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**PATTERNS OF COPING AND PSYCHOLOGICAL
ADJUSTMENT IN WOMEN WITH EARLY
BREAST CANCER**

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ABSTRACT

This study explored the cognitive and behavioural coping responses to early breast cancer in the first post-operative year. The association between these coping responses, other psychosocial factors, physical variables and psychological outcome, was analysed.

Literature review highlighted difficulties in the definition and measurement of coping. Consequently, this study included the methodological development of two existing coping measures, comprising a standardised questionnaire and an interview designed specifically for patients with cancer, which were based on Lazarus and Folkman's transactional model of stress and coping. The adapted measures were subsequently used in the main longitudinal study of 107 women with early breast cancer, who were interviewed pre-operatively and at three and twelve months after operation.

The study demonstrated the use of a wide repertoire of coping responses. Patterns of use of individual coping strategies varied over the course of the first post-operative year. Initial levels of mood disturbance were high, but these declined significantly after operation. An overall approach of 'selective ignoring' associated with lower levels of mood disturbance, involved attempts to continue life as normal, cognitive avoidance and positive appraisal of the disease. Use of humour and acceptance of the diagnosis were also related to better psychological outcome. Increased mood disturbance was associated with pre-occupation with the disease, a fatalistic attitude towards the prognosis, and denial of the threat of the disease.

Positive support from a close confidante was not associated with mood. However, negative or critical relationships as well as the active seeking of support were associated with increased mood disturbance.

Psychosocial variables related to a poorer psychological outcome included marital status, previous psychological treatment, family history of malignant disease, personal history of benign breast disease, age, menopausal status and the presence of young children at home. The effect of surgical procedure and adjuvant treatment were inconclusive.

The implications of this research for the delivery of care to women with early breast cancer are considered. Suggestions are made for the practical application of these results in a therapeutic intervention.

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TABLE OF CONTENTS

	<u>Page</u>
<u>Abstract</u>	2
<u>Acknowledgements</u>	4
<u>Introduction</u>	14
<u>Chapter 1: The experience of breast cancer</u>	16
1.1 Breast cancer and its treatment	16
1.1.1 Definition of early breast cancer	16
1.1.2 Histology of breast cancer	16
1.1.3 Detection of breast cancer	18
1.1.4 Investigations of breast cancer	19
1.1.5 Surgical treatment of breast cancer	19
1.1.6 Adjuvant treatment of breast cancer	22
1.1.7 Outpatient follow-up	22
1.2 Psychological morbidity in breast cancer	23
1.2.1 Levels of psychological morbidity in early breast cancer	23
1.2.2 Comparisons of levels of psychological morbidity associated with mastectomy versus breast conservation	25
1.2.3 Psychological morbidity in women offered a choice of surgical treatment for early breast cancer	30
1.2.4 Conclusion	32
<u>Chapter 2: Coping with cancer: Theory, methodology and findings</u>	33
2.1 Definition of coping	33
2.1.1 Stimulus-based models	33
2.1.2 Psychoanalytic models	34
2.1.3 Cognitive-phenomenological models	35

2.2	Measurement of coping	37
2.2.1	Measurement of coping as a personality trait or style	37
2.2.2	Measurement of coping as a process	38
2.2.3	Stages of coping	39
2.2.4	Criticisms of the measurement of coping as a process	39
2.2.5	Theoretical versus empirical measures of coping	40
2.3	Coping and outcome	41
2.3.1	Psychological outcome	41
2.3.1.1	Avoidant coping and outcome	41
2.3.1.2	Emotion focused coping versus problem focused coping	41
2.3.1.3	Coping and depression	43
2.4	Coping and outcome in breast cancer	45
2.4.1	Coping and psychological outcome in cancer	46
2.4.1.1	Psychoanalytic models of coping and psychological outcome	46
2.4.1.2	Coping styles and psychological outcome	46
2.4.1.3	Individual coping strategies and psychological outcome	47
2.4.1.4	Denial and psychological outcome	48
2.4.1.5	Cognitive-phenomenological approaches to coping and psychological outcome	49
2.4.1.6	Choice of outcome measure	50
2.4.2	Coping and physical outcome in cancer	50
2.4.3	Interaction between physical and psychological outcome in cancer	53
2.5	Conclusions	55

<u>Chapter 3: Social support and other mediating factors in psychological adjustment to breast cancer</u>	56
3.1 The role of social support in cancer	56
3.1.1 Definition and measurement	56
3.1.2 Social support and physical outcome	57
3.1.3 Social support and psychological outcome	59
3.1.4 Social support and interventions	60
3.1.5 Social support and coping	61
3.1.6 Negative effects of social support	63
3.2 Further mediating factors	64
3.3 Conclusions	66
<u>Chapter 4: Conclusions from the review of the literature and implications for the current study</u>	67
4.1 The importance of psychological outcome in breast cancer	67
4.2 Factors associated with psychological outcome	68
4.2.1 Disease and treatment	68
4.2.2 Coping responses	69
4.2.3 Explanations for inconsistencies in the effects of coping	70
4.2.3.1 Definitions of coping	70
4.2.3.2 Measurement of coping	71
4.2.3.3 Methodology	72
4.3 Further factors associated with psychological outcome	72
4.4 Summary	73

<u>Chapter 5: Aims of current research and research design</u>	74
5.1 Aims	74
5.1.1 Exploration and description	74
5.1.2 Cross-sectional analyses	74
5.1.3 Longitudinal analyses	74
5.2 Hypotheses	75
5.2.1 Cognitive and behavioural responses	75
5.2.2 Social support from a confidante	75
5.2.3 Further mediating factors	75
5.3 Research design	76
<u>Chapter 6: Adaptation and development of two measures of coping for women with breast cancer</u>	77
6.1 Introduction	77
6.2 Adaptation and use of the Ways of Coping Questionnaire	79
6.2.1 Patients and methods	79
6.2.2 Analyses and results	80
6.3 Adaptation and use of the Faith Courtauld Schedule for Coping with Cancer	85
6.3.1 Patients and methods	85
6.3.2 Analyses and results	86
6.4 Discussion	90
6.5 Conclusions	94

<u>Chapter 7: Patterns of coping and psychological adjustment in women</u>		
<u>with early breast cancer: Longitudinal study</u>		95
7.1	Introduction	95
7.2	Method	95
	7.2.1 Setting	95
	7.2.2 Patients	95
	7.2.3 Procedure	96
	7.2.3.1 Pre-operative interview	96
	7.2.3.2 Three months after operation	97
	7.2.3.3 One year after operation	97
	7.2.4 Measures	98
	7.2.4.1 Sociodemographic data	98
	7.2.4.2 Cognitive and behavioural responses to cancer	98
	7.2.4.3 Measures of mood	100
	7.2.4.4 Social support	101
7.3	Results	102
	7.3.1 Exploration and description	102
	7.3.1.1 Attrition from the study	102
	7.3.1.2 Sociodemographic and treatment data for all patients	104
	7.3.1.3 Cognitive and behavioural coping responses	107
	7.3.1.4 Measures of mood	117
	7.3.1.5 Measure of social support	124
	7.3.2 Cross-sectional analyses	130
	7.3.2.1 Cognitive and behavioural coping responses and measures of mood	130
	7.3.2.2 Social and demographic variables and measures of mood	138
	7.3.2.3 Physical and pathological variables and	

9.2	Implications for the delivery of care to women with early breast cancer	220
9.2.1	Identification of women who might experience significant distress	220
9.2.2	Pre-operative distress	221
9.2.3	When to intervene after operation?	222
9.2.4	What type of intervention could be offered?	222
9.2.5	Conclusions	224
	<u>References</u>	225
	<u>Appendices</u>	252
Appendix 1:	'Measuring coping in breast cancer'	254
Appendix 2:	Frequency of scores for each item on the adapted Ways of Coping Questionnaire. Data gathered from the methodological development of the questionnaire.	264
Appendix 3:	Factors and factor loadings from the factor analysis of the adapted Ways of Coping Questionnaire. Data gathered from the methodological development of the questionnaire.	269
Appendix 4:	Original categories from the Faith Courtauld Schedule for Coping with Cancer.	272
Appendix 5:	Sociodemographic data rating form.	276
Appendix 6:	Pre-operative coping interview from the Faith Courtauld Schedule for Coping with Cancer.	280

Appendix 7: Post-operative coping interviews from the Faith Courtauld Schedule for Coping with Cancer.	282
Appendix 8: Adapted manual from the Faith Courtauld Schedule for Coping with Cancer.	284
Appendix 9: Adapted Ways of Coping Questionnaire.	287
Appendix 10: Hospital Anxiety and Depression Scale.	292
Appendix 11: Profile of Mood States questionnaire.	293
Appendix 12: Social Evaluation and Social Support scale.	294
Appendix 13: Inter-rater reliability data for the adapted Faith Courtauld Schedule for Coping with Cancer.	297
Appendix 14: Frequency data for the coping categories from the adapted Faith Courtauld Schedule for Coping with Cancer.	298
Appendix 15: Graphs of the distribution of scores on each sub-scale from the Profile of Mood States.	299
Appendix 16: Independent variables included in the regression analyses	305
a) Prediction of mood at three months after operation	305
b) Prediction of mood at one year after operation	306

INTRODUCTION

The studies in this thesis focus on the psychological impact of early breast cancer. In particular, to explore the cognitive and behavioural strategies used to cope with the diagnosis and treatment. The influence of these ways of coping and other psychosocial variables in determining mood are examined.

Several relevant areas of literature are reviewed to provide a background to this research. First, the experience of breast cancer including its definition and the process of detection, diagnosis and treatment are considered. In addition, the levels of psychological morbidity in women with early breast cancer and their association with the physical aspects of the disease or treatment are reviewed.

The second chapter reviews the psychological influences on distress in women with early breast cancer, with particular reference to the cognitive and behavioural methods of coping. The effect of the different models which have informed the study of coping in terms of definition and measurement are discussed. These are then considered in relation to the association between coping and psychological outcome in the general population, as well as both psychological and physical outcomes in women with breast cancer.

The last area of literature reviewed comprises other psychosocial variables which have been found to have an impact on psychological outcome in women with breast cancer. Social support in particular has been widely studied in relation to outcome. This is examined in terms of its definition and measurement, as well as its association with physical and psychological outcome including its effect on coping strategies. Further mediating factors considered include socio-demographic variables such as age, religion, previous history of psychological treatment, life events, marital and socioeconomic status.

General conclusions are drawn from the literature reviewed. These are used to inform the aims and hypotheses of the current research. One conclusion concerns the need for the development of specific measures of coping for the population of women with early breast cancer in the study. An initial study to adapt two existing coping measures to

achieve this purpose is described. This is followed by the main longitudinal study, including the methods and results. The results section is subdivided into three parts: First, a description of the pattern of results obtained for each variable over the first post-operative year; second, the examination of the associations between the measures of mood and use of coping and other psychosocial variables which were measured at the same assessment; finally, regression analyses are used to examine the effect of coping and other psychosocial variables on the measures of mood which were assessed at subsequent time points.

The final part of the thesis comprises a discussion of these results in terms of the hypotheses which were proposed. A critique of this research and implications for future study are discussed, as well as the implications of the results for the delivery of care for women with early breast cancer.

CHAPTER 1. THE EXPERIENCE OF BREAST CANCER

Each year around 12,000 women die from breast cancer in the United Kingdom. It is the most common cancer affecting women with around one woman in twelve having the diagnosis and is the commonest cause of death amongst women aged 35-55 years. This chapter examines the nature of breast cancer and the processes women go through in its detection and treatment. The levels of psychological morbidity associated with the disease are considered as well as possible physical reasons for this morbidity such as the effect of the surgical treatment.

1.1 BREAST CANCER AND IT'S TREATMENT

1.1.1 Definition of early breast cancer

Cancer is defined as an uncontrolled growth of cells which exceeds that of normal tissue repair and maintenance and can occur in almost any part of the body. Growth continues indefinitely and the resultant tumour can extend beyond the micro-anatomical boundaries leading to disruption of the tissue function. There is enormous variation in the natural history, treatment and prognosis depending on the site of the primary tumour. Psychosocial morbidity associated with the diagnosis of cancer also varies accordingly. In order to control for the variability associated with the cancer site, stage of disease and the subsequent differences in treatment, the current research focuses specifically on the diagnosis and treatment of early breast cancer.

1.1.2 Histology of breast cancer

Even within breast cancer there is a wide variation in tumour biology and prognosis. Prognosis is associated with the degree of invasion of the tumour. Intraduct or lobular cancer in situ are pre-invasive cancers which have not extended beyond the margins of the cell wall. If left untreated there is a high probability they will become invasive. However, if treated the prognosis is very good. The most common form of invasive cancer is invasive ductal carcinoma, which is subdivided according to grade of the tumour. Tumour grade refers to the degree of differentiation of the tumour cells and can be determined by histological examination. Grades can range from cancer cells which retain the characteristics of the original breast structures such as ducts or tubules, which

carries a good prognosis, while the other extreme, with a very poor prognosis, are cancer cells which have extended beyond the cell margins, thus rendering the original structure and function of the cell unrecognisable.

It is possible to stage breast cancer according to the degree of spread of the disease. One of the most well known staging systems which is recommended by the International Union against Cancer (UICC) is the TNM system described in table 1.1.

TABLE 1.1

<u>Tumour status</u>	
T ₀	No palpable tumour
T ₁	Tumour \leq 2cm with no fixation
T ₂	Tumour $>$ 2cm but $<$ 5cm with no fixation
T ₃	Tumour \geq 5cm
T ₄	Tumour of any size with fixation to chest wall or skin ulceration
<u>Nodal status</u>	
N ₀	No palpable axillary lymph nodes
N _{1a}	Palpable axillary nodes believed to be benign
N _{1b}	Palpable axillary nodes believed to contain tumour
N ₂	Node $>$ 2cm or fixed to each other and deep structures
N ₃	Supraclavicular or infraclavicular nodes
<u>Metastases</u>	
M ₀	No clinically apparent distant metastases
M ₁	Clinically apparent distant metastases

Another form of invasive cancer is lobular carcinoma, although this is more uncommon than ductal carcinoma. Lobular invasive carcinoma is often associated with pre-invasive or invasive cancer in the same breast or contralateral breast. Patients may also present to their doctor with a skin disorder surrounding the nipple called Paget's disease, which is often a marker for an underlying breast malignancy.

1.1.3 Detection of breast cancer

The majority of breast tumours are detected by women on self-examination or by chance e.g. when washing. Alternatively it may be detected on a routine examination by the General Practitioner or Family Planning clinic. In addition, women between the ages of 50 - 65 years are offered the chance of a regular mammogram to check for the presence of malignancy. Mammography involves an x-ray of the breast and whilst not a painful procedure, it does involve a degree of discomfort. A mammogram can facilitate the diagnosis of cancer in a nodular breast where it is difficult to feel a small discrete tumour, enable localisation of a lump to aid accurate surgery or reveal another cancer in the same or contralateral breast. Mammograms are also used to screen for new cancers in women who have already had a tumour removed and who consequently stand an increased chance of developing another cancer in the same or opposite breast.

According to records made in the 19th Century, the natural history of an untreated breast cancer shows skin infiltration fourteen months after detecting a lump. Six months later, skin ulceration occurs followed by fixation to the chest wall after another two months and invasion of the second breast after three years. Cancer of the breast can also spread to the lymph nodes in the axilla which manifests itself as a hard lump under the arm and can be followed by infiltration and ulceration of the skin. Nineteenth Century records show that enlarged axillary nodes appear roughly fifteen months after the tumour was detected. One year later around one quarter developed distant deposits of cancer or metastases whilst one quarter did not develop metastases until three years later. Only around 10% of those without treatment survived ten years whereas the current ten year survival rate with treatment is around fifty percent.

The most common symptom of breast cancer is the presence of a lump in the breast or underarm. Other signs include dimpling caused by infiltration of the cancer along the ligaments of the breast which pull in the overlying skin. Nipple inversion or discharge can be caused by invasion along the lactiferous ducts. Further symptoms include pain or nodularity.

1.1.4 Investigations of breast cancer

After detection of symptoms and referral to a specialist breast clinic, the woman is first given a full clinical examination. If a discrete breast lump is found the next step is to ascertain whether it is a cyst through test aspiration. If the lump is fully resolved by aspirating clear, bloodless fluid the woman will be offered a mammogram as a precaution but otherwise she will be reassured and given a follow-up appointment. Alternatively, if the fluid is blood stained or a lump remains after fluid has been removed then a needle biopsy is performed. Similarly, solid lumps which do not reveal any fluid on aspiration will be investigated by needle biopsy. This involves the insertion of a cutting needle into the lump under local anaesthetic and the removal of a small core of tissue which is then examined for the presence of cancer cells. If cancer cells are present then a definitive diagnosis of cancer is given. However, a negative result may indicate that the cutting needle had not been inserted correctly and the woman is then advised to have an excision biopsy. This is performed under a general anaesthetic and will usually involve removal of the whole lump. In some hospitals, a frozen section of tissue is sent immediately for histopathological examination while the patient remains under anaesthetic. If cancer is subsequently diagnosed then the whole breast may be removed whilst the woman is asleep. This technique has been criticised for heightening the anxiety of the patient who does not know whether she will awake from their operation with or without her breast and a diagnosis of cancer. In the unit where the current study was conducted those patients whose needle biopsy resulted in a positive diagnosis of cancer were told between 3-10 days later in the outpatient clinic, whilst those who required an excision biopsy were offered a date for an operation within 2 weeks and received the results 5 days after surgery whilst they remained on the ward. A date would then be set for any further surgical procedures to be performed within a fortnight and usually this would be performed within a few days.

1.1.5 Surgical treatment of breast cancer

Surgical procedures for breast cancer have developed as theories regarding the course of the disease have changed. Early theories suggested that breast cancer followed an orderly and predictable pattern of spread from local involvement to regional and axillary lymph node infiltration and finally to disseminated disease. Consequently, treatment involved

an extensive operation in order to clear all possible sites of disease. In the early part of the 20th Century breast cancer was routinely treated by Halsted mastectomy which involved the removal of all breast tissue including both pectoralis muscles and axillary lymph nodes resulting in a concave scar with the underlying ribs clearly visible. Some surgeons also performed an extended or super-radical mastectomy which further removed the lymphatic tissue from the centre of the chest. However, studies have since found no evidence to suggest that an extended operation improves relapse or survival rates (Veronesi & Valagussa, 1981).

Surgical interventions for breast cancer have become less radical as it became accepted that the disease was systemic with the possibility of micro-metastases occurring even before a lump is detected. The modified radical mastectomy became the standard treatment for breast cancer from the 1940's almost until the present day. This also involves the removal of all breast tissue but only removed the pectoralis minor muscle and lymph nodes. This results in a smaller, flatter scar which can usually be effectively disguised by the wearing of a prosthesis. Alternatively, some women choose to have a breast reconstruction. The centre in the current study usually only offered the option of reconstruction two years after operation because of the possibility that it may mask signs of local recurrence. An alternative operation is the simple, or confusingly titled, total mastectomy which again removes all breast tissue but leaves both pectoralis muscles intact and only samples the lower lymph nodes. In a summary of randomised trials comparing Halsted with modified radical mastectomy, Henderson and Canellos (1980) conclude that the smaller operation does not have an adverse effect on survival rates.

