to me</i>
I have been doing things that I believe will improve my health e.g. changed my diet.	1	2	3	4
I feel I can't do anything to cheer myself up.	1	2	3	4
I feel that problems with my health prevent me from planning ahead.	1	2	3	4
I believe that my positive attitude will benefit my health.	1	2	3	4
I don't dwell on my illness.	1	2	3	4
I firmly believe that I will get better.	1	2	3	4
I feel that nothing I can do will make a difference.	1	2	3	4
I've left it all to my doctors.	1	2	3	4
I feel that life is hopeless.	1	2	3	4
I have been doing things that I believe will improve my health e.g. exercising.	1	2	3	4
Since my cancer diagnosis, I now realize how precious life is and I'm making the most of it.	1	2	3	4
I've put myself in the hands of God.	1	2	3	4
I have plans for the future e.g. holiday, jobs, housing.	1	2	3	4
I worry about the cancer returning or getting worse.	1	2	3	4
I've had a good life; what's left is a bonus.	1	2	3	4
I think my state of mind can make a lot of difference to my health.	1	2	3	4
I feel that there is nothing I can do to help myself.	1	2	3	4



4 0 0 2

	<i>Definitely does not apply to me</i>	<i>Does not apply to me</i>	<i>Applies to me</i>	<i>Definitely applies to me</i>
18. I try to carry on my life as I've always done.	1	2	3	4
19. I would like to make a contact with others in the same boat.	1	2	3	4
20. I am determined to put it all behind me.	1	2	3	4
21. I have difficulty in believing that this happened to me.	1	2	3	4
22. I suffer great anxiety about it.	1	2	3	4
23. I am not very hopeful about the future.	1	2	3	4
24. At the moment I take one day at a time.	1	2	3	4
25. I feel like giving up.	1	2	3	4
26. I try to keep a sense of humour about it.	1	2	3	4
27. Other people worry about me more than I do.	1	2	3	4
28. I think of other people who are worse off.	1	2	3	4
29. I am trying to get as much information as I can about cancer.	1	2	3	4
30. I feel that I can't control what is happening.	1	2	3	4
31. I try to keep a very positive attitude.	1	2	3	4
32. I keep quite busy, so I don't have time to think about it.	1	2	3	4
33. I avoid finding out more about it.	1	2	3	4
34. I see my illness as a challenge.	1	2	3	4
35. I feel fatalistic about it.	1	2	3	4
36. I feel completely at a loss about what to do.	1	2	3	4
37. I feel very angry about what has happened to me.	1	2	3	4
38. I don't really believe I had cancer.	1	2	3	4
39. I count my blessings.	1	2	3	4
40. I try to fight the illness.	1	2	3	4

Thank you for taking the trouble to complete this scale!

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Code 4920 04 4



Body Image Questionnaire

In this questionnaire you will be asked how you feel about you appearance, and about any changes that may have resulted from your disease or treatment. Please read each item carefully, and place a firm tick on the line alongside the reply which comes closest to the way you have been feeling about yourself, during the past week.

	Not at all	A little	Quite a bit	Very much
Have you been feeling self-conscious about your appearance ?
Have you felt <u>less</u> physically attractive as a result of your disease or treatment ?
Have you been <u>dissatisfied</u> with your appearance when dressed ?
Have you been feeling <u>less</u> feminine/masculine as a result of your disease or treatment ?
Did you find it difficult to look at yourself naked ?
Have you been feeling <u>less</u> sexually attractive as a result of your disease or treatment ?
Did you avoid people because of the way you felt about your appearance ?
Have you been feeling the treatment has left your body less whole ?
Have you been <u>dissatisfied</u> with your body ?
Have you been <u>dissatisfied</u> with the appearance of your scar ?
N/A			

THE BASIC EMOTIONS SCALE

The purpose of this scale is to find out about how much or how often you experience certain emotions, and then to ask some questions about how you feel actually during particular emotions themselves.

The first part of the scale is designed to explore how you have felt **DURING THE LAST WEEK**. For each emotion, please circle **ONE** number only between 1 and 7, to indicate how you have felt.

OVER THE PAST WEEK I HAVE FELT :

	Not at all					All of the time	
ANGER	1	2	3	4	5	6	7
SADNESS	1	2	3	4	5	6	7
DISGUST	1	2	3	4	5	6	7
FEAR	1	2	3	4	5	6	7
HAPPINESS	1	2	3	4	5	6	7
SHAME	1	2	3	4	5	6	7
GUILT	1	2	3	4	5	6	7

In the second part of this questionnaire we would like to know about how you feel **IN GENERAL**. The question asks about **HOW OFTEN** you feel the emotion. **Again**, for each question please circle **ONE** number only between 1 and 7 to indicate how you feel.