In recent years, the emphasis has been placed on attempts to conserve the breast with removal of the lump alone (lumpectomy) or the breast quadrant containing the lump (quadrantectomy) usually in association with dissection of the axillary lymph nodes. A large scale trial was conducted by the National Surgical Adjuvant Breast Project (NSABP) and reported by Fisher and colleagues (Fisher, Redmond, Fisher & al., 1985). The aim of the study was to compare total mastectomy with lumpectomy with or without radiotherapy and involved 1843 women with early breast cancer ($T_{0-2} N_{0-1} M_0$) who had accepted randomisation. Amongst the conclusions from the trial it was found that

preserving the patient's breast did not adversely affect rates of distant recurrence or overall survival. However, for some women, breast conservation is not an option, these include women with large tumours or a medium sized tumour in a woman with a small breast or for women whose tumour lies beneath the nipple.

An additional finding from the NSABP trial showed that the irradiation of the breast reduced the risk of recurrence in the same breast after lumpectomy. The aim of breast irradiation is to improve the local control of the disease and is usually offered to women with a higher risk of local recurrence such as those with a large primary tumour or involved lymph nodes. It is also routinely offered to women having a breast conserving operation. There are few side effects, the main one being tiredness although this may be due to the daily visits to hospital for radiotherapy lasting for 4-6 weeks. Some women, especially those with fair skins, may experience some skin burning and a few may feel nauseous. In very rare cases radiation fibrosis may occur. Radiotherapy can also depress the lymphocyte count, but this has not been found to have any clinical relevance.

An alternative form of radiotherapy involves passing iridium wires through the tumour and a high dose of radiation is then delivered directly to the tumour site. Again the side effects are few and the actual insertion and removal of the wires is remarkably painless, with a good final cosmetic result. The main problems arise from the isolation of the woman in a single room for around five days whilst undergoing therapy. Because of the nature of the treatment, visitors cannot stay long and have to remain behind protective screens. Consequently some women report feelings of loneliness or claustrophobia.

The breast unit studied in the current research offered the opportunity of breast conservation to the majority of women. This comprised either iridium implants or removal of the lump followed by daily radiotherapy for five weeks. Simple mastectomy was offered to women with larger tumours, or those who could not travel for daily radiotherapy. This often meant that older women (aged 60 years or more) were treated by mastectomy.

1.1.6 Adjuvant treatment of breast cancer

Current theories suggest that around 70% of tumours will have micro-metastasised before surgery. Consequently many women are offered adjuvant systemic therapy which aims to destroy cancer cells which may have lodged in other parts of the body. However, these treatments tend to have unpleasant side-effects, therefore only those patients who would benefit the most, such as women with axillary lymph node involvement, are offered such treatment.

Adjuvant systemic therapy consists of either endocrine or cytotoxic treatment. Endocrine treatment affects levels of the hormone oestrogen which is believed to facilitate the growth of cancer cells. Treatment for pre-menopausal women includes surgical removal of the ovaries (oophorectomy) or ovarian irradiation, both of which render the woman menopausal with associated symptoms. Post-menopausal women may be given corticosteroids to inhibit the adrenal gland and thus the production of hormones. This can have the unpleasant side effect of rapid weight gain. Steroids are often given in conjunction with Tamoxifen which is an anti-oestrogen treatment with few side effects although some women also experience menopausal symptoms such as hot flushes.

Cytotoxic treatment is currently administered as a cyclical combination of chemotherapy drugs which attack all growing and dividing cells. Chemotherapy is usually given to pre-menopausal women who are found to have axillary lymph node involvement. Benefits for post-menopausal women are equivalent to those of Tamoxifen but cytotoxic treatment has more side effects. These include alopecia, nausea and vomiting, bone marrow suppression and disturbed ovarian function which can result in disrupted menstruation and amenorrhoea. Recent studies have shown significantly improved 10 year survival rates for both endocrine and cytotoxic treatments (Early Breast Cancer Trialists Collaborative Group, 1992).

1.1.7 Outpatient follow-up

Women who have undergone surgery for breast cancer and possibly some form of adjuvant treatment will then receive regular outpatient appointments to monitor their progress. At the breast unit where the current study was conducted this entailed three

monthly visits for the first two years, then six monthly visits for the next three years from when the visits are yearly. Whilst many women may feel reassured by such regular contact, it also provides a repeated reminder of their disease and can arouse fears of recurrence related to what the doctor might find on examining their breast.

1.2 PSYCHOLOGICAL MORBIDITY IN BREAST CANCER

1.2.1 Levels of psychological morbidity in early breast cancer

One of the first descriptions of the distress caused by breast cancer was provided by Renneker and Cutler (1952). They studied fifty women with breast cancer and described their reactions which included depression, anxiety and sleeplessness as well as some suicidal ideation and feelings of shame and worthlessness. They suggested that these reactions were very similar to reactions of mourning which they ascribed to the loss of the breast. Bard and Sutherland (1955) described a very similar collection of symptoms but they found that their patients were more preoccupied with thoughts of death and dying rather than breast loss.

Research on the prevalence of psychological morbidity in women with breast cancer has often involved the use of a control group of women with benign breast disease as a comparison. Morris and colleagues (Morris, Greer & White, 1977) studied 69 women with early breast cancer who were mainly treated by mastectomy and compared their psychological morbidity with 91 women who were found to have benign breast lumps after biopsy. Assessments were made prior to the diagnosis and then at three, twelve and twenty-four months after operation (or an equivalent time span for the controls). Levels of depression over time amongst the women with breast cancer, according to the Hamilton Rating Scale, ranged from a minimum of 17% to a maximum of 23% and were consistently higher than those of the controls. This difference only reached significance at two years after operation when 22% of the breast cancer patients were depressed compared with only 8% of the controls. Patients were also questioned about the 'psychological stress' caused by their diagnosis and treatment and again around one quarter of patients reported continuing stress two years after their operation. However the authors do not provide a clear definition of 'psychological stress'.

A similar prospective study was conducted by Maguire and colleagues (1978), with assessments prior to biopsy and then at four and twelve months after treatment. Seventy-five women undergoing mastectomy for breast cancer were compared with fifty matched controls who were diagnosed with benign breast disease. Psychiatric ratings for anxiety and depression were made on a four point scale from no symptoms present to mild, moderate or severe symptoms. Levels of post-operative anxiety for breast cancer patients were 21% and 19% at four and twelve months respectively whilst levels of depression were slightly higher at 27% and 21%. These levels were significantly higher than those of the controls at both time points. The overall prevalence of psychiatric morbidity at one year post-operation was 25% for the women with breast cancer against 8% for the controls. This has been frequently cited as the general level of psychological morbidity experienced by women with early breast cancer. However, as the authors point out, no differentiation was made according to the extent of surgery comparing radical with modified radical mastectomy, or by adjuvant treatment such as radiotherapy. It is possible that such differentiations may highlight differences in psychiatric morbidity according to type of treatment.

Hughes (1982) studied forty-four women who were all treated by simple mastectomy although with varying adjuvant treatments. Patients were again studied prospectively with initial assessment prior to diagnosis and follow-up assessments at three, six, and nine to twelve months after operation. Psychological morbidity was measured using both a questionnaire and a semi-structured interview which enquired about feelings of anxiety and depression. The majority of patients reported feelings of anxiety or depression prior to diagnosis with 25% experiencing severe distress and 66% reporting mild or moderate distress. These extremely high levels of distress may be explained by the investigation procedure which involved taking frozen sections for diagnosis. Patients found to have malignant disease would then have their breast removed under the same anaesthetic. This might engender a great deal of uncertainty and anxiety since patients did not know whether they would wake up with a diagnosis of benign breast disease or a cancer plus a mastectomy. Psychological morbidity in the first year after mastectomy remained quite high with 18% reporting severe symptoms of anxiety or depression and 36% experiencing mild to moderate distress although prevalence was reported according to results from the

non-standardised interview alone.

The use of a standardised method of assessing psychological morbidity enables replication and comparison with other studies. One such interview, the Present State Examination (PSE), was used by Dean (1987) in a study of factors which may predict post-operative psychological morbidity. Dean used research diagnostic criteria in order to assign diagnoses of anxiety or depression in 122 women with breast cancer treated by mastectomy and compared them with 122 matched community controls. Prior to operation almost half (46.5%) of the mastectomy sample reported symptoms of anxiety or depression. This level fell to 29% and 26% at three and twelve months respectively after operation compared with around 11% psychiatric morbidity in the community sample. However, most of the psychiatric morbidity was of a minor nature, mainly minor depressive disorder. Whilst there was a significant difference between the levels of minor distress in the breast cancer patients and the control group, no difference was found between levels of severe psychiatric disorder.

Despite the use of different methods of assessment, the studies reported have generally found that around one quarter of women with early breast cancer experience significant post-operative psychological morbidity. A recent study by Watson and her colleagues (Watson, Greer, Rowden et al., 1991) using the Hospital Anxiety and Depression (HAD) scale with 359 patients with breast cancer in the first three months after operation found greatly reduced levels of psychological morbidity. Sixteen percent of the patients were found to be anxious whilst only 6% were rated as depressed. Such low levels of distress could be due to the methods used to define psychological morbidity. Specifically, the cut-off of ≥ 10 for anxiety and ≥ 8 for depression may not be sensitive enough to pick up distress in women with breast cancer.

1.2.2 Comparison of levels of psychological morbidity associated with mastectomy versus breast conservation

The generally high levels of psychological morbidity reported in women with early breast cancer are frequently attributed to the mutilation of mastectomy. However in recent years there has been a move away from such radical surgical techniques towards breast

conservation in conjunction with radiotherapy. Randomised control trials comparing survival and relapse-free intervals of patients treated by mastectomy or breast conservation methods have shown no significant differences (Fentiman, Chaudary, Wang et al., 1988; Fisher, Redmond, Fisher et al., 1985).

The change in surgical emphasis has enabled the study of the psychological effects of different types of primary treatment, though many of these studies have been methodologically flawed. Irvine and her colleagues (Irvine, Brown, Crooks, Roberts & Browne, 1991) have produced a comprehensive overview of psychosocial adjustment to breast cancer, including comparisons between different methods of surgery. The research is critically appraised according to methodological standards devised by Sackett and colleagues (Sackett, 1979; Department of Clinical Epidemiology and Biostatistics, 1981). These provide useful guidelines for evaluating the quality of studies, many of which are criticised for having retrospective designs, small numbers and a lack of standardised assessments.

One of the first studies to compare the effect of type of surgery on adjustment to breast cancer was performed by Kemeny and co-workers (Kemeny, Wellisch & Shain, 1988), although it contained all three methodological errors cited above. A postal questionnaire devised by the authors was despatched to patients with breast cancer but only 62% responded. Eight months later these respondents were sent the Brief Symptom Inventory to elicit symptoms of psychological distress to which 71% of the original respondents replied. This resulted in a small sample with only twenty-five patients treated by breast conservation and twenty-seven by mastectomy. Patients treated by breast conservation were less emotionally distressed than mastectomy patients but a global index of psychological morbidity showed no significant difference. Despite flawed methodology, this study is frequently quoted in support of the conclusion that there is no difference in the psychological effects of mastectomy compared with breast conservation.

Another frequently cited study which showed no difference in psychological morbidity between the two treatment groups was performed by Sanger and Reznikoff (1981) using the Minnesota Multiphasic Personality Inventory. This was similarly flawed by a

retrospective design and small numbers, with only twenty in each treatment group. There was a wide variation in time since treatment which ranged from two months to four and a half years. Furthermore, the mastectomy operation was chosen by the surgeon and these patients volunteered for the study, although surgeons did not permit the questioning of patients with psychological difficulties. Conversely, the conservation treatment was chosen by the patient who was referred to the study by their surgeon or radiotherapist. Data on selection criteria and refusal to participate in the study were not given.

A similar small sample was used in a retrospective study by Schain and colleagues (Schain, Edwards, Gorrell et al., 1983) where time since surgery ranged from two to twenty months. No difference was found between the two surgical groups on thirteen psychosocial variables including anxiety, anger, sleeping problems and fear of recurrence using a non-standardised postal questionnaire. Although the study was flawed by its design and choice of assessment, the authors made the interesting suggestion that the high levels of morbidity recorded in their sample were due to having breast cancer rather than the effect of surgical treatment.

Much larger numbers were studied by Bartelink and co-workers (Bartelink, Van Dam & Van Dongen, 1985) who assessed one hundred and fourteen patients treated by breast conservation and fifty-nine by radical mastectomy. Whilst the study again employed a retrospective design, the interval between surgery and assessment was shorter than many of the earlier studies. The study of psychological morbidity was stated as one of the principal aims, but the results mainly concentrated on problems with body image. Unsurprisingly, patients treated by breast conservation techniques had fewer problems with body image than patients who had their breast removed, although conservation patients also expressed less fear of recurrence. These findings were based on a non-standardised postal questionnaire which consisted of only nine items.

Lasry and co-workers (Lasry, Margolese, Poisson et al., 1987) studied one hundred and twenty-three women with breast cancer who were randomly assigned to mastectomy, lumpectomy or lumpectomy plus radiotherapy, concentrating on symptoms of depression using the self-report Centre for Epidemiological Studies Depression scale (CES-D).

Results showed levels of morbidity which were twice those found in a normal population but lower than that found in a psychiatric population. No significant differences in psychological morbidity were found between the three groups, although there was a trend towards greater morbidity in women with lumpectomy plus radiotherapy. The authors concluded that radiotherapy may have a greater effect on morbidity than the type of operation, but this was based on retrospective data gathered from one to nine years after primary operation.

Two studies conducted in the same year, employing standardised assessments of mood, found no significant difference between breast conservation and mastectomy patients and overall levels of psychological morbidity were low (Ashcroft, Leinster & Slade, 1985; Steinberg, Juliano & Wise, 1985). Steinberg and colleagues applied the Profile of Mood States (POMS) and the Beck Depression Inventory (BDI) in a retrospective assessment of psychological morbidity fourteen months after surgery. The authors suggested that levels of morbidity may have been underestimated because a number of the patients who refused assessment were obviously distressed. Furthermore, they suggested that the assessments, although standardised instruments, may not have been appropriate as they had been formulated with psychiatric patients and were possibly not sensitive enough to detect distress in a physically ill population. Ashcroft and co-workers used a prospective design with the Leeds depression scale and Spielberger state/trait anxiety assessments. They found that pre-operative anxiety was comparable with general surgical patients. Some of the patients in both studies were offered a choice of treatment but no data were given on who had been offered the option between surgical techniques, which may have subsequently affected their results.

Wolberg and colleagues (Wolberg, Romsaas, Tanner & Malec, 1989) also used standardised assessments in a prospective study with relatively large numbers of patients. Seventy-two women with benign breast disease, seventy-eight women treated by mastectomy and forty-one treated by breast conservation were assessed using the POMS, Health Locus of Control scale and Psychological Adjustment to Illness scale. Unlike other studies, Wolberg's research was one of the few to find a difference between the psychological morbidity of breast conservation and mastectomy patients. Sixteen months

after the operation the conservation group had significantly higher scores on the POMS vigour scale. Like the previously cited research, this study also had problems regarding choice of surgery - all of the breast conservation group had been offered the choice of treatment.

Taylor and her co-workers (Taylor, Lichtman, Wood et al., 1985) reported another of the few studies to find a difference in psychological morbidity between the two treatment options. Using the standardised assessments of the POMS and Global Adjustment to Illness scale they measured the psychological morbidity of seventy-eight women with breast cancer. The patients were not selected for type of operation and there were consequently unequal numbers in each treatment group. Nine women were treated by Halsted (radical) mastectomy, thirty-one women had a simple/modified radical mastectomy and twenty-six women had only the lump removed. No detailed data were given on the levels of psychological morbidity. However the patients treated by Halsted mastectomy had the highest levels of distress, whilst patients treated by lumpectomy fared the best. The authors suggest that this result is mediated by sense of disfigurement and sexual and affectional changes in marriage. Once again the study design is open to criticism with retrospective assessments made between two months and five years after operation.

A study by McArdle and colleagues (McArdle, Hughson & McArdle, 1990) also found a significant difference between levels of psychological morbidity in patients treated by mastectomy or lumpectomy. Fifty-two patients treated by mastectomy and sixty-seven women who had a lumpectomy and radiotherapy were given the General Health Questionnaire (GHQ) and Leeds scale for anxiety and depression at six, nine and twelve months after operation. They found that mastectomy patients had higher scores on anxiety and depression on both scales and that this difference was significant on the GHQ depression scale. No data were given on the criteria used to assign the women to each treatment group. Furthermore, there was four times more missing data in the lumpectomy group. Missing data were replaced with mean scores from the previous completed assessments. This procedure may mask higher levels of psychological morbidity in the lumpectomy patients, particularly if the reasons for refusal were because the patients were too distressed.

Conversely, Maunsell and her colleagues working in Canada (Maunsell, Brisson & Deschenes, 1989) found a difference in levels of morbidity in women treated by total or partial mastectomy (including tumourectomy, quadrantectomy or segmental mastectomy) such that the women treated by the less mutilating procedure had higher levels of anxiety and depression three months after primary treatment. These results were based on the assessment of 227 women using the Psychiatric Symptom Index (PSI). Two hundred and five women were available for reassessment fifteen months later when the PSI was again used along with the Diagnostic Interview Schedule which used DSM-III criteria for major depression. No differences were found between the two treatment groups on reassessment although this was due to an increase in distress in the total mastectomy group rather than a decline in the partial mastectomy group. Levels of psychological morbidity were identical in the two groups at 35.1% eighteen months after surgery. Psychosocial factors were found to have a confounding effect on the association between type of surgery and distress. Older women and those with a lower level of education combined with a partial mastectomy operation were found to have greater levels of distress. However the numbers in these subgroups were small. Furthermore the patients were not randomised to treatment options.

1.2.3 Psychological morbidity in women offered a choice of surgical treatment for early breast cancer

Several studies have been conducted which take into account the effect of choice of treatment on the psychological morbidity associated with type of surgery. Meyer and Aspergren (1989) studied 30 patients treated by modified radical mastectomy and 28 by breast conservation. Type of surgery was chosen by the patients in conjunction with the surgeon. Assessments were made using a standardised clinical interview and questionnaire to measure psychiatric state. A prevalence of 30% psychiatric disorder was found in both groups. However, psychiatric disorder was defined as a heightened anxiety or mood state compared with pre-operative levels. Since the study was retrospective, with an interval since surgery of up to five years, the recall of pre-operative mood state may not be reliable.

Morris and Royle (1987) similarly found no difference in psychological morbidity

between women who chose mastectomy and those who chose wide excision of the lump with radiotherapy. In addition, the authors examined the effect of being given the option to choose surgical treatment. Results demonstrated that not having the option to choose was associated with greater morbidity. Unfortunately, the numbers involved were small.

A similar study using women randomised to treatment options was performed by Fallowfield and her colleagues (Fallowfield, Baum & Maguire, 1986) but only those women who had expressed no strong preference for a treatment were included in the study. Consequently fifty-three women were randomly allocated to mastectomy and forty-eight to breast conservation. Standardised interviews and questionnaires were used to assess psychological morbidity. These included the PSE, HAD scale and the Rotterdam Symptom Checklist. Overall levels of distress of 33% and 38 % for mastectomy and lumpectomy patients respectively were not significantly different but the lumpectomy group reported more worries about having had the 'wrong' operation and fears of the cancer recurring. This study has been criticised because of a possible source of bias in the selection procedure. Those women who report no strong preference for treatment may be a very select group and not representative of women with breast cancer in general. Furthermore, the data was gathered retrospectively with a range from four to thirty-two months after operation.

These criticisms were addressed by the authors in a prospective study (Fallowfield, Hall, Maguire & Baum, 1990). Two hundred and sixty-nine women with breast cancer referred by twenty-two different surgeons who favoured either mastectomy, breast conservation or choice of treatment were assessed over the first year after operation. Assessments were by standardised questionnaires including the HAD scale, Rotterdam Symptom Checklist and Spielberger State/Trait Anxiety Inventory. No significant differences were found between the levels of anxiety of mastectomy and lumpectomy patients. Anxiety levels in both groups fell from around 42% pre-operatively to 28% one year after operation. Levels of depression were slightly lower in the lumpectomy group but this difference was not significant. However, the patients who were offered a choice of treatment had significantly lower levels of psychological morbidity than the patients who were not offered choice. In addition, those patients within the whole sample who

felt that they had been well informed about their treatment were significantly less anxious or depressed. The authors suggest that a longer follow-up period is needed to establish whether these factors exert long-term effects.

1.2.4 Conclusion

Whilst a large number of the studies examining the association between type of primary treatment for early breast cancer and levels of post-operative psychological distress have been weakened by small numbers, retrospective design and non-standardised assessments, overall their conclusions are remarkably consistent. Levels of psychological morbidity in early breast cancer are high in both mastectomy and lumpectomy patients with the majority of studies finding no significant difference between the two groups. A number of authors therefore conclude that breast conservation does not protect women from the development of post-operative psychological morbidity and that the high levels of distress are engendered by the diagnosis of cancer rather than the effects of treatment. Consequently, patients treated by breast conservation techniques merit study and require as much counselling and concern as mastectomy patients.

Overall, the search for explanations for the high levels of distress experienced by women with breast cancer has not discovered obvious physical factors, and this has led to a development in research on the psychosocial factors which may contribute to the post-operative psychological adjustment. These will be reviewed in the following two chapters.

CHAPTER 2. COPING WITH CANCER: THEORY, METHODOLOGY AND FINDINGS

The absence of obvious physical factors to explain the distress experienced by women with breast cancer has meant that attention has turned to the psychological stress imposed by the diagnosis. It has long been acknowledged that stress affects the mental health of an individual and whilst correlations between levels of stress and psychological outcome have been consistent, they have also been modest. Therefore, it has been suggested that the individual's appraisal and coping responses to stress may be more important to well-being (Antonovsky, 1979; Lazarus, 1981).

The concept of coping has been strongly influenced by theories of stress. Traditional approaches to coping were formulated according to stimulus-based and psychoanalytic models which had distinct definitions of stress and the subsequent coping responses. Both theories provided some insight for the study of coping but were limited in their predictive power. A cognitive-phenomenological theory which aimed to study coping as a dynamic process was subsequently formulated in an attempt to address the limitations of the traditional approaches.

This chapter will examine each of these three approaches in terms of their definition of coping and subsequent influence on methods of measurement. The application of these methods in studying the effects of coping on psychological outcome in community samples and patients with breast cancer will then be considered. Finally, the association between coping and physical outcome in patients with cancer will be discussed.

2.1 DEFINITIONS OF COPING

2.1.1 Stimulus-based models

The stimulus-based approach to coping arose from Hans Selye's experiments with animals (Selye, 1976). Within this model stress is perceived as a stimulus, often consisting of a noxious agent or threatening event. Coping is defined as the subsequent response aimed at controlling the adverse environment and reducing the associated psychophysiological disturbance (Miller, 1980; Ursin, 1980). Because of the reliance on

animal experimentation and the conceptualisation of coping according to theories of stimulus-response, this definition simplifies coping into behavioral terms, taking little account of cognitive and emotional factors and appears to provide little insight into the complexity of human responses.

2.1.2 Psychoanalytic models

Psychoanalytic theories of coping ascribe less importance to an individual's behaviour, concentrating instead on thoughts (ego processes), specifically the ways in which a person thinks about their relationship with a stressful environment. Coping is defined as realistic and flexible ways of thinking and behaving aimed at problem solving and the alleviation of stress. Psychoanalytic theory further differentiates between types of responses, organising them along a hierarchy from mature strategies to immature responses which distort reality (Vaillant, 1977). The most mature and adaptive strategies, which acknowledge the existence of a problem and the need to change the situation or oneself, are termed 'coping'. Lower in the hierarchy come 'defences' which are deemed to be less adaptive, often unconscious processes, aimed at protecting the ego often by means of self-deception or the distortion of reality (Freud, 1946). Finally, at the least adaptive level are processes termed fragmentation or ego-failure (Haan, 1977), or alternatively described as regressive/psychotic levels of ego-functioning (Menninger, 1963).

Both the psychoanalytic and the stimulus-based approaches equate 'coping' with a successful outcome and this has been translated into the popular understanding of the term. A person who has 'coped' with a situation is perceived to have solved the problem or regulated their emotional response whilst 'not coping' implies failure. This is particularly apparent in psychoanalytic theories where 'coping' is distinguished from 'defences' by the adaptiveness of the outcome. Consequently the process of coping is confounded with the outcome of the coping response. Folkman and colleagues argue that the theoretical separation of coping efforts from outcomes is necessary if the coping construct is to be used to predict outcome, "conceptualisations that define coping in terms of a value or outcome tend to create a tautology, whereby the coping process is confounded with the outcomes it is used to explain" (Folkman, Lazarus, Dunkel-Schetter et al. 1986 p.993).

Similarly, traditional approaches tend to equate successful coping with mastery over a problematic environment. The main aim of coping is therefore perceived as problem-solving, particularly within stimulus-based models. These do not take into account those situations which are not amenable to change such as natural disasters or life threatening diseases. In addition, little importance is given to the regulation of emotion or maintenance of self-esteem.

2.1.3 Cognitive-phenomenological theories

In response to the limitations of the traditional approaches and their methods of measurement, Lazarus and Folkman (1984) proposed a cognitive theory of coping where stress is perceived as a mental construct; consequently a situation is stressful if the individual appraises it as threatening. Coping is defined as "constantly changing cognitive and behavioral efforts to manage specific external &/or internal demands that are appraised as taxing or exceeding the resources of the person" (p.141). This definition has since been widely applied in research on coping. All coping responses are included regardless of outcome thus avoiding prior assumptions about their success. It stresses the term 'manage' as distinct from the idea of mastery thereby including responses aimed at regulating the emotional response to stress as well as problem-solving.

Two further limitations of the traditional approaches are addressed with emphasis given to the importance of studying coping as a dynamic process as well as distinguishing between coping and automatic behaviour.

A process-oriented approach focuses on what a person is actually doing in a specific situation rather than studying what a person would usually do. It includes the context of the stressful situation, in order to provide information about the demands made on the individual. Furthermore it views coping as a transactional process which changes as the demands of the situation change rather than as a stable coping disposition favoured by the application of psychoanalytic theories.

Lazarus and Folkman also make the distinction between automatic and effortful responses, suggesting that coping responses require effort and occur in response to a new

or threatening event. In contrast, automatic adaptive behaviours are formed as a result of learning processes and occur in response to routine or non-threatening events. They suggest that coping may be important in the early stages of the acquisition of skills which subsequently become automatic responses with familiarity.

This theory identifies two processes of cognitive appraisal and coping responses. Cognitive appraisal involves a primary appraisal of the effect of a particular situation, for example, does the situation pose a threat to the physical or emotional well-being of the self or a loved one? This appraisal is informed by characteristics of the individual's personality including their values, goals and beliefs. Secondary appraisal involves an evaluation of the resources available to deal with the situation and possible methods for utilising these resources.

Coping refers to the actual cognitive and behavioral responses shown in a specific situation. It is suggested as having two main functions: Firstly, problem-focused which is aimed at dealing directly with the stressful problem such as leaving a stressful environment or seeking medical advice for an illness. The second function is emotion-focused and concentrates on the regulation of the emotions aroused by the distress, for example through avoidance of painful thoughts or relaxation techniques. These functions can facilitate each other, such as when a student facing an important exam regulates emotions of anxiety in order to facilitate the problem focused strategy of revision and study. Alternatively, the two functions may impede one another as when an individual denies the presence of a pain or a lump and so fails to obtain medical advice. Leventhal proposes a similar dichotomy of function (Leventhal, 1980), suggesting that an individual can focus on regulation of the danger being faced (problem-focused) or the fear which is aroused (emotion-focused). Pearlin and Schooler (1978) suggest that a third function involving manipulation of the meaning or implications of the stress in order to reduce its threat. Lazarus and Folkman discuss the manipulation of meaning but do not consider it a function of coping, perceiving it instead as a form of appraisal or 'reappraisal'. However, Ray and her co-workers (Ray, Lindop & Gibson, 1982) argue that all appraisals and reappraisals function as coping and that little is gained by attempting to distinguish between them.

2.2 MEASUREMENT OF COPING

2.2.1 Measurement of coping as a personality trait or style

The measurement of coping has been dominated by the psychoanalytic ego psychology models. These have been narrowly applied with the classification of individuals into particular types of coping dispositions. Coping is consequently viewed in terms of personality traits or styles and measurement often consists of scoring an individual along a continuum between two opposite coping responses such as approach/avoidance or repression/sensitisation (Byrne, 1964). The main difference between traits and styles is one of degree. Coping styles refer to broader ways of relating to people or situations such as a controlling or permissive style of response. Coping traits are narrower in scope, referring to particular characteristics of an individual's personality, for example denial-acceptance which refers to an individual's tendency to avoid or face up to the realities of the situation.

Implicit in the study of coping styles and traits is the assumption of consistency in responses. Coping responses are perceived as characteristics of a stable personality which dispose people to react in a certain way across all situations. Consequently, coping is assessed independently of a specific event often using questionnaire or projective techniques which ask about how the individual usually responds. For example, Andrew (Andrew, 1967; Andrew, 1970) used a general sentence completion task with patients awaiting surgery to assess the degree to which they used 'coping' (sensitising) or 'avoiding' (repressing) strategies. Results were used as a measure of how much the individuals would cope with or avoid the specific stress of surgery. Cohen and Lazarus (1979) argue that if this position were valid then research on coping would be simple. Once an individual trait is measured then responses to future stress could be accurately predicted. However there is little evidence of such predictive power and correlations between the measurement of traits and the actual behaviour observed have been weak or non-significant.

Cohen and Lazarus (1973) also studied surgical patients with regards to the amount of information they had received, as well as how much they had wanted to receive about their surgery. They employed a process measure to assess the specific thoughts and

behaviours exhibited in response to the situation as well as Byrne's trait measure of repression/sensitisation (Byrne, 1964). There was no correlation between the process and the trait measure, furthermore, the trait measure did not predict how people actually coped with the stress of surgery. Only the process measure predicted the speed and course of recovery with avoiders of information doing better than seekers of information.

Lazarus and Folkman (1984) argue that research attempting to assess consistency in coping across situations has been contradictory. They cite research by Gorzynski and co-workers (1970; in Lazarus and Folkman 1984). This reassessed 30 patients whose coping responses to a breast biopsy had been previously studied by Katz and colleagues (Katz, Weiner, Gallagher & Hellman, 1970). Use of the same assessment techniques showed a stability in coping responses and associated cortisol secretion rates, with "psychological defense patterns" remaining consistent with the earlier results in 9 out of 10 patients. Conversely, Pearlin and Schooler (1978) found little consistency in coping responses exhibited by individuals according to the stresses exerted within four different role areas; spouse, parent, householder provider and co-worker.

2.2.2 Measurement of coping as a process

The process oriented approach of Lazarus and colleagues does not completely reject the idea that there is some consistency in coping responses, suggesting instead that there is both stability and change. They argue that the measurement of coping traits underestimates its complexity, treating it as a uni-dimensional concept. Research has shown that stress imposes multiple demands. Moos and Tsu (1977) cogently describe the many different sources of stress of physical illness. Mages and Mendelsohn (1979) outline the changing demands of cancer in particular, as well as the variety of strategies used in response. Cohen and Lazarus (1979) suggest that this variability in coping processes "lends support to the argument that dispositional tests of coping provide inadequate measures of actual coping" (p.224). They argue that if the antecedents and consequences of coping are to be fully understood, then coping needs to be directly assessed within the context of the changing demands of the situation.

The process approach to coping often involves measurement by situational inventories.

These assess the strategies used in response to a specific stress such as the information-seeking exhibited by patients awaiting surgery as described above (Cohen & Lazarus, 1973). Some state theorists argue that coping is entirely situational, with no cross-situational personality characteristics. Thus, Mischel (1968) suggested that coping responses were not immutable aspects of personality which were expressed across situations, but were learned patterns of behaviour and that these were prompted by environmental cues. Other state theorists believe that this is an extreme view and accept the possibility of some stabilities in response.

2.2.3 Stages of coping

An early process view considered coping in terms of stages which described a series of demands imposed by a stressful situation evoking a general pattern of response. Some theorists outline various emotional stages which an individual must pass through before the stress can be resolved. For example, Kubler-Ross (1969) proposed a five stage framework of coping with dying in which the final stage is resolution and acceptance of the situation. These theories have been criticised for failing to explain the individual differences demonstrated in responses to the same situation. Shontz addressed this criticism in relation to the stages of coping with a serious physical illness or disability. Coping stages were suggested as consisting of shock and denial, then anxiety and helplessness, this is followed by retreat or denial again but is finally replaced by reality testing (Shontz, 1975). Individual differences are explained by a continual shifting between confrontation and retreat from the situation. A review of studies of the staged theory of response found the research to be limited and did not provide clear evidence for a series of stages in emotional and coping reactions to stress (Silver & Wortman, 1980). Instead the evidence tended to highlight the large amount of variability in responses rather than a consistent pattern, which reinforces the necessity for studying the actual coping responses as they occur in a specific situation.

2.2.4 Criticisms of the measurement of coping as a process

Assessment of the wide variety of strategies exhibited in response to stress is not without problems. The study of coping as a process entails an all inclusive approach (as opposed to restricting research to a limited number of traits) and results in difficulties in the

description and analysis of coping. Furthermore, situational inventories are often self-report and incorporate the inherent assumption that the respondents are conscious of the coping responses they are using and are able to operationalise them in the same terms used by the researcher. Singer (1984) suggests that discrepancies also occur between theorists as to what precisely is being measured because of ambiguities in the operationalisation of coping concepts, although these problems are not confined to cognitive or process theorists. Consequently, problems arise in comparisons between studies purporting to measure the same concept but which employ different methods of operationalising and assessing responses. In addition, the study of the coping process has resulted in a proliferation of scales measuring coping with specific stresses as well as multiple proposed factor structures for the same measure applied to different populations.

2.2.5 Theoretical versus empirical measures of coping

A further dichotomy in approaches to the measurement of coping occurs between scales which start from a theoretical base from which a list of coping strategies is formulated, and those which are derived empirically. Theoretically driven scales, such as the Ways of Coping Questionnaire (Folkman & Lazarus, 1980) devised within the framework of a cognitive-phenomenological approach to coping, have the advantage of being generalisable across a variety of situations and are useful for providing information on the ways in which the coping process works. Although such scales may contain a wide variety of strategies, they are unlikely to be exhaustive and may omit specific strategies which are exhibited within a particular situation. In contrast, scales which are derived from observations of responses to a specific stress such as Hackett and Cassem's Denial Scale for myocardial infarct patients (Hackett & Cassem, 1974) provide detailed information on how people cope with a specific situation. These are particularly useful to clinicians through the identification of responses which are important for adjustment but the results cannot be generalised to other stresses. The choice as outlined by Folkman (Folkman, Lazarus, Dunkel-Schetter, DeLongis & Gruen, 1986) is between "those that can be used with a variety of people in a variety of situations versus those that are richer in descriptive power, but limited to specific people in specific contexts" (p.1002). These and other problems in the measurement of coping are illustrated in the variety of results obtained in research on coping and outcome.

2.3 COPING AND OUTCOME

Coping is rarely studied in isolation. As its various definitions imply, coping is perceived as an intervening variable between a stress and an outcome, often termed adjustment. The study of the outcome of coping includes psychological outcomes such as anxiety or depression, or physical outcomes which are often researched in relation to recovery from illness. These will be discussed later in relation to cancer.

2.3.1 Psychological outcome

2.3.1.1 Avoidant coping and outcome

According to the psychoanalytic model, 'coping' by definition indicates a favourable outcome and 'defences' which involve a denial of the reality of the situation are associated with a poor outcome (Haan, 1977). This has since been countered with research which shows that responses of denial are adaptive for short term outcomes (Hackett & Cassem, 1973). A meta-analysis of avoidant versus non-avoidant strategies, including the trait measures of repression-sensitisation, illustrates this problem. Whilst an overall analysis discovered little evidence for the superiority of one strategy over the other with regards to both physical and psychological outcome, specific analyses on short and long term outcomes were more illuminating. Avoidance was associated with better outcomes in the short run but improved long term outcomes were related to vigilant responses (Suls & Fletcher, 1985).

2.3.1.2 Emotion focused versus problem focused coping

The process approach to coping has been widely applied in studies of the outcome of individual responses to severe life events, chronic stress and daily hassles. The difficulty of analysing a large number of specific coping strategies has been addressed by focusing on emotion versus problem focused coping responses. Previous investigations have shown that both types of coping are used in response to most stressful situations (Folkman & Lazarus, 1985; Folkman, Lazarus, Dunkel-Schetter et al., 1986) but in general, problem focused coping has been found to be adaptive in situations which were amenable to change whilst emotion focused responses were more effective in immutable situations.