IN GENERAL, I FEEL THIS EMOTION :

	never			sometimes		very often
ANGER	1	2	3	4	5	6 7
SADNESS	1	2	3	4	5	6 7
DISGUST	1	2	3	4	5	6 7
FEAR	1	2	3	4	5	6 7
HAPPINESS	1	2	3	4	5	6 7
SHAME	1	2	3	4	5	6 7
GUILT	1	2	3	4	5	6 7

In the third part of this questionnaire we would like to ask you for some information about **HOW YOU FEEL** when you experience that emotion. **Please note:** even if you **never** experience a particular emotion, please answer the question by imagining how you think you would feel if you **did** experience that emotion. **Again**, for each part of the question, please circle **ONE** number between 1 and 7 to indicate how you feel.

How much in control do you feel ?

	completely in control					completely out of control	
ANGER	1	2	3	4	5	6	7
SADNESS	1	2	3	4	5	6	7
DISGUST	1	2	3	4	5	6	7
FEAR	1	2	3	4	5	6	7
HAPPINESS	1	2	3	4	5	6	7
SHAME	1	2	3	4	5	6	7
GUILT	1	2	3	4	5	6	7

Thank You Very Much For Your Help With This Questionnaire

Appendix 3

SCOTSMAN 16/06/01.

Cancer 'cure' is found

**Alastair Jamieson
and Michelle Nichols**

EARLY tests of a revolutionary drug and radiation cancer treatment invented by British scientists have proved dramatically successful, it was revealed yesterday.

Laboratory mice genetically engineered to grow human tumours were completely cured in 85 per cent of cases.

More than nine months after the treatment was stopped there was no evidence of any residual cancer in the animals.

One half of the treatment consists of a drug called Combretastatin - based on a tree-bark extract used by Zulu warriors as a charm to ward off their enemies - which targets newly-forming blood vessels that nourish tumours.

The other comprises antibodies tagged with a radioactive "warhead" which they ferry into cancer cells.

The therapy was pioneered by Cancer Research Campaign scientists at the Royal Free Hospital in London and the Gray Laboratory Cancer Research Trust at Mount Vernon Hospital, Middlesex.

Human clinical trial: are expected to begin next year. If successful they could lead to the treatment being available in five years.

Professor Richard Begent, head of oncology at the Royal Free, said: "Combretastatin has been given to patients on its own before but the response has not been very good. In most cases, the cancer continues to grow. But when you put the two treatments together it's then possible in these animals to cure the cancer completely with just a single treatment.

"It is rather exciting. We're now working towards carrying out some clinical trials with the Cancer Research Campaign."

Tumours cannot live without blood and generate their own special network of blood vessels to provide an adequate supply. Combretastatin specifically targets and cuts off the cancer blood network by binding on to the dividing cells creating the new capillaries.

Researchers found a ring of cells around the central tumour

do not rely on the cancer blood supply system - they use normal blood vessels instead - and are thus free to keep growing.

The antibodies tackle these by zapping them with radioactive material.

The experiments at the Royal Free Hospital were led by Dr Barbara Pedley, head of tumour biology at the Cancer Research Campaign's targeting and imaging group.

Dr Pedley said: "We are excited by these results. These are human tumours grown in mice.

"Although we have been mainly looking at colorectal cancer, it works on a very wide range of cancers - all the solid tumours, which includes breast cancer."

The key to the therapy is that it ensures that no residual cancer is left.

Combretastatin attacks the tumour from the inside out by cutting off its blood supply. The radioactive antibodies work from the outside in.

Excitement about Combretastatin began four years ago when Cancer Research Campaign scientists found it could kill up to 95 per cent of cells in solid tumours in the laboratory.

**Vitamin C can increase
the risk of cancer Page 6**

However, in patients, the small number of cancer cells left behind allowed the disease to return.

Dr Lesley Walker, director of cancer information at the Cancer Research Campaign, said: "This good news confirms what we have been saying all along - that treatments that directly target cancers and spare normal tissue will be the cancer therapies of the future.

"By combining radioimmunotherapy with Combretastatin, doctors could in the future be able to launch a two-pronged attack on the cancer cells, effectively delivering a 'double-blow' and preventing tumours from regrowing.

"As well as improving the effectiveness of treatment, it should greatly reduce side-effects for the patient."

Dr Walker said patient trials involving Combretastatin were due to start early next year and a number of trials were expected to use a combination of the drug in conjunction with other chemotherapy agents and/or radiotherapy.

About 200 patients with a variety of different cancers would be recruited



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