Collins and colleagues (Collins, Baum & Singer, 1983) studied the chronic stress associated with living near the site of the nuclear accident at 3-mile island, using a control group of people living near an undamaged nuclear plant. They used Folkman and Lazarus' Ways of Coping Questionnaire (WCQ - Folkman & Lazarus, 1980) as well as adding two extra scales to specifically assess denial and reappraisal. Outcome was measured in terms of psychological, physical and emotional symptoms, performance on behavioral and motivational tasks and levels of catecholamine in urine. Significant associations between coping and outcome were only found in the group living near 3-mile island. Individuals employing more emotion focused strategies had fewer symptoms of distress whilst strategies aimed at trying to solve the problem were associated with increased symptoms. No differences were found on behavioral task performance or hormone levels. More detailed analyses showed that denial was associated with heightened distress and poorer concentration and motivation whilst reappraisal showed the opposite effect as well as lower urinary norepinephrine levels. The authors conclude that the most adaptive form of coping with chronic, immutable stress involves reappraisal and management of emotions, although emotion focused coping and reappraisal were highly correlated and may have been measuring the same construct.

Similar results were obtained by Forsythe and Compas (1987) in their study of the interaction of coping and major life events and chronic daily hassles in college students. They also used the WCQ in conjunction with a self-report assessment of the cognitive appraisal, rating cause of the event and the degree of control. Separate analyses of emotion and problem focused coping did not yield significant results, but analysis of the relative proportions of coping was more productive. Where perceived control was high and problem focused coping predominated over emotion focused coping, symptoms of distress were few. Conversely, high perceived control in conjunction with low levels of problem focused in relation to high emotion focused coping was related to increased distress. The reverse relationship applies with regards to low perceived control when higher proportions of emotion focused coping are more adaptive. This was only found in response to major life events. The mismatch between appraisals of control and coping responses did not appear as important in daily hassles. This research might be criticised for the theoretical distinction between appraisals and coping responses. It can be argued

that appraisals of control may themselves be considered as coping responses.

Both of the aforementioned studies employed cross-sectional designs which limits causal inferences about coping responses. Aldwin and Revenson (1987) addressed this problem in a longitudinal community survey assessing responses to the WCQ and their relation with psychological distress. Coping responses still explained a significant amount of the variance in distress after taking into account prior psychological symptoms. Two emotion focused strategies were found to have direct effects on outcome such that escapism and self-blame increased emotional distress. Problem focused strategies only showed interaction effects with instrumental action acting as a stress buffer. The other problem focused strategy, negotiation, decreased distress when the coping effort was perceived as successful but increased distress when the effort was not perceived as successful. The authors suggest that the difference in the effects of emotion and problem focused strategies may reflect the relative importance of personality and situational factors. Thus, how the emotional aspects of a situation are dealt with may be a function of the individual's personality whilst problem solving strategies are more likely to be a function of the environmental factors.

2.3.1.3 Coping and depression

An alternative method of examining the relationship between coping and psychological outcome involves the study of individuals who are currently experiencing psychological distress or psychiatric disorder. This has been applied to depressed patients in particular. McLean (1976) suggested that a "major difference between depressed and non-depressed persons is their manner of coping with and preventing stress" (p.313) and this view has been supported in a number of studies.

Coyne and coworkers (Coyne, Aldwin & Lazarus, 1981) conducted a study with community residing adults in order to provide data on how depressed subjects cope with the stresses of everyday life. The subjects were interviewed once a month for a year with regard to a stressful event experienced within the previous month. Coping was assessed using the Ways of Coping Questionnaire and the Hopkins Symptom Checklist was used to identify individuals with high ratings for symptoms of depression. Depressed

subjects were found to be significantly different from non-depressed subjects for both appraisals and coping responses. They tended to appraise situations as requiring more information before they would be able to take any action, but were less likely to make appraisals of acceptance. The coping responses of depressed subjects included more wishful thinking and seeking of emotional and informational support but they were not significantly different from non-depressed people in their use of problem focused coping or self-blame. In contrast, Billings and Moos (1984) found that depressed people made fewer efforts to solve problems than non-depressed people.

Folkman and Lazarus (1980) also conducted a prospective study examining the appraisal and coping of adults in the community. Seventy-five couples were interviewed monthly over a five month period and the CES-D scale was used to define depressed subjects who had a significant number of depressive symptoms but were not necessarily clinically depressed. A Stress Interview was used to gather information of primary appraisal (what was at stake) and secondary appraisal (options for coping) whilst the WCQ was used to assess the actual coping strategies used. Subjects with a high level of symptoms of depression were more vulnerable to feelings of threat such that they felt they had much more at stake in stressful situations and responded with more worry and fear than those subjects with few symptoms. Depressed subjects used more hostile coping responses and responses directed at self-control and self-blame as well as seeking more support but were not more likely to appraise situations as unchangeable or accept them.

These findings are consistent with cognitive theories of depression which propose that depressive feelings arise from a negative perception of the self and environment (Beck, 1967; Beck, 1976). The main tenet of these theories is that disturbed mood is preceded by disturbed cognitions, although this cannot be substantiated by the research of Folkman or Coyne and their colleagues. Despite the apparent prospective design of the research, neither one attempts to analyse the temporal sequence of coping and emotions, consequently causal direction cannot be ascertained.

Parry and Brewin (1988) state the aim of their study to be to search for evidence of the existence of prior cognitive vulnerability in people who become depressed after stress.

They conclude that their results support the alternative aetiologies model of depression such that disturbed mood can result from a severe life event or from a negative cognitive style but that the two do not have to present in conjunction as the vulnerability model suggests. However, once again such causal inferences are limited by the cross-sectional design.

Parker and colleagues (Parker, Brown & Blignault, 1986) conducted a prospective study to assess the affect of coping responses on pre-existing depression. The strongest association was between the use of responses of self-consolation, such as increased eating and drinking, and no improvement in levels of depression. Weaker associations were found between responses of distraction and a similarly poor outcome whilst responses of tension reduction were weakly associated with an improvement in depression. Personality factors such as locus of control did not predict the course of depression. The authors suggest that the study could be criticised for over-refining their coping questionnaire which was reduced from 24 questions to 6 subscales in a factor analysis. This questionnaire was derived from a review of the literature and from interviews with depressed and non-depressed individuals, but has not been validated by other studies. A further criticism of this study is that it did not take into account the effect of the psychotherapies which subjects were receiving.

2.4 COPING AND OUTCOME IN BREAST CANCER

Variation in the conceptualisation of coping and its subsequent measurement has meant that there is little consensus on the effect of coping on outcome in cancer. In addition, studies of coping in general populations have demonstrated that the type of problem can affect the relationship between coping and outcome (Pearlin & Schooler, 1978). The importance of this for the study of cancer is suggested by Jenkins and Pargament (1988) who argue that specific coping responses may be related to the degree of threat posed by specific cancer sites. Studies of heterogenous cancer populations or comparisons between studies of patients with different diagnoses may provide an additional reason for the inconsistency of results. Therefore the following presentation of findings will be restricted, as far as possible, to research with women with breast cancer.

2.4.1 Coping and psychological outcome in cancer

2.4.1.1 Psychoanalytic models of coping and psychological outcome

The development of theories and measures of coping in cancer have mirrored the development of research in the general population and its associated problems. Magarey and co-workers (Magarey, Todd & Blizard, 1977) conducted a focused and non-directive interview with ninety women with symptoms of breast disease from which they devised operational definitions of forty psychological variables. These were used to rate the use of classic ego defence coping responses according to the psychoanalytic definition of coping. Consequently, a priori assumptions were made about the adaptiveness of responses with the classification of responses into 'coping' or 'defences'. The use of these definitions subsequently confuses coping with outcome.

Research conducted by Weisman and Worden (1976) employed a measure of coping consisting of "fifteen broad types of behaviour frequently observed when people try to deal with a specific problem" (p.5). Unlike the list compiled by Magarey and colleagues, this list was insufficiently comprehensive and was not specific to the threat being faced by their subjects (diagnosis of cancer). Coping was again equated with success in the discussion where results are presented in terms of 'good' and 'poor' copers. Good copers, that is subjects who had low levels of mood disturbance and vulnerability, employed confrontation, redefinition (reappraisal) and compliance with authority in response to their diagnosis, whilst poor copers were stoically submissive and responded with suppression, passivity and tension-reduction.

2.4.1.2 Coping styles and psychological outcome

The psychoanalytic tradition has also resulted in a number of dispositional measures of coping in cancer where responses are assumed to be characteristic of a particular coping style. One of the most well known measures of coping styles was devised by Greer and co-workers (Greer, Morris & Pettingale, 1979) and was based on interviews with patients with breast cancer about their perception of the nature and seriousness of their diagnosis and how this had affected their lives. Their verbatim statements were then classified into four mutually exclusive categories of response; denial, fighting spirit, stoic

acceptance and helplessness/hopelessness, which were subsequently analysed in relation to physical morbidity. Dean (1987) employed this classification of coping in relation to psychiatric morbidity in a prospective study of 122 women with breast cancer. Patients who coped with denial had the lowest levels of psychiatric disorder, whilst fighting spirit and stoic acceptance were also associated with reduced mood disturbance. Limiting coping to the measurement of exclusive coping styles does not encompass the complexity of the coping strategies which might be used in response to a diagnosis of cancer. Furthermore, as has been previously argued, dispositional measures assume a consistency in responses.

An attempt to address these limitations with a systematic, semi-structured interview based on the cognitive-phenomenological theory of coping, failed to replicate the four coping styles described above (Burgess, Morris & Pettingale, 1988). Instead it was found that individual cancer patients used a variety of cognitive and behavioral responses which often reflected all four coping styles in one interview. A more detailed analysis of the interview found increased anxiety was associated with lower expectations of life and attributions of blame while decreased anxiety was related to responses of passive acceptance of the diagnosis, cognitive strategies to reduce its impact and some confronting responses. Greer and colleagues have since attempted to measure their four coping styles systematically in a self-rating questionnaire (Greer & Watson, 1987) but they concede that the questionnaire "was not intended to measure every conceivable psychological response a patient might have to the diagnosis of cancer. Instead it is confined to the response dimensions identified in our previous studies" (p.447). The measurement of denial proved to be a problem since only one question obtained statistical significance in a multivariate analysis of their data from 236 cancer patients. Denial was subsequently labelled 'avoidance' and an additional response category of anxious pre-occupation was included.

2.4.1.3 Individual coping strategies and psychological outcome

A number of other studies have been similarly limited by the range and relevance of the coping responses assessed. Orr and Meyer (1990) concentrated on assessing minimisation of the threat of disease in 49 breast cancer patients compared with 57 healthy controls.

Breast cancer patients consistently appraised diseases more optimistically than the control group and minimisation of threat was prospectively related to a better social adjustment. Hopkins (1985) examined the coping strategy of information seeking in breast cancer patients undergoing adjuvant chemotherapy treatment. Information seeking was found to be unrelated to adaptation as assessed by the Sickness Impact Profile and the Profile of Mood States. Coping has also been assessed indirectly through measures of social interaction and sense of control (Ell, Nishimoto, Morvay, Mantell & Hamovitch, 1988). Poor psychological adjustment as measured by the Mental Health Index was associated with a low sense of control and poor emotional support.

2.4.1.4 Denial and psychological outcome

Problems of definition also apply to single coping strategies. One of the most frequently studied responses in cancer is denial which has been related to both increased levels of distress (Weisman & Worden, 1977) and decreased mood disturbance in patients with breast cancer (Dean, 1987; Watson, Greer, Blake & Shrapnell, 1984). Weisman and Worden used the term 'denial' to include avoidance of the word "cancer", ignoring the disease, reluctance to talk about symptoms and minimising potential areas of threat. Watson and co-workers employed the definition given by Hackett and Cassem (1974) where denial is described as a measure used by patients "to reduce a threatening portion of reality in order to allow the person to function under less psychic stress" (p. 2008).

Lazarus and Folkman (1984) argue that denial, defined as a disavowal of reality, is often confused with avoidance where the reality of the illness is acknowledged but the individual chooses not to think about it. Breznitz (1983) further subdivides the concept of denial in an analysis which identified seven different kinds of denial including denial of information, threatening information, personal relevance, urgency, vulnerability-responsibility, affect and affect relevance. It is therefore not surprising that global measures of denial, which do not specify which precise aspects are being assessed, have been associated with both positive and negative mood outcomes.

Meyerowitz (1983) in a study of 113 breast cancer patients, employing an 18 page

questionnaire to assess coping and emotional responses in the previous month, found cancer specific denial to be associated with low distress. However, denial was defined as low cancer upset, consequently the coping response was confounded with the mood outcome being measured.

2.4.1.5 Cognitive-phenomenological approaches to coping and psychological outcome

Morris (1984) took a cognitive-phenomenological approach to the study of coping in cancer, employing a semi-structured interview to elicit detailed information on the specific cognitive and behavioral response used in the first post-operative year in 170 breast cancer patients. Results demonstrated that low levels of anxiety and depression were not associated with confronting responses or fighting spirit as had been expected, rather that a strategy of "selective ignoring" was associated with decreased distress. This involved concentrating on ways to make life more enjoyable and not attempting to change the immutable aspects of the disease. High levels of distress were correlated with individual attempts to try not to think about the diagnosis which subsequently failed to keep out painful emotions as well as an absence of cognitive strategies. Similar results were found when the WCQ was used in a study of chronic illness including cancer (Felton, Revenson & Hinrichson, 1984). Cognitive strategies including the seeking of information were associated with positive affect whilst emotion focused strategies such as avoidance, blame and emotional ventilation were related to negative affect.

Despite the current move towards research into coping as a process, many studies continue to employ cross-sectional designs. An investigation by Heim into the coping of 72 women with breast cancer and 79 women with benign breast disease highlighted the importance of a longitudinal design (Heim, 1991). Results demonstrated a variation in coping responses over time and their relationship with psychological outcome such that the responses assessed later in the course of the disease had a greater impact on well-being. Overall, high distress was associated with resignation (fatalism), social withdrawal, rumination or pre-occupation with thoughts of the disease and emotional release. Low levels of distress were related to dissimulation and isolation-suppression of emotion.

Felton and Revenson (1984) also employed a longitudinal investigation from which they conclude that coping and psychological outcome show a bi-directional relationship such that poor psychological adjustment was related in a vicious circle to the coping response of wish-fulfilling fantasy. Filipp and co-workers similarly questioned the assumption of a uniform causal direction between coping and adjustment (Filipp, Klauer, Freudenberg & Ferring, 1990). In a detailed analysis of 332 cancer patients they found that only one coping strategy, threat minimisation (including positive thinking and a compliant attitude) was predictive of an improvement in well-being over time. The search for affiliation was the only strategy which had a positive effect on levels of well-being assessed at the same time. Other strategies such as rumination (pre-occupation with disease and social withdrawal) were predicted by prior adjustment rather than vice versa such that low levels of well-being resulted in greater rumination.

2.4.1.6 Choice of outcome

Variation in the choice of outcome measure could provide a further explanation for inconsistent results between studies. For example, Bloom and Spiegel found denial and avoidance were related to a poorer outcome in contrast to the results of Watson and colleagues and Dean previously discussed (Dean, 1987; Watson, Greer, Blake & Shrapnell, 1984) where denial was associated with lower levels of mood disturbance. Apart from the differing conceptualisations of denial, the outcome measured by Bloom and Spiegel involved levels of social functioning as opposed to the psychological and psychiatric morbidity which was assessed by Watson and Dean respectively. Outcome measures in the study of coping with cancer have included compliance and self-esteem, self-report questionnaires on adjustment to illness, ratings of uncertainty, semi-structured interviews to assess emotions and Nurse's rating of adjustment (Ell, et al., 1988; Heim, 1991; Irvine & Brown, 1984; Jenkins, et al., 1988; Molleman, et al., 1984; Timko & Janoff-Bulman, 1985). In addition, coping in cancer patients has been studied in relation to its effect on the physical course of the disease.

2.4.2 Coping and physical outcome in cancer

There are numerous anecdotal reports of a relationship between patients' attitude towards their disease and subsequent disease outcome. Patients who survive for longer than

expected have been observed to have an attitude of fighting spirit whilst shorter survival has been associated with an attitude of fatalism and giving up (Stoll, 1979). Individual observations cannot be considered as scientific proof of an association between coping and prognosis, but many of the early attempts to examine this link systematically were inconclusive due to methodological shortcomings (Fox, 1982). For example, Achterberg and colleagues (Achterberg, Lawlis, Simonton & Matthews-Simonton, 1977) conducted a study with 126 cancer patients using well-validated methods of measuring psychological variables. Results demonstrated that a poorer prognosis was related to denial, a lack of fighting spirit and a significance dependence on others, but patients were only followed-up for two months.

Greer and Watson (1987) outline a number of methodological requirements for studies of the effect of coping on the prognosis of cancer. These include a prospective design, a consecutive series of randomly selected patients, standardised psychological tests or clearly specified clinical ratings of psychological variables, complete data on type and stage of cancer as well as treatment, an adequate follow-up period which should exceed 12 months at the least, and statistical analyses which take into account any correlations between known biological prognostic factors and the psychological variables.

Unfortunately, few studies conform to these specifications, including the most widely quoted research in this area which was conducted by Greer and his colleagues (Greer, Morris & Pettingale, 1979). The four coping styles previously described were assessed in 57 women with breast cancer, three months after operation. Follow-up assessments conducted five years later found that responses of denial and fighting spirit were significantly associated with longer recurrence free survival periods than responses of helplessness/hopelessness and stoic acceptance. They found no evidence to suggest that this difference was due to biological factors, since the patients in the different coping groups were similar in terms of clinical and prognostic factors. These results were confirmed at 10 year follow-up (Pettingale, Morris, Greer & Haybittle, 1985). Psychological responses were again found to be independent from prognostic variables and were the most significant factors in predicting recurrence or death. These results have to be interpreted cautiously due to the small number in the sample. In addition, two

important prognostic indicators of lymph nodes and hormone receptor status were not included in the analysis since methods for their measurement were not available when the study was conducted. Further criticisms include their measure of coping and the classification into mutually exclusive global categories of response which do not encompass the range of thoughts and behaviours exhibited by patients with breast cancer, as well as the timing of the assessment which took place three months after operation when the first stage of adjustment was over.

Whilst these findings were partially confirmed by research with malignant melanoma patients (DiClemente & Temoshok, 1985), another prospective study with patients with advanced breast cancer failed to find any association between helplessness/hopelessness and disease outcome (Cassileth, Lusk, Miller, Brown & Miller, 1985). It has been suggested that this inconsistency could be due to the use of different populations and measures of coping. A later study attempted to replicate these findings in a larger sample of both breast cancer, Hodgkins and non-Hodgkins lymphoma patients (Pettingale, Burgess & Greer, 1988). A semi-structured interview was employed to gather more detailed data on coping, and assessments were conducted at 3 and 12 months post operation. No significant associations were discovered between coping responses and the clinical and treatment variables in breast cancer although there were some significant findings with the lymphoma patients. The authors conclude that this supports their earlier findings since coping was not related to prognostic variables, therefore it must have an independent effect on outcome. However the follow-up period was too short to replicate the relationship of coping on recurrence or death. Despite the use of a detailed interview, responses were summed into three very broad groups which did not conform to the previous four styles.

Another study aimed at replicating Greer's original research was less supportive, Dean and Surtees (1989) also used a larger sample and included histological node status but they conducted pre-operative as well as post-operative assessments. Coping responses were categorised into four coping styles according to the methods employed in the original study. The disease outcome of 122 women with primary operable breast cancer were then reassessed 6-8 years after operation. Regression analyses were employed to

assess the predictive significance of the psychological variables after accounting for the effects of demographic, disease and treatment variables. Overall survival was found to be associated with pre-operative psychiatric symptoms of distress and denial measured at three months post-operation. Similar relationships were found with recurrence free survival, but unlike Greer's study, this was additionally related to pre-operative responses of helplessness/hopelessness and stoic acceptance. Thus, only the original finding regarding denial and a favourable outcome was confirmed. However, this relationship was dependent on when coping was measured, as responses were not consistent over time. The authors are tentative in their conclusions as they suggest that the final sample was still small and regression analyses had included a large number of variables which limits their significance. In addition, they concede that the measurement of coping is unsatisfactory.

2.4.3 Interaction between physical and psychological outcome in cancer

It has been suggested that coping may exert an indirect effect on physical outcome through an interaction with the associated emotional responses. For example, several studies have documented an association between expressed emotion and a favourable prognosis. Derogatis and colleagues (Derogatis, Abeloff & Melisartos, 1979) divided 35 women with metastatic breast cancer into short and long term survivors depending on whether they had died within one year of the baseline evaluation. These took place on the patients second visit to the outpatient department. Long term survivors exhibited significantly greater levels of anxiety, hostility and psychotic symptoms and were perceived as less well-adjusted and with more negative attitudes to their disease and treatment, as assessed by physicians, than the short term survivors. However, the study was flawed by the small sample size, non-inclusion of clinical variables in the analysis and apparently arbitrary assignment of survival categories. Short term survivors also had a significantly greater exposure to chemotherapy than long term survivors. Furthermore, analyses did not take into account the causal direction of the relationship, therefore it cannot be discounted that coping responses may have been caused by the progressive disease rather than the other way round.

The prospective study conducted by Dean and Surtees (1989) described above, provides

stronger evidence for a link between emotions and outcome. They noted that psychiatric status was associated with recurrence and survival such that the expression of distress was related to a better prognosis. It has been suggested that unexpressed emotion may produce an unfavourable biological reaction (Levy & Wise, 1988) and increased natural killer cell activity has been demonstrated in breast cancer patients exhibiting greater distress and maladjustment after operation (Levy, Herberman, Maluish, Schlien & Lippman, 1985). Thus, coping responses to a diagnosis of cancer may have an effect on the regulation of emotions for which there are endocrinological sequelae resulting in an effect on the prognosis of the disease. Magarey (1988) further suggests that psychological factors can have a more direct effect on disease outcome through early detection and compliance with treatment.

Recently, a study was conducted which conformed to all the methodological requirements outlined by Greer and Watson (1987) but which found no significant correlations between psychological variables, including coping, and course of disease (Buddeberg, Wolf, Sieber et al., 1991). Research was conducted on a consecutive series of 107 patients who had been treated for primary operable breast cancer six months earlier. Psychosocial data were collected using standardised measures every 3 months for the first year and then six monthly for the next two years. Somatic data were collected yearly and results have been reported from a three year follow-up. Individual analyses of coping responses demonstrated both stability and flexibility in responses. Whilst none of the coping responses predicted the course of disease, initial tumour size and histological node status were found to be significantly correlated with tumour stage 3 years later and an unfavourable prognosis.

These results highlight the criticisms of many of the studies of coping in cancer. The use of detailed analyses revealed that individual long-term coping processes show a wide-variability which cannot be assessed in studies of a limited range of coping responses or styles or through the use of a cross-sectional design. With regards to physical outcome, the authors conclude that "somatic parameters of breast cancer are much more important for the course of the disease than psychological aspects of coping" (p.156). They believe that studies which show a positive relationship between coping and

physical outcome are frequently methodologically flawed by small sample sizes, insufficient data on the somatic variables and incomplete follow-up data on psychological variables.

2.5 CONCLUSIONS

The influence of models of stress on the definition and measurement of coping has meant that some coping research has been restricted to limited coping traits or styles. These cannot fully reflect the diversity of responses needed to cope with the multiple stresses imposed by the diagnosis and treatment of breast cancer. Such dispositional definitions assume a consistency in responses across situations which is not supported in the coping literature. Other research has made a priori assumptions regarding the efficacy of certain coping strategies, thereby confounding coping with psychological outcome.

A cognitive approach to the study of coping as a dynamic process has attempted to take these criticisms into account. Coping responses are considered as cognitive and behavioural strategies to manage a situation which is appraised as stressful. All coping responses are included, regardless of efficacy. These responses are expected to vary as the demands of the situation changes. Consequently, the measurement of coping has tended to include a wide-range of strategies which can lead to difficulties in analysis. Furthermore, a larger number of coping responses can lead to ambiguities in their individual description and operationalisation.

Varying results have been found in the application of measures of coping to the study of psychological and physical outcomes from breast cancer. These can partly be explained by the choice of definition or measurement of coping strategies. Methodological problems such as small numbers, cross-sectional designs, length of follow-up and choice of outcome measures have contributed to the inconsistency of these results. Overall, there is some agreement that cognitive and behavioural strategies to cope with a stressful situation such as breast cancer have some effect on outcome.

CHAPTER 3: SOCIAL SUPPORT AND OTHER MEDIATING FACTORS IN PSYCHOLOGICAL ADJUSTMENT TO BREAST CANCER

In addition to coping responses, several socio-demographic and personal characteristics have been suggested as playing a mediating role in outcome after the diagnosis of a life-threatening disease. The support patients receive is believed to be crucial in helping them adjust to the disease. Furthermore, socio demographic factors such as social class, employment status, and age as well as personal factors including previous history of psychiatric treatment are considered as risk factors for post-surgical psychological morbidity. This chapter reviews the research on the relationship of each of these factors with both psychological and physical outcomes from breast cancer.

3.1 THE ROLE OF SOCIAL SUPPORT IN CANCER

3.1.1 Definitions and measurement

Social support is widely considered as having a beneficial effect on both physical and emotional health and empirical evidence has indeed shown that social support can reduce psychological morbidity in response to stressful situations within the general population (Billings & Moos, 1982; Brown & Harris, 1978; Kaplan, Robbins & Martin, 1983). Brown and Harris (1978) report extensive research on the relationship between social support and clinical depression in a population of women residing in the community. They found that social support provided by a confidante (usually a spouse or boyfriend) mitigated the effects of stressful life events or difficulties such that only 4% of women with a confidante experienced clinical levels of depression compared with 38% of those women with no confidante.

Despite the widespread acknowledgement of the beneficial effects of social support, studies of social support in cancer patients have been subject to similar criticisms as coping research. Specific criticisms include a lack of consensus regarding the definition and subsequent operationalisation of the concept of social support. Many of the early researchers failed to provide any specific definition and those definitions which were outlined were often imprecise or tautological (House, 1981). Subsequent operationalisations of the concept were varied, including aspects such as financial

resources, job satisfaction, social class, marital status and self-esteem. Furthermore, social support mirrored the problem with coping research in producing operational definitions which were confounded with outcome such as 'adaptability' (Thoits, 1982). Research into social support has also been criticised for the extensive use of cross-sectional designs, with conclusions about causal direction between support and physical or psychological outcome based on correlational data collected at a single time point. Conceptual and methodological difficulties in research on social support have been fully discussed in reviews on studies in the general population (Brownell & Schumaker, 1984; Turner, 1983) and specifically in relation to cancer (Bloom, 1982b; Broadhead & Kaplan, 1991; Vernon & Jackson, 1989; Wortman, 1984).

The importance of viewing social support as a multi-faceted concept is stressed by Bloom (Bloom, 1982b) because "the indicators may have different relations to outcome and as perceptual rather than behavioral because not all well-intended social exchange is perceived by the target as supportive" (p. 1331). Wortman, in her widely quoted review (Wortman, 1984), suggests that the researcher interested in studying the influence of social support needs to consider a number of questions which can be summarised as: who is providing the support (e.g. partner, friend, physician), what type of support is being provided (e.g. emotional, financial, informational), when the support is offered (in relation to disease stage) and what outcome measure is employed. A further decision is required as to whether available measures of social support should be employed or whether a specific scale for the particular cancer population should be devised. Different decisions on these questions have in part been responsible for the varying strength and direction of the relationship between social support and outcome that is found in the literature.

3.1.2 Social support and physical outcome

Examination of social support in relation to short-term recovery from surgery for breast cancer, in a retrospective study by Funch and Mettlin (1982), demonstrated a significant association with physical health. One hundred and fifty one patients were interviewed between three and twelve months after surgery regarding the availability of social, professional and financial support. Outcomes included the separate measurement of

physical recovery and psychological adjustment (discussed below). Physical recovery was significantly and positively related to financial support after controlling for socio-demographic and disease/treatment factors. However, the use of a retrospective design means that conclusions can only be tentative as the causal direction of the relationship between social support and health cannot be ascertained. It is possible that the diagnosis of a life threatening illness could effect the availability and perception of support.

An extensive review of the literature on social support and cancer by Vernon and Jackson (1989) provides evidence for an association with rates of mortality, although the results are not always consistent. The authors discuss a number of reasons for this inconsistency which include the use of retrospective data collection and the divergent definitions of social support, with some definitions consisting of marital status alone. Frequently, the concept was poorly operationalised, involving such diverse aspects as financial or tangible support, marital satisfaction and support from a confidante. Specific measures of support varied in each study, thus comparisons across studies are limited.

A meta-analysis examining the association between social support and physical health found that the overall effect of support on physical outcome was a small but negative one (Leppin & Schwarzer, 1990). Specific analyses of the type of support offered demonstrated larger effects such that actual support showed a stronger relationship than the mere existence of social relationships. Additionally, qualitative aspects of support (satisfaction) were found to have a greater impact on health than quantitative aspects (number of contacts). Practical support was also found to be more important than emotional support, which is not surprising when it is remembered that the outcome measure was one of physical rather than emotional health. It is suggested that emotional support may show a stronger relationship with emotional outcome. The authors outline a number of criticisms which again include the widespread use of cross-sectional designs and the consequent limitations for causal interpretation. A further criticism is of the lack of specific measures of support and their relationship with specific outcome measures as opposed to general indicators of health or illness. Reference is made to another meta-analysis by the authors (Schwarzer & Leppin, 1989) in which social support

demonstrated a stronger association with depression than physical health.

3.1.3 Social support and psychological outcome

The strong association between social support and distress has been further highlighted in research with patients with cancer. Funch and Mettlin (1984) demonstrated a significant and positive relationship between social and professional support and psychological adjustment in addition to the association between financial support and physical recovery discussed above.

The question of what type of support is perceived as the most beneficial has been specifically addressed in studies with cancer patients. Eighty-one percent of the patients responding to research by Dunkel-Schetter (1984) indicated that emotional support was perceived as most helpful, whilst 41% perceived informational support as somewhat helpful. Only 6% of respondents felt that tangible support was helpful. Dunkel-Schetter's research also examined the effect of who was providing the support. Interestingly, emotional support was perceived as helpful regardless of who provided it, i.e. partner, family or physician. The perceived helpfulness of tangible support was similarly unaffected by provider. In contrast, information and advice was perceived as helpful when provided by physicians or medical personnel but unhelpful if offered by family or friends. Other important providers of support include "some one person" who is a significant member of the supportive network (Abbey, Abramis & Caplan, 1981) or the presence of at least one intimate and dependable relationship which is perceived as critical for the psychological well-being of cancer patients (Lowenthal & Haven, 1986). These are similar to the importance of support provided by a confiding relationship as described by Brown and his colleagues (1978). Other cancer patients have also been shown to be an important source of informational and emotional support, the shared experience having a strong distance-reducing effect (Van den Borne, Pruyn & Van den Heuvel, 1987).

It has been argued that the context in which the support is offered has an influence on the relationship with outcome. Winnubst and colleagues (Winnubst, Couzijn & Ros, 1990) review research which demonstrates that the kind of support required by the cancer

patient varies according to their disease stage and the associated stresses and demands. Women with early breast cancer reported that the support from other patients was important for their post-surgical adjustment (Vachon, Lyall, Rogers, Cochrane & Freeman, 1982), whilst patients with a good prognosis required greater informational support than those with a poor prognosis (Gordon, et al., 1980). It is notable that whilst the effect of support appears to vary with the provider and the context of support, emotional support consistently remains an important source of support irrespective of who is providing it or when it is provided (Dunkell-Schetter, 1984).

Despite these positive findings, research on social support with patients with breast cancer does not always show an association with psychological outcome. In a recent study by Roberts and colleagues (Roberts, Cox, Shannon & Wells, 1994), moderate correlations between greater psychological distress and lower levels of social support were reduced or eliminated when the personality variable of social desirability was included. The authors conclude that characteristics of the person, rather than the stressful situation, underlie the apparent relationship between social support and psychological outcome.

3.1.4 Social support and interventions

Early evidence of a beneficial effect of social support on physical and emotional health prompted the development of a number of interventions designed to enhance the support received by patients. Bloom and colleagues (Bloom, Ross & Burnell, 1978) examined the effect of support provided by an oncology counsellor who offered information about cancer and its treatment as well as support to women with breast cancer from the time of diagnosis until two months after mastectomy. These were compared with a group of women not receiving this professional support. Whilst the supported group showed greater fluctuations in mood immediately after surgery, the two groups had comparable scores on a health locus of control scale. Two months after surgery, the treatment group reported increased feelings of effectiveness compared with the group which had received standard medical care.

Similarly positive results were reported by Spiegel in conjunction with Bloom & Yalom in 1981 which examined the effect of a social support group with women with metastatic

breast cancer (Spiegel, Bloom & Yalom, 1981). Patients were randomly assigned to a treatment or control group and followed up for one year. The treatment group participated in weekly group meetings and subsequently reported fewer feelings of tension, confusion and fatigue with increased vigour and fewer maladjusted coping responses and phobias than the control group. Spiegel and his colleagues subsequently followed up their participants ten years later in order to determine whether the support group had an effect on survival. Much to the surprise of the researchers, the mean survival time from randomisation for patients in the treatment group was 36.6 months (SD 37.6 months) compared with a significantly lower mean time of 18.9 months (SD 10.8 months) for the control group. This result is not without controversy and has been criticised for the lack of evidence of homogeneity for disease and treatment factors between the two groups. For example, the initial staging of the disease for the treatment group displayed less advanced disease progression. A number of studies have supported the suggestion that social support groups can help lower the levels of distress associated with cancer (Bloom & Ross, 1977; Ferlic, Goldman & Kennedy, 1979; Maisiak, Cain, Yarbrow & Josof, 1981). However, some of the evidence is ambiguous because of the failure to use an adequate control group (or any control group at all) or a longitudinal design. Furthermore, the combined use of informational and emotional support, such as in the study by Bloom and colleagues, make it difficult to evaluate which specific aspect of support is effective. Social support groups are often described as psychotherapy groups which indicate a confusion between support and teaching coping skills (including teaching hypnosis for the control of pain in the study by Spiegel and colleagues). Consequently, it becomes less certain whether it is the support aspect or the coping skills which produce the reduction in distress or improvement in physical recovery.

3.1.5 Social support and coping

Some researchers have attempted to examine the effects of social support and coping separately. Bloom (Bloom, 1982b) integrated research on coping and social support through the examination of the effects of support on psychological adjustment and whether coping mediated in this relationship. One hundred and thirty-one women with non-metastatic breast cancer were interviewed immediately after operation and two and a half years later. The measure of support included the collection of data on emotional

support, social affiliation (perception of social contact and amount of leisure activity) as well as the presence of a confidante. Coping was described in terms of nine negative coping behaviours such as increased smoking and drinking. Support was demonstrated as affecting adjustment via the effect on coping responses such that increased support was associated with fewer negative coping behaviours which were subsequently related to an increased self-concept, sense of power and decreased psychological distress. In addition, higher socio-economic status and employment had direct effects on self-concept and increased sense of power. Criticisms of the study include its restriction of the measurement of coping to nine behaviours as well as employing only one item each to assess the two aspects of perceived support.

Ell and her co-workers (Ell, Mantell, Hamovitch & Nishimoto, 1989) also sought to examine the association between social support and coping response as well as the severity of illness and personality characteristics. In addition, they attempted to assess the impact of support on outcome after taking these variables into account. They interviewed 369 newly diagnosed cancer patients (breast, colorectal and lung cancer) between 3 and 6 months after diagnosis with regard to the availability and perceived adequacy of close and distant social relationships. Measurements of coping responses were restricted to two dimensions after factor analysis; active reliance on religion and cognitive restructuring. In accordance with the literature previously reviewed they found that "the relationship between support and adaptation to cancer varied, depending on the specific dimension of support, the status of the patient's illness, and the specific outcome" (p.83). Specifically, well-being was influenced by the adequacy of attachment, whereas distress was associated with poor social integration. They conclude that social support has a significant independent effect on outcome and may provide an additional coping resource. Unlike Bloom's results, measures of social support showed only a weak association with coping responses whereas measures of personal control were highly correlated with coping. These two studies do not enable direct comparison because of differences in the sample populations as well as the use of very different measures of social support and coping. Neither study provided information regarding the direction of the association between support and outcome because of their cross-sectional designs.

3.1.6 Negative effects of social support

In spite of the apparently overwhelming evidence in favour of the positive effects of social support, a number of researchers point out that not all support is perceived as helpful, and that some forms of support can actually be detrimental for well-being. In the widely quoted review of social support and the cancer patient, Wortman (1984) quotes evidence that a significant amount of daily stresses arises from problems with social relationships, and an association between unpleasant social interactions and psychiatric morbidity has been reported (Fiore, Becker & Coppel, 1983; Henderson, Byrne, Duncan-Jones & al, 1978).

An over protective attitude and oversolicitous approach by carers can result in feelings of inadequacy and incompetence in patients as demonstrated by Peters-Golden (1982). The perceived social support of 100 women with breast cancer and the anticipated support of 100 disease free individuals were examined and results indicated that the healthy subjects would expect that cancer patients might be stigmatised and avoided, although they believed that if they had cancer themselves then they would be able to mobilise a dense network of support. The cancer patients reported the non-materialisation of expected support and subsequent problems with adjustment to their diagnosis. Furthermore, they stated that support was often inappropriately directed towards the loss of the breast when their main concern was the fact of having cancer, and that carers frequently avoided discussing the illness at all because it was perceived as unhealthy or indicating a lack of adjustment.

Dunkell-Schetter and Wortman review evidence which suggests that carers, such as family, friends and medical personnel, exhibit both positive and negative behaviours as a result of their conflicting feelings about cancer (Dunkell-Schetter & Wortman, 1982; Wortman, 1984). Consequently, the patient receives confusing messages from their support network and may sometimes be subjected to negative outbursts because of the strain of caring for someone with a life-threatening disease. Wortman points out the irony that whilst the diagnosis of cancer undoubtedly requires an increased level of social support, the fears and stigma associated with the disease and subsequent problems with communication mean that social relationships come under severe pressure and can be

undermined, thereby actually adding to levels of stress.

Winnubst and colleagues (Winnubst, Couzijn, & Ros 1990) discuss an additional problem for the cancer patient of an imbalance of power within social relationships. They favour a definition of social support which emphasises reciprocity in relationships with shared power and mutual obligations and argue that the patient is in a position of only partial reciprocity because of their illness, having moved from a relatively independent position to one of dependency. Therefore, the patient requires help but is unable to reciprocate and this can engender feelings of powerlessness and distress.

3.2 FURTHER MEDIATING FACTORS

Additional personal and demographic factors which have been suggested as affecting adjustment have included pre-operative mental state (Dean, 1987; Hughes, 1981; Morris, Greer & White, 1977), previous history of psychiatric treatment (Dean, 1987; Maunsell, Brisson & Deschenes, 1989) religion (Carey, 1974), recent severe life events (Maunsell, Brisson & Deschenes, 1989) as well as marital status, social class, age and employment status which were included in the study of social support and coping by Bloom (1982) and outlined above. Her results demonstrated a significant association between higher socio-economic status and employment and a raised self-concept and increased sense of power. Older women, being married, and increased time for leisure activities were also associated with lower levels of psychological distress, although these results were not statistically significant. Disease and treatment variables have been considered as possible mediating factors as discussed in chapter one.

The effects of personal and demographic variables on the physical outcome of breast cancer has also been examined. Marshall and Funch (1983) found that American women from higher social classes had greater rates of survival from breast cancer than women from lower social classes. These findings have been recently supported by a study examining survival rates of Finnish breast cancer patients (Karjalainen & Pukkala, 1990). The researchers linked the medical data for over 10,000 women from the Finnish Cancer Registry with their social status, based on their reported occupation in a census of 1970. Results showed that women from the lowest social class had 1.28 times the risk of cancer

death than those from social class I, after taking into account mortality from other causes, stage of disease and age at diagnosis. Examination of the data in relation to age found that differences in survival were greater in women who were post-menopausal and were hardly apparent in pre-menopausal women.

The patients' delay in first presenting to their Doctor has been proposed as an explanation for the difference in survival between social classes (Hackett, Cassem & Raker, 1973). Patients from higher social classes sought help significantly sooner than those from lower classes. Similarly, older patients may delay longer than young patients (Karjalainen, et al., 1989), thus accounting for the interrelationship between age and social class. Karjalainen and Pukkula concede that the differences in delay in their study could not be completely removed by controlling for stage of disease at diagnosis.

Other suggested reasons for the difference in survival rates relate to possible variations in treatment and follow-up and compliance with treatment. Hackett and colleagues (1973) noted that physicians tend to communicate differently with patients from different social classes. Patients from lower social classes tended to receive briefer and more simplified explanations and this may subsequently affect their compliance with treatment.

Age of the patient at diagnosis has been proposed as exerting an independent effect on the outcome in breast cancer such that older women appear to find it easier to adjust to the loss of a breast than younger women (Jamison, Wellisch & Pasnau, 1978). Further research indicates that these findings may be explained in terms of menopausal status rather than chronological age. Pre- and peri-menopausal women have been found to exhibit greater difficulty in coming to terms with mastectomy than women who are postmenopausal (Morris, Greer & White, 1977).

Dean (1987) examined a number of pre-operative predictors of psychiatric morbidity in 122 women following mastectomy. These included socio-demographic, psychosocial, coping, support, disease and treatment factors. A logistic regression analysis to predict psychiatric cases 12 months after operation found that marital status, social class, menopausal status and pre-operative mental state had significant, independent effects on

outcome. Previous history of psychiatric treatment was a significant risk factor in univariate analyses. It is noted that these factors are similar to those found to be associated with high risk of psychiatric morbidity in a random community sample (Surtees, Dean, Ingham et al., 1983) which suggest that they are not specific to women with breast cancer but may operate in the presence of any severe life event.

Maunsell and associates conducted a similar, longitudinal study on a larger cohort of patients in Canada (Maunsell, et al., 1989). A history of psychological problems was again found to be a risk factor for psychological distress at 3 and 18 months after surgery, disease stage at diagnosis predicted distress only at 18 months. In addition, the effect of severe life events in the past five years was examined. The experience of a high number of severe life events was found to be a further risk factor for post-surgical distress. Life events have also been associated with physical outcome in cancer. A retrospective study by Ramirez and colleagues (Ramirez, et al. 1989) demonstrated a significant relationship between life events and first recurrence in women with breast cancer.

3.3 CONCLUSIONS

Despite conceptual and methodological problems, overall the literature on social support and the cancer patient suggests that the presence of support can ameliorate the detrimental physical and emotional effects of the diagnosis of a life-threatening disease. The actual relationship between social support and outcome is dependent on which aspect of support being measured. This includes consideration of who provides the support, what form of support is provided and when it is offered. Both Wortman (1984) and Winnubst and colleagues (1990) further emphasis the importance of the ability of the cancer patient to actually mobilise their support network. Winnubst states that while "the presence of a social network in itself has positive effects, it is the ability to mobilise the support system which really counts in time of personal crisis" (p.209). Thus, social support and coping skills are inextricably linked and whilst one may be given more emphasis, each one needs to be given consideration in research on the emotional outcome of a diagnosis of cancer. Clinical evidence demonstrates that demographic and other personal variables must be considered as possibly exerting an additive or independent effect on outcome.

CHAPTER 4: CONCLUSIONS FROM THE REVIEW OF THE LITERATURE AND IMPLICATIONS FOR THE CURRENT STUDY

A review of the literature on the psychological aspects of breast cancer enables a number of questions to be posed. These include the fundamental question of why it is important to assess the psychosocial outcome of patients which is highlighted by the prevalence of distress. Further questions include which variables determine the outcome of diagnosis and treatment and what reasons account for inconsistency in previous findings. The answers to these questions have implications for future research and provide the basis for the current study.

4.1 The importance of psychological outcome in breast cancer.

Cancer has a direct or indirect effect on almost everyone in the general population. The widespread frequency of the disease means that most people either know someone who has been diagnosed with cancer, or will be so diagnosed themselves. Consequently it is the subject of both general and scientific interest. Cancer can affect a wide range of body sites and patients are extremely heterogeneous in terms of their prognosis and treatment. Examination of factors associated with the outcome of the disease requires as homogeneous group of patients as possible in order to minimise the effects of the primary tumour site or radically different treatments. Therefore it is preferable to restrict research to the study of one specific cancer site.

Unlike a number of other cancers which are associated with increasing age, breast cancer affects a wide age range. It is the most common form of cancer in women, affecting one woman in every twelve and provides a large and important area of research. It has been suggested (Kaplan, 1990) that research in Health Psychology has attempted to justify itself through demonstrating an association between psychological variables and a physical outcome such as recovery after surgery or time until recurrence or death. Recent improvements in treatment have meant that 50% of women diagnosed with breast cancer will survive at least 10 years, and there is now a greater number of women who are living with breast cancer rather than dying

from it. Yet the process of diagnosis and subsequent treatment remains a source of considerable psychological stress. It is therefore increasingly important to study psychosocial factors as outcome variables.

Studies of the prevalence of psychological disturbance in women with breast cancer have resulted in figures of between 6-36% depending on the severity of the distress and the method of assessment. The majority of studies found that around 25% of women with breast cancer experienced clinically significant symptoms of anxiety and depression, whilst a measure of milder symptoms found a higher prevalence. This research has been criticised for a lack of homogeneity in samples, with inclusion of a range of disease stages and treatments, as well as a lack of standardised and comparable measures.

Previously, research has tended to concentrate on measures of psychopathology, with particular emphasis on clinical levels of anxiety and depression. It has been suggested that a wider range of mood states, including positive psychological outcomes which are experienced by a greater number of women merit further examination. Consequently, the current study incorporates two standardised measures of psychological outcome. The first gathers data on severe symptoms of anxiety and depression which have clinical implications for treatment. In addition, a second broader measure of a range of positive and negative mood states is employed.

4.2 FACTORS ASSOCIATED WITH PSYCHOLOGICAL OUTCOME

4.2.1 Disease and treatment

Individual differences in response to the diagnosis and treatment of breast cancer were initially thought to be determined by physical factors such as the severity of the illness, but research demonstrated only a weak association. It was further believed that these differences could be related to the extent of the surgical intervention, yet the majority of studies reviewed failed to find a significant difference between the distress experienced by mastectomy and conservation patients. A number of authors concluded that the psychological morbidity was associated with the diagnosis of a potentially life threatening disease, rather than the specific effects of treatment.

Consequently, the current research includes a mixed group of patients in terms of surgical treatment, although of similar disease stage and prognosis. However, a small number of studies did find an effect according to surgical treatment, such that mastectomy patients appeared to be at greater risk of experiencing problems related to their body image, whilst patients treated by conservation techniques demonstrated increased fear of recurrence. Therefore, analysis of the factors which affect psychosocial outcome in the current study will include an examination of the possible effect of type of surgery .

4.2.2 Coping responses

With the failure of physical factors to explain a significant amount of the variation in psychosocial morbidity, attention focused on psychological variables. Stress literature suggested that the individual thoughts and behaviours (coping responses) played an important role in ameliorating the effect of severe stress on subsequent mood. Importantly, the identification of the effects of coping responses offers an opportunity to intervene in order to reduce levels of psychosocial morbidity.

Findings in relation to the effects of coping within research on breast cancer have been mixed. There is some consensus that active responses such as confrontation (or fighting spirit), seeking information and cognitive reappraisal as well as acceptance of the diagnosis are associated with lower levels of distress. Conversely, passive responses including resignation, preoccupation, suppression of thoughts, low sense of control and social withdrawal are associated with increased symptoms of anxiety and depression. A combination of responses, such as those termed 'selective ignoring', which include an avoidance of thoughts about the implications of the diagnosis and a positive appraisal of other aspects of life, have been related to a better psychological outcome. Other responses, such as denial, have been related to both positive and negative mood outcomes. Research on coping in relation to physical outcome discovered a similar pattern such that fighting spirit was associated with improved prognosis whilst fatalism and dependence were associated with shorter disease free intervals. Denial, helplessness and stoic acceptance were found to be related to both improved and worsened prognoses. One prospective study found that

coping had no significant effect on physical outcome.

4.2.3 Explanations for inconsistencies in the effects of coping.

It has been proposed that contradictory findings in relation to the outcome of coping with cancer are a result of the wide variation in the definition of coping responses and their subsequent measurement, as well as methodological problems inherent in the design of a number of studies.

4.2.3.1 Definitions of coping

Early definitions of coping tended to be in terms of successful methods of alleviating stress. The stimulus-based model was based on animal experiments examining responses which successfully avoided a stressful stimulus, where coping was largely defined in behavioral terms. The psychoanalytic model, which has had a greater influence on conceptualisation and measurement, defined adaptive responses (both thoughts and behaviours) as 'coping' whilst unsuccessful methods were termed 'defences'. Such definitions in terms of success limit the study of the association between coping and outcome, since they contain a priori judgements regarding the effect of the response. Furthermore, both the psychoanalytic and stimulus-based models focus on coping as responses aimed at problem-solving, rather than the regulation of emotion. This restricts the examination of situations which are not amenable to problem-solving techniques or change, including the diagnosis of a potentially terminal disease such as breast cancer.

A staged model of coping has been outlined which attempts to explain the changing nature of coping responses in respect of the changing demands of the situation. This has been found to be too restrictive and there is little evidence to support a staged series of responses; rather research has highlighted the wide variation in coping.

The current study employs the cognitive model of coping as the theoretical base. This was formulated in an attempt to overcome the criticisms of previous models and has been widely applied in the study of coping with cancers thus enabling comparisons with other findings. This definition of coping includes all responses,

both cognitive and behavioral, regardless of their outcome. It views coping as a process which is constantly changing in accordance with the changing demands of a specific situation. The aim is to manage the stress caused by the situation, including the emotional reactions, as opposed to mastering or solving the cause of the stress.

4.2.3.2 Measurement of coping

The measurement of coping has been largely influenced by the model employed. Thus the stimulus-based model concentrates on the assessment of coping behaviours, whilst the psychodynamic approach has tended to assess coping in terms of relatively enduring modes of responding to a variety of situations, akin to personality traits. A review of the research using trait measures has demonstrated a lack of consistency in responses to different situations. In addition, correlations between these measures and the observed behaviour have been low. Cognitive theorists conclude that dispositional measures of coping do not enable the assessment of the complexities of responses. They propose that these can only be understood through the use of process measures, which enable the direct assessment of coping within a specific situation.

A number of process measures have been devised, including both self-report and interviews. These can be further sub-divided into theoretically driven scales as against empirically derived measures. The former enable the comparison of responses across a variety of situations whilst the latter provide more detailed information about the coping responses within a specific stressful situation. Folkman and colleagues (Folkman, Lazarus, Dunkel-Schetter et al, 1986) summarised this dichotomy in choice as between "those that can be used with a variety of people in a variety of situations versus those that are richer in descriptive power, but limited to specific people in specific contexts" (p.1002). However, these measures are not necessarily mutually exclusive and it is possible to employ both a theoretically and an empirically derived measure. Consequently, the current study employs a standardised, process measure of coping, which has been used with breast cancer patients and enables cross-study comparisons. In addition, a semi-structured interview, which was devised specifically

for women with breast cancer, is used to gather detailed and specific descriptions of the cognitions and behaviours in breast cancer patients.

4.2.3.3 Methodology

Methodological problems are apparent throughout the review of the literature. These include small sample size and a lack of standardised measures of both coping and psychological outcome. An important requirement in the examination of the effect of factors on psychosocial outcome is the ability to assess the direction of causality. It has been suggested that some coping responses may show a bi-directional relationship with psychological adjustment, but the widespread use of retrospective and cross-sectional designs necessarily limits the assessment of causal direction. Therefore the current study is prospective in design, with the first assessment occurring prior to surgical treatment and with a one year follow-up.

4.3 FURTHER FACTORS ASSOCIATED WITH PSYCHOLOGICAL OUTCOME

Early research on the prevalence of distress found that a number of psychosocial variables were related to the degree of mood disturbance, but these results were largely from retrospective designs. Two prospective studies have also demonstrated an effect on both psychological and physical outcome of psychosocial variables which included pre-operative mental state, marital status, a previous history of psychological treatment, social class and age (or menopausal status). Many of these variables are similar to risk factors for psychiatric morbidity after a severe life event in the general population. This finding, whilst undoubtedly important, does not offer an opportunity to reduce distress since factors such as age are not amenable to change.

Research in the general population has also demonstrated the beneficial effects of social support in protecting the individual from raised levels of psychological morbidity after a stressful life event. The study of the effects of social support in breast cancer has been subject to similar criticisms as research on coping, namely the variety of definitions, measures and methodologies employed. Overall, the effect of social support appears to be associated with who is providing the support, what sort

of support is provided and when it is provided in relation to disease stage. Not all intended support is actually perceived as supportive by the recipient. In general, emotional support and support from a close confidante appear to have a positive effect regardless of when it is provided. A number of authors suggest that the effect of social support is inextricably linked to coping responses which enable the mobilisation of the available social resources. Thus social support and coping should be assessed in conjunction.

4.4 SUMMARY

A review of the literature highlights the importance of studying psychological outcome after the diagnosis and treatment of breast cancer. Factors which may influence such outcomes include the individual cognitive and behavioral response, social support, age, social class, previous psychological treatment and pre-operative mental state. In addition, disease and treatment factors should be included in analyses. These need to be assessed prospectively, using standardised and validated measures in order to enable the examination of the direction of effect between these variables and standardised measures of clinically significant symptoms of distress as well as general mood states. The current study emphasises the examination of coping responses since they provide an opportunity for intervention at the level of the individual patient in order to facilitate improved psychological outcomes.

CHAPTER 5: AIMS OF CURRENT RESEARCH AND RESEARCH DESIGN

5.1 AIMS

As a consequence of the review of the literature the current study has three general aims. The first is to describe and explore the cognitive and behavioral responses to early breast cancer and the associated mood states. The second aim is to examine the association between a number of psychosocial and physical variables and the measures of mood made at the same assessment. Third, it aims to examine the relationship between coping responses, psychosocial and physical variables with concurrent and subsequent measures of mood. Specifically the aims are as follows:

5.1.1 Exploration and description

- * To describe the specific thoughts and behaviours used in response to the diagnosis treatment of early breast cancer.
- * To examine the distribution of these responses and how they vary over the first post-operative year.
- * To assess the prevalence of clinical levels of anxiety and depression as well as the pattern of mood states over the first post-operative year.

5.1.2 Cross-sectional analyses

These aim to examine the relationships between:

- * Cognitive and behavioral responses and measures of mood at the same assessment.
- * Social support provided by a confidante and measures of mood at the same assessment.
- * Current treatment and measures of mood at the same assessment.

5.1.3 Longitudinal analyses

These aim to examine the relationship between:

- * Cognitive and behavioral responses and measures of mood at different assessments, i.e. the effect of coping responses on subsequent measures of mood.
- * Social support from a confidante and measures of mood at subsequent

assessments.

* Disease and treatment factors and subsequent measures of mood.

* Psychosocial variables and subsequent measures of mood. These variables include age and menopausal status at diagnosis, social class, occupation and a previous history of psychological treatment.

5.2 HYPOTHESES

On the basis of previous research, the following specific hypotheses will be tested:

5.2.1 Cognitive and behavioral responses

- Active coping responses such as cognitive reappraisal and seeking information will be associated with lower levels of mood disturbance.
- Passive coping responses such as resignation, social withdrawal and preoccupation with thoughts of the disease will be associated with increased mood disturbance.
- Initial avoidance of the stressful aspects of the diagnosis will be associated with decreased mood disturbance.
- The number of women reporting the use of cognitive and behavioural responses to coping with their disease will decrease over the first post-operative year. Post-operative coping responses will show a larger number of associations with concurrent and subsequent measures of mood than pre-operative coping responses.
- An indiscriminate use of a wide range of responses will be associated with greater mood disturbance.

5.2.2 Social support from a confidante

- Positive emotional support from a confidante will be associated with lower levels of mood disturbance.
- The receipt of negative support (e.g. critical comments) from a confidante will be associated with increased mood disturbance.

5.2.3 Further mediating factors

- High preoperative levels of mood disturbance will be associated with increased mood disturbance after operation.

- No association will be found between type of surgery and measures of mood.
- Women undergoing adjuvant chemotherapy will experience higher levels of mood disturbance than those not undergoing chemotherapy.
- The following psychosocial variables will be associated with increased mood disturbance; young age at diagnosis, lower social class, unmarried (including widowed or divorced) and a previous history of psychological treatment.

5.3 RESEARCH DESIGN

The present investigation will be based on a correlational study which makes use of cross-sectional and prospective designs, employing a single, large cohort of women with early breast cancer. Repeated observations are made on three occasions on several psychosocial factors and there is no direct experimental manipulation of variables. The use of repeated measures enables comparisons to be made within the group and there are no independent controls. Repeated measures also enable comparisons over time.

Measures of mood are employed as dependent variables. Independent variables include cognitive and behavioral responses to diagnosis and treatment, social support from a confidante, disease and treatment factors, psychosocial factors such as age and social class. Possible confounding variables such as disease stage, prognosis and associated treatment are controlled for by the use of a consecutive series of women with a clinical diagnosis of early breast cancer.

Women will be grouped on the basis of their scores on specific measures and between-group analyses will be performed. Parametric and non-parametric univariate analyses will be used to examine the relationships between each independent variable and concurrent assessments of mood. Multivariate regression analyses will be used to determine which of the independent variables make a significant contribution to the prediction of mood scores over time, after controlling for previous mood.

In order to develop these aims, it was felt to be necessary to adapt existing measures of coping. Hence, a further aim of the study was to develop measures which were appropriate for use with women with breast cancer. This methodological development is described in the next chapter.

CHAPTER 6: ADAPTATION AND DEVELOPMENT OF TWO MEASURES OF COPING FOR WOMEN WITH BREAST CANCER

The review of the literature on coping highlighted two main criticisms of previous research, namely the definition of coping and the lack of a standardised, situation-specific method of measurement, which need to be addressed before the association of coping responses and psychosocial outcome can be examined in the prospective study. This chapter describes the development of two pre-existing measures of coping to provide assessments which are appropriate for use with a population of women with breast cancer. This has been published under the title 'Measuring Coping in Breast Cancer' (Jarrett, Ramirez, Richards & Weinman, 1992) which can be found in appendix 1.

6.1 INTRODUCTION

Discussion of the competing models of coping in chapter two led to the conclusion that the cognitive model of coping as outlined by Lazarus and Folkman (1984) was the most applicable in the study of responses to the diagnosis and treatment of breast cancer. Coping is defined as "the person's constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person."(p.141). The inclusion of all coping responses, without a priori judgements regarding their success, enables the assessment of coping in relation to psychosocial outcome. In addition, the view of coping as a dynamic process which can change in accordance with the changing demands of the situation as well as the emphasis on the function of coping as one of management as opposed to problem-solving is appropriate for the study of breast cancer where the stresses change over the course of diagnosis and treatment and are not amenable to personal control or mastery.

An equally important decision in the study of coping involves the choice of measurement. Thus, comparisons between studies have been inconsistent and limited by the failure to employ a standardised measure, whilst those studies which have used systematic assessments of coping have been criticised for failing to assess the responses which may be specific to a particular stress such as the diagnosis of breast cancer. This choice can

be characterised by the choice between a theoretically driven or an empirically driven scale, but as concluded in chapter four, the use of these scales does not have to be mutually exclusive, rather the use of both types of assessment can provide complementary information. Two such measures have been employed separately in previous studies with patients with breast cancer and have the advantage of sharing the same theoretical base taken from cognitive models of coping.

The first is the standardised Ways of Coping Questionnaire which was developed by Folkman and Lazarus (1980). This describes a wide range of cognitive and behavioral strategies which may be used in response to a specified stressful situation. The identification of coherent groups of items by factor analysis has produced varying factor structures in different populations (Aldwin, Folkman, Scheafer, Coyne & Lazarus, 1980; Aldwin & Revenson, 1987; Folkman & Lazarus, 1986; Vitaliano, Russo, Maiuro & Becker, 1985). However, its use with patients who have cancer suggests some relationship between specific ways of coping and emotional well-being (Felton & Revenson, 1984; Hilton, 1989).

The second measure is a systematic, semi-structured interview which was developed for use with women with breast cancer in an attempt to replicate the research by Greer and his colleagues (Greer, Morris & Pettingale, 1979). The Faith Courtauld Schedule for Coping with Cancer (Morris, Blake & Buckley, 1985) was largely unsuccessful in reproducing these four styles of coping (Burgess, Morris & Pettingale, 1988). Instead it was found that individual patients with cancer used a variety of cognitive and behavioral responses which often reflected all four coping styles in one interview. The large number of possible coping responses within the schedule limited further analysis and interpretation of the data.

The use of both a specific interview and standardised questionnaire to measure coping enabled both the collection of detailed data regarding the responses of women with breast cancer as well as comparisons with the results from other studies. However, these measures are not without problems. The adaptation of the WCQ and Faith Courtauld Schedule for Coping with Cancer in the development of a situation-specific approach to

the measurement of coping in women with breast cancer will be described, and comparisons between the information provided by both the interview and questionnaire methods of measurement will be made.

6.2 ADAPTATION AND USE OF THE WCQ

The WCQ was originally designed for use with a general population and contained 66 self-report items. These comprised cognitive and behavioral responses which may be employed in a stressful situation which is specified by the researcher or respondent before completion of the questionnaire. On examination of the original scale, some of the items were considered to be inappropriate for patients with breast cancer (e.g. "I tried to get the person responsible to change their mind"). The questionnaire was therefore modified by asking ten professionals, involved in the care of breast cancer patients, to rate each of the items on the WCQ for its acceptability or appropriateness to patients with cancer. An agreement of 50% or more on the unacceptability or inappropriateness of an item led to its removal. Thirteen items which mainly described efforts to remove or change the source of the stress, namely the cancer, were consequently eliminated (table 6.1).

6.2.1 Patients and method

The modified 53-item WCQ was completed by one hundred and fifty three women who had been treated for early breast cancer and who were attending their routine follow-up outpatient appointments. The first fifty questionnaires were given to patients by the researcher who remained available whilst they were being completed in order to answer any queries and to collect the respondents comments about the questionnaire. Since the aim of the study was to evaluate the questionnaire, detailed information about the participants was not collected except for the ages and time since diagnosis for the first fifty women. The remaining questionnaires were completed anonymously by women attending the outpatient clinic who were given the questionnaires by the reception staff, since it was not possible for the researcher to be present during completion of all the questionnaires. Data on the number of women offered the questionnaire and the number refusing were not collected, although the refusal rate amongst the first fifty women was very low with only two women declining to complete the questionnaire.

Table 6.1: Items considered to be unacceptable/inappropriate for patients with breast cancer

Items removed from the WCQ
I bargained or compromised to get something positive from the situation
I tried to get the person responsible to change their mind
I tried not to burn my bridges, but leave things open somewhat
I expressed anger to the person who caused the problem
I apologised or did something to make up
I accepted the next best thing to what I wanted
I took a big chance or did something very risky to solve the problem
I changed something so things would turn out alright
I stood my ground and fought for what I wanted
I drew on past experiences, I was in a similar position before
I promised myself things would be different next time
I came up with a couple of different solutions to the problem
I tried to see things from the other persons point of view

All patients were in remission at the time of the study and data from the first fifty women indicated that remission times ranged from around nine months to ten years according to self-report. The modified WCQ asked the women to reply in terms of the responses they were currently employing to cope with their diagnosis and treatment.

6.2.2 Analyses and results

Frequency analyses were performed for all 53 items of the modified questionnaire. Multivariate analysis comprised a principal components analysis with mean substitution for missing data using the Statistical Package for Social Scientists (Norusis, 1985). The BioMedical Data Package was used to perform a cluster analysis with median substitution for missing data and minimum distance (single linkage) rules for amalgamation of clusters (Hartigan, 1985). BMDP was also employed for a factor analysis with median

substitution for missing data and orthogonal rotation. Kaiser's criterion was used for factor selection whereby factors were retained if they had an eigenvalue greater than or equal to 1 (Frane, Jennrich & Sampson, 1985).

Frequency analysis showed that the distribution of the questionnaire scores was skewed. Over 70% of women identified 9 of the 53 ways of coping as responses they used 'sometimes' or 'a lot'. These items reflected cognitive avoidance, positive reappraisal of their illness and life, control of emotional expression and concentration on aspects of the disease over which they have some control (table 6.2). The pattern of scores for each item is given in appendix 2.

Table 6.2: Items from the adapted WCQ to which over 70% of women responded as used 'sometimes' or 'a lot'

Items from the adapted WCQ	Frequency %
I remind myself how much worse things could be	88.0
I try to improve my general health	87.3
I look for the silver lining, try to look on the bright side of things	85.6
I try to keep my feelings from interfering with other things too much	77.3
I maintain my pride and keep a stiff upper lip	77.3
I know what has to be done so I double my efforts to make things work	76.2
I try to keep my feelings to myself	76.0
I try to rediscover what is important in life	75.3
I go on as if nothing has happened	74.2

In addition there were a number of ways of coping which the majority of women did not use. Over 70% identified 10 of the 53 items which they used 'never' or only 'occasionally' (table 6.3). These included strategies of wishful thinking, social avoidance and blaming of self or others.

Examination of the responses of individual women identified a group who used very few ways of coping. Thus 9 women responded to more than 35 of the 53 items as 'not used'. This cut-off was equal to two standard deviations or more above the mean number of questions answered as 'not used'. The items which they reported using comprised a similar pattern to the one described by Pearlin and Schooler (1978) and Morris (1984), consisting mainly of strategies of cognitive avoidance e.g. "I try to forget the whole

Table 6.3: Items from the adapted WCQ to which over 70% of women responded as 'not used' or used 'occasionally'

Item from the adapted WCQ	Frequency %
I take it out on other people	91.5
I think I brought the problem on myself	
I generally avoid being with people	87.2
I refuse to believe it's happened	85.4
I have fantasies or wishes about how things may turn out	84.2
I daydream or imagine a better time or place than the one I am in	77.0
I have found new faith	75.5
I do something which I don't think will work but at least I am doing something	74.5
I think about how a person I admire would handle the situation and use it as a model	72.0
I try to make myself feel better by eating, drinking or smoking etc	71.2
	70.2

thing" and "I go on as if nothing has happened" and attempts to improve those areas of life which are within the patients control e.g. "I try to improve my general health". A cluster analysis identified a similar group of women. The remaining clusters, however, contained only one or two women and were therefore inconclusive.

Examination of the data also identified a group of 8 women who responded to more than 38 of the 53 items as used 'sometimes' or used 'a lot'. The fact that some of the women responded positively to most of the ways of coping was supported by a principal components analysis in which the first component comprised 44 of the 53 items from the questionnaire. The nine items which were not included in the first component consisted mainly of strategies of avoidance (table 6.4).

Table 6.4: WCQ items which had a factor loading of less than 0.3 on the first principal component.

Items from the adapted WCQ	Factor Loading
I try to forget the whole thing	-0.250
I go on as if nothing has happened	0.031
I don't let it get to me, I refuse to think too much about it	0.155
I avoid being with other people	0.191
I refuse to believe that it has happened	0.201
I get professional help	0.259
I make light of the situation, refuse to get too serious about it	0.270
I accept the situation	0.278

Further examination of the data based on individual items was limited by the large number of questions. A factor analysis was therefore performed in order to determine whether the items on the WCQ could be sorted into coherent groups on the basis of a correlation matrix. The factor analysis was only partially successful. The first two factors identified after orthogonal rotation contained distinct groups of items which described 'seeking social support' and 'wishful thinking' respectively. A factor loading of ≥ 0.4 was used for retaining items (table 6.5). These 2 factors explained 7% of the variation in the distribution of scores on the WCQ. The remaining 15 factors extracted contained a variety of items which could not be summarised under single headings. The

variance explained by all of the 17 factors was 35.6% (full results and factor loadings in appendix 3).

Apart from seeking social support, the factors identified in this study were unlike those defined by Folkman and Lazarus (1980) using similar multivariate analyses on data from a general population. These comprised eight factors which were termed: confrontive coping; distancing; self-controlling; seeking social support; accepting responsibility; escape-avoidance; planful problem-solving and positive reappraisal.

Table 6.5: Factor analysis of the adapted WCQ - first two factors

Factor 1 - 'Seeking social support/information'

Items from the adapted WCQ	Factor Loading*
I talk to someone who can do something concrete about the problem	0.809
I ask advice from a relative or friend I respect	0.704
I get professional help	0.698
I talk to someone about how I am feeling	0.549
I accept sympathy and understanding from someone	0.545
I talk to someone to find out more	0.497
I let my feelings out somehow	0.436
I try to analyse the problem in order to understand it better	0.419

Factor 2 - 'Wishful thinking'

Items from the adapted WCQ	Factor Loading*
I wish that I could change what has happened or how I feel	0.734
I wish that the situation would go away or somehow be over with	0.726
I turn to work or substitute activity	0.529
I hope for a miracle	0.482
(I have fantasies or wishes about how things may turn out)	0.384

* Factor loadings greater than 0.4 extracted in a factor analysis with median substitution for missing data and orthogonal rotation.

Application of Folkman and Lazarus' factors to the current data set from breast cancer patients was therefore limited. This was not surprising as most of the items from the original factor of 'confrontive coping' had been removed during the adaptation of the questionnaire. In addition, correlation matrices of the questionnaire items from the breast cancer data showed that the items within the other factors described by Folkman and Lazarus were poorly correlated.

6.3 ADAPTATION AND USE OF THE FAITH COURTAULD SCHEDULE FOR COPING WITH CANCER

The Faith Courtauld Coping Schedule comprises an interview which elicits the women's cognitive and behavioral responses to their breast cancer, as well as a manual which is used to rate the statements which refer specifically to their diagnosis and treatment. Areas of enquiry within the interview include the patient's discovery of symptoms, understanding of the diagnosis and its implications, beliefs about outcome and sense of control. Coping responses are operationally defined in the detailed manual which avoids psychoanalytic language and value judgements concerning the function of the response. Responses are subdivided into seven categories; appraisal statements (their understanding of the meaning of their diagnosis and its implications), palliating statements (ways to reduce the impact of the diagnosis), facilitating statements (attempts to discover something positive within the situation), descriptions of behaviours related to their diagnosis or treatment, outcome beliefs (attitudes to the prognosis and possibility of recurrence), control of outcome (beliefs regarding the possibility of having some influence over the outcome), and interview ratings (observations made by the interviewer about the style or content of the interview). Each category was further subdivided into a number of specific operationalised responses, with 72 possible response ratings (see appendix 4).

6.3.1 Patients and methods

The interview was given to 49 women who were in remission following treatment for early breast cancer, remission ranging from six months to twelve years based on date of diagnosis. These women were separate from the questionnaire group, forming part of a larger study on life events and relapse from breast cancer and details of recruitment and

socio-demographic variables are reported elsewhere (Ramirez, et al., 1989). The interviews were audiotaped and subsequently transcribed; the transcriptions were then rated using the Faith Courtauld manual. Initial use of the manual highlighted a number of methodological problems. Some of the response categories were not mutually exclusive which made reliable rating difficult. Also, a number of the categories were rarely reported by patients. Finally, the large number of response categories made statistical analysis difficult, as has already been described by Burgess and her colleagues (Burgess, Morris & Pettingale, 1988).

A revised manual was compiled by removing redundant items and combining those which were similar. Response categories were subsequently reduced from 72 to 23 (table 6.6). The revised categories of coping responses were used to re-rate the 49 coping interviews. As in the original manual, ratings were intended to be situation-specific and were only given for statements which referred to the patient's reaction to the diagnosis or treatment of breast cancer. Ratings were made according to the patient's verbatim statements regarding their thoughts and behaviours in response to their cancer. Consensus was reached on difficult ratings with a senior colleague who was familiar with both the original and revised manuals. The frequency of responses during the interview was recorded.

6.3.2 Analyses and results

The number of women responding to each of the 23 categories from the revised manual was analysed. In addition, the repertoire of responses (i.e. the number of different cognitive and behavioural strategies reported in the interview) was analysed in relation to time since diagnosis using the Kruskal-Wallis test for significant differences between groups. Multivariate analysis involved a cluster analysis with median substitution for missing data and minimum distance (single linkage) rules for amalgamation of clusters using the BioMedical Data Package (Hartigan, 1985). This enabled the examination of the pattern of responses used by groups of women.

The frequency analysis of the data from the interview and revised manual is illustrated in table 6.6. Almost 90% of the women used some form of cognitive avoidance in

relation to their cancer. Sixty-five percent described a positive reappraisal of their illness or life in general and a similar percentage described fear in relation to their diagnosis and treatment. Three quarters expressed uncertainty regarding the prognosis of their cancer.

Coping strategies described by only a minority of women included use of humour, behavioral attempts to facilitate recovery (for example, adopting a special diet), religion and prayer, social avoidance and seeking information. Less than 5% said that they had not considered their prognosis at all and very few believed that they would definitely suffer relapse. Only 20% of women made statements regarding their perceived control over the disease, although the majority of these felt that they had some control.

The frequency analysis highlighted the concurrent use of apparently conflicting responses. This is particularly evident for a number of women who reported differing outcome beliefs within their interviews. This usually involved expressing both the belief that they were cured and uncertainty about their prognosis.

The responses which were described by the majority of women also tended to be those which were reported several times during their interviews. Those responses which were reported by only a minority of women tended to be mentioned only once during their interviews.

Examination of the number of categories rated for each woman identified a group of ten women who reported the use of less than four different coping responses during their interview. These responses included avoidance, positive reappraisal and expressions of fear regarding the implications of the diagnosis. A cluster analysis of the response categories used by each woman identified a similar but larger group of 21 women whose predominant responses were also avoidance, positive reappraisal and fear regarding the implications of both the diagnosis and treatment, as well as uncertainty regarding the prognosis. A second cluster comprised four women who expressed little or no apprehension regarding their diagnosis and stated the belief that they would suffer no adverse consequences as a result of their disease (table 6.7). The remaining two clusters each contained only two women and were therefore inconclusive.

Table 6.6: Frequency of coping categories according to the revised Faith Courtauld Coping Schedule

Coping Category	Frequency %
Cognitive avoidance	89.8
Uncertain whether will suffer adverse consequences	75.5
Fear of diagnosis	69.4
Positive reappraisal of illness and life	65.3
Concern regarding treatment	61.2
Neutral preoccupation with thoughts of the disease	36.7
Seeking social support	24.5
Believes will suffer no adverse consequences	22.5
No change in thoughts/behaviours	20.4
Avoidance of relevant information	20.4
Fatalistic and passive acceptance	18.4
Realistic acceptance	18.4
Believes can have some control over outcome	14.3
Anger	10.2
Active attempts to return to normal	8.2
Humour	8.2
Social avoidance	8.2
Seeking information	8.2
Religion and prayer	6.1
Behaviours to aid recovery	6.1
Believes probably/certainly will suffer adverse consequences	6.1
Believes has little/no control over outcome	6.1
Claims not to have considered outcome	4.1

Table 6.7: Frequency of the reported use of each coping category for the women in the first two clusters.

Coping Category	Cluster 1 (n=21) Frequency %	Cluster 2 (n=4) Frequency %
Cognitive avoidance	100.0	100.0
Uncertain whether will suffer adverse consequences	95.2	0
Fear of diagnosis	85.7	25.0
Positive reappraisal of illness and life	90.5	50.0
Fear of treatment	71.4	100.0
Neutral preoccupation with thoughts of the disease	38.1	0
Seeking social support	14.3	25.0
Believes will suffer no adverse consequences	9.5	100.0
No change in thoughts/behaviours	14.3	25.0
Avoidance of relevant information	23.8	25.0
Fatalistic and passive acceptance	9.5	25.0
Realistic acceptance	19.0	0
Believes can have some control over outcome	4.8	0
Anger	4.8	50.0
Active attempts to return to normal	4.8	25.0
Humour	9.5	0
Social avoidance	9.5	0
Seeking information	4.8	0
Religion and prayer	0	0
Behaviours to aid recovery	4.8	0
Believes probably/certainly will suffer adverse consequences	0	25.0
Believes has little/no control over outcome	9.5	0
Claims not to have considered outcome	0	0

The effect of time since diagnosis on the amount of coping the women described was examined. This was made possible by the availability of accurate information regarding the date of diagnosis (unlike the questionnaire group who gave an approximation of the length of time they had the disease by self-report). The women were divided into three groups according to their remission times (≤ 2 years; 3-5 years; ≥ 6 years). These divisions were based on the changes in their frequency of follow-up. They were seen three monthly for the first two years post diagnosis, then six monthly until five years and thereafter yearly. There was no difference in the median number of responses made by the women in the three groups ($P > 0.05$, Kruskal-Wallis test, table 6.8).

Table 6.8: Comparison of the number of coping responses employed by women according to the length of time since diagnosis. Kruskal-Wallis test for significance between groups.

Time since diagnosis	Median number of coping responses	Z Value
≤ 2 Years (n=21)	6.0	-0.64
3 - 5 Years (n=17)	7.0	1.09
≥ 6 Years (n=11)	6.0	-0.49

H = 1.198

H (adjusted for ties) = 1.254 P > 0.05

6.4 DISCUSSION

This chapter demonstrates that it is possible to develop a method of measuring coping responses which are specific to women with breast cancer yet enable cross-study comparisons through the adaptation of the Ways of Coping Questionnaire and the Faith Courtauld Coping Schedule. In addition, it highlights the strengths and weaknesses of these questionnaire and interview approaches to measurement.

The modified WCQ only took about 5-10 minutes for the patients to complete and eliminated observer bias. A possible drawback of a questionnaire approach is the difficulty patients may have in recognising and categorising their thoughts and behaviours in response to their cancer through self-report. This is likely to be a particular problem in the assessment of strategies which involve avoidance. This problem was similarly encountered by Watson and her colleagues (Watson, et al., 1988) in their development of a self-report questionnaire to identify the four styles of coping previously described. Only one of the questions which was designed to measure denial/avoidance obtained statistical significance in a multivariate analysis of their data from 236 cancer patients. However, the questions in the WCQ which describe strategies of avoidance were among the most frequently chosen by the respondents and a cluster analysis demonstrated that those women who reported the use of very few strategies still employed methods of cognitive avoidance.

Analysis of the data from women with breast cancer using the modified WCQ demonstrated that it is not appropriate to impose a factor structure on the data as previous researchers have done (Felton, Revenson & Hinrichson, 1984). The 17 factors extracted explained only a small proportion of the variance. In addition, the majority of the factors contained dissimilar items which could not be summarised by single headings. However, it is interesting that 'seeking social support' and 'wishful thinking' did emerge as two distinct factors. This may be because the relevant items are particularly clear and unambiguous. Furthermore, the seeking of social support and wishful thinking are perhaps easier to comprehend compared with the more complex cognitive manipulations such as emotional control.

The limited success in applying Folkman and Lazarus' factors (1980) to this dataset suggests that factors derived from other populations are not applicable in assessing coping in women with early breast cancer. Nor was it possible to define a separate factor structure specific to the women with breast cancer in this study, as demonstrated by the disparate results from the factor analysis. Consequently, analysis of the WCQ can be made at the level of individual items as shown in this chapter, which provides detailed and informative data, or it can be broadened to a dichotomous analysis of

emotion-focused and problem-focused coping responses as demonstrated by other studies using the WCQ (see chapter two).

The Faith Courtauld Coping Schedule provides a more flexible, individually orientated approach to the assessment of coping with cancer. It avoids the forced choice of responses required by a questionnaire and provides the opportunity for patients to describe coping strategies on more than one occasion which may reflect the degree to which they are employing these strategies. Furthermore, the interview approach allows patients to express ambivalence in their responses as evidenced by the conflicting outcome beliefs expressed by some women. Apparently conflicting responses may reflect the uncertainty associated with the diagnosis and treatment of breast cancer.

The limitations of an interview include the time consuming nature of the collection and collation of data and difficulty with data analyses. A further problem relates to the responses which are not described by a patient during an interview. This may indicate that the particular response is not used but it may also reflect a lack of specific probing by the interviewer or a difficulty in describing the coping response on the part of the patient. The appropriateness of detailed probing when exploring sensitive areas such as the thoughts and beliefs regarding a potentially life threatening situation such as cancer can be difficult to judge. Insufficient probing may mean that some strategies are missed whilst excessive questioning may cause distress and challenge coping responses such as avoidance. The interview was used in this chapter to enquire about the coping responses employed over considerable lengths of time and could therefore be subject to the bias of retrospective recall. This limitation would not apply in the main study which is prospective in design.

An additional strength of the interview is that it enables the expression of beliefs and emotions regarding the disease. Thus the interview data identified the prevalence of fear related to the diagnosis and treatment of cancer and uncertainty regarding disease prognosis. All patients in this study were informed of their diagnosis of cancer and their fear and uncertainty probably demonstrates a generally high level of realistic understanding of the disease and its implications.

This chapter suggests that the modified WCQ and Faith Courtauld Coping Schedule can complement one another and indeed produce similar results. Both methods identified the extensive use of cognitive avoidance and positive reappraisal. These may correspond to an overall strategy of 'selective ignoring' which was defined by Pearlin and Schooler (1978) as ignoring the unpleasant aspects of a situation and concentrating instead on positive attributes. They found that the strategy of selective ignoring was adaptive in situations which are not amenable to personal control. Similarly, Folkman and Lazarus (1980) have found that health problems which are appraised as not amenable to personal control are more effectively dealt with through emotion-focused strategies. These are responses directed at the regulation of painful emotions engendered by the health problem rather than attempting to change the cause of the problem. Results using the original Faith Courtauld Schedule to assess coping in patients with cancer have suggested that an overall strategy of selective ignoring is related to reduced levels of anxiety and depression one year after diagnosis (Morris, 1984). In this context, selective ignoring involved not attempting to change aspects of the disease which are outside the patient's control and concentrating instead on ways to make life more enjoyable.

Conversely, strategies of wishful thinking and blaming oneself or others were used infrequently by most women on both questionnaire and interview methods of measurement. This contrasts with the results from a study which found that attributions of blame were prevalent amongst American women with breast cancer (Taylor, Lichtman & Wood, 1984), although these were focused on causes of the disease. Attributions of blame as well as wishful thinking have been related to a poor psychological outcome in patients with cancer and other chronic illnesses (Felton & Revenson, 1984; Felton, Revenson & Hinrichson, 1984; Hilton, 1989).

Two interesting subgroups of patients were identified in this study. The first was identified by both the interview and the questionnaire. It contained women who used very few ways of coping except for avoidance and some responses of positive reappraisal. The second subgroup was identified by the WCQ and consisted of women who reported using most of the ways of coping in response to their cancer. This latter finding in particular challenges the concept of exclusive styles of coping. There is disagreement in

the literature about the adaptiveness of a wide repertoire of coping responses. In studies of the general population it has been associated with both increased and decreased emotional distress (Coyne, Aldwin & Lazarus, 1981; Pearlin & Schooler, 1978). The interview data suggest there is little change in the number of coping responses the women use in relation to the time since their diagnosis. This is perhaps not surprising in view of the chronic nature of the threat of breast cancer. It is a threat of which they are constantly reminded by regular hospital check-ups to examine for evidence of disease progression and increasingly frequent reports of breast cancer and related survival statistics in the media. It is possible that some individual changes may be masked by a cross-over effect in the group analyses. These can only really be assessed by a longitudinal analysis of individual coping responses. Furthermore, it is likely that specific examination of coping responses in the weeks and early months following initial diagnosis would reveal a peak in the frequency of coping responses.

6.5 CONCLUSION

The use of situation-specific interview and questionnaire methods of assessing coping in women with early breast cancer has highlighted the complex nature of these responses. Both approaches identified a number of ways of coping with the stress of the diagnosis and treatment. The measures developed in this chapter will enable detailed examination of the relationship between coping responses and psychological outcome in the main prospective study which now follows.

CHAPTER 7: PATTERNS OF COPING AND PSYCHOLOGICAL ADJUSTMENT IN WOMEN WITH EARLY BREAST CANCER: LONGITUDINAL STUDY

7.1 INTRODUCTION

Results from the methodological development of two detailed coping measures outlined in chapter six demonstrated a wide pattern of responses shown by women with a diagnosis of breast cancer, challenging the notion of particular styles of coping. These studies were cross-sectional in design, gathering information about coping responses from women with variable lengths of time since diagnosis. The longitudinal study was intended to extend this research with the application of the two adapted measures of coping in women who are newly diagnosed with breast cancer with a one year follow-up period. This will enable the specific exploration of the pattern of coping in relation to the initial diagnosis and treatment and how this might change over the first post-operative year. In addition, the collection of information regarding the pattern of psychological morbidity will enable the examination of associations between coping and mood as well as other psychosocial and physical variables.

7.2 METHOD

7.2.1 Setting

The study was conducted in a specialist oncology unit in an urban teaching hospital. The unit contained two wards, one of which was specifically for women with breast cancer. This was further divided into two sections, surgical and medical. The surgical side contained those women who were having biopsies to investigate primary cancer or metastatic spread, or who were receiving their initial treatment for breast cancer. The medical arm of the ward contained those women who had established metastatic breast cancer.

7.2.2 Patients

The patients comprised a consecutive series of 107 women with operable breast cancer ($T_{1,2} N_{0,1} M_0$) who presented to the unit. The usual method of referral was through their General Practitioner and the women came mainly from the surrounding health region, although some travelled from outside the region in order to attend the unit. Selection

criteria included: being aged under 70, having no previous history of malignant disease and awareness of their diagnosis. A further criterion required the diagnosis to have been given by one of the doctors on the unit. The average time from diagnosis to operation was 16.6 days (SD 10.6, range 3-56 days). The treatment protocol involved either mastectomy or lumpectomy with iridium implant and external beam irradiation.

7.2.3 Procedure

Patients were interviewed on three occasions during their first pre-operative year. All the interviews were audio-taped, with the women's consent, in order that they could be rated afterwards. None of the women who agreed to participate refused permission to audiotape the interviews.

7.2.3.1 Pre-operative interview The first interview was conducted in a small side room of the hospital ward either the day before, or on the day of their operation. The women were verbally informed of the aims of the study and their consent to participate in the study was obtained. Only one woman declined to take part at the first interview. She appeared quite anxious and said that she had "talked it over with friends and other patients and I don't want to talk any more".

Information collected at this assessment included cognitive and behavioural coping responses, social support and socio-demographic data using semi-structured interviews. Two standardised questionnaires were used to assess psychological morbidity. Cognitive and behavioural coping responses were assessed by the Faith Courtauld Coping Schedule only, as the WCQ was considered to be inappropriate for the pre-operative interview. It was expected that this would be a time of heightened distress, occurring relatively soon after diagnosis and shortly before surgery, and it was possible that the women would not be sufficiently conscious of the cognitive and behavioural responses they were employing in order to complete such a detailed questionnaire. Furthermore, the detailed questionnaire may have possibly added to their distress. Thus, the shortened semi-structured interview alone was felt to be a more sensitive and appropriate method of assessment for the pre-operative interview.

7.2.3.2 Three months after operation The second interview occurred three months after operation. This usually coincided with the women's first post-operative outpatient appointment and was conducted in the outpatient clinic. A few women undergoing chemotherapy were interviewed in the clinic where they received their treatment or on the ward. Each woman was contacted by telephone or letter before the interview to obtain consent and to arrange a suitable time. Five women said that they did not want to re-interviewed on this occasion. The main reasons were a lack of time, such as a relative waiting to take them home, or an unwillingness to answer "any more questions". In addition, two women could not be located for follow-up at three months but at subsequent meetings they indicated a willingness to continue with the study. These two were not included in the final analysis because of the missing data at the three month assessment.

Cognitive and behavioural coping response were assessed using both the Faith Courtauld Coping Schedule and the WCQ at this assessment. Additional information included both questionnaire measures of mood and the semi-structured interview on levels of social support.

7.2.3.3 One year after operation The final interview was around one year after operation (range 10-15 months, mean 12.38, SD 0.89) and was again timed to coincide with outpatient appointments. Those women who could not be seen in the hospital were visited at home. Women were again contacted by telephone or letter to gain consent and arrange a convenient time. Two women declined this final interview, both saying that they did not like answering questions. A further two women could not be located for follow-up.

The final interview collected the same data as had been gathered at the second assessment.

In addition, physical and pathological data were obtained from the patient's medical notes. This included the type of operation, adjuvant treatment, number of nodes, histology and the date and type of any subsequent recurrence of the disease within the first post-operative year.

7.2.4 Measures

7.2.4.1 Sociodemographic data

A semi-structured interview was used to elicit socio-demographic information such as age and occupation as well as life stage. This is an index which reflects the age and number of children still residing in the household. The interview also gathered information concerning the woman's previous psychiatric history and any delay in presentation of their symptoms of breast cancer. Previous psychiatric history was defined as contact with either a Psychiatrist or treatment by their G.P. for a non-physical illness. Delay in presentation was represented by self-report as the approximate time between the first observation of symptoms of breast disease by the woman and the first visit to a Doctor with their concerns. (The areas covered in the socio-demographic interview can be found in appendix 5).

7.2.4.2 Cognitive and behavioral responses to the cancer.

These were assessed using the measures developed in the previous chapter:

The Faith Courtauld Schedule for Coping with Cancer (Morris, Blake & Buckley, 1985).

As previously described, the Faith Courtauld Schedule consists of a semi-structured interview and manual for the rating of responses. The original interview contained questions regarding the discovery of symptoms, understanding of diagnosis, beliefs about outcome and their sense of control over the disease. This interview was designed for use at 3 months post-diagnosis. Some of these areas of enquiry were felt to be inappropriate and possibly distressing for inclusion in the pre-operative interview, particularly those regarding beliefs about outcome and sexual adjustment. Consequently, the interview was adapted in order to be applicable and sensitive for each assessment point:

Pre-operative interview: This interview was shortened and included questions concerning the first discovery of symptoms, the process of diagnosis and their understanding of it, how much they thought about their diagnosis and methods used to avoid thinking about it (appendix 6).

Three & twelve months post-operative interviews: These interviews concentrated on the women's current understanding of their diagnosis and its implications, including their beliefs about the outcome and sense of control (appendix 7). Questions concerning social support, self-esteem and psychiatric treatment were omitted since they were fully assessed using other measures in the current study. The Faith Courtauld Schedule for coping with Cancer also enquired about employment and sexual adjustment. These were included in the interview but do not form part of this thesis.

The audio-tapes of the interviews were transcribed and rated according to the revised manual described in chapter 6. These were completed by two raters and consensus was reached on difficult ratings with a third person who had been involved in the revision of the manual. Only those statements which referred to the woman's response to her diagnosis &/or treatment were rated. Inter-rater reliability was obtained by the two raters double rating of one third of the interviews. Details about the inter-rater reliability are provided in the results section.

The Ways of Coping Questionnaire - WCQ (Folkman & Lazarus, 1980).

The WCQ is a widely used self-report coping assessment which was adapted for use with cancer patients (described in the previous chapter). The revised WCQ describes fifty-three cognitive and behavioural methods of coping. The respondent is required to indicate whether they use each of the strategies 'a lot', 'quite a bit', 'occasionally' or 'does not apply/not used' in response to a specified stressor. The instructions in the current study asked the women to respond in terms of "how much you presently use the methods listed to help you cope with your breast trouble" (see appendix 9).

The original 66 items on the WCQ were grouped into eight factors termed; confrontive coping, distancing, self-controlling, seeking social support, accepting responsibility, escape-avoidance, planful problem-solving and positive reappraisal. A factor analysis of the adapted WCQ with one hundred and fifty-three women with breast cancer failed to replicate these factors, with the exception of seeking social support. Nor could a separate factor structure for this population be defined, as the items in each factor were disparate and explained a small amount of the total variance. Consequently, analyses of the

adapted WCQ comprised examining the use of each individual item.

The adapted WCQ was completed by the patients at the second and third assessments only. It was felt to be inappropriate for the pre-operative interview as previously discussed.

7.2.4.3 Measures of mood.

Mood was assessed using two measures in order to gather information on clinically significant levels of mood disturbance as well as transient mood, which includes both positive and negative affective states.

The Hospital Anxiety and Depression Scale - HAD scale (Zigmond & Snaith, 1983).

The HADS is a widely used and standardised assessment of mood. It comprises a fourteen item, self-report questionnaire which enquires about symptoms of mood disturbance over the previous week. It contains two subscales of seven questions each which measure levels of anxiety and depression respectively (appendix 10). Scoring for each question ranges from 0-3 with a maximum of fourteen on each subscale. It was specifically designed for use in non-psychiatric hospital departments, and avoids the measurement of somatic symptoms of mood disturbance which may be confounded with physical illness. Thus symptoms of headaches, dizziness or fatigue have been omitted. Consequently, it is a particularly relevant for use with women with breast cancer.

The scoring includes a series of cut-off scores which indicate the probability of a clinically significant, borderline or non-significant mood disturbance (non-case = score ≤ 7 ; borderline case = score 8-10; case = score ≥ 11).

The Profile of Mood States - POMS (McNair & Lorr, 1964)

The POMS is a 65 item, self-report, adjective rating scale which gathers data on transient affective states, including both positive and negative mood (appendix 11). It is a standardised assessment which is widely used with physically ill populations. Patients are asked to indicate, on a 5 point scale, how much each adjective describes how they have been feeling in the past week. Scores are summed according to six subscales;

tension (range 0-36), depression (range 0-60), anger (range 0-48), vigour (range 0-32), fatigue (range 0-28) and confusion (range 0-28), as well as providing an overall summed score of mood disturbance (range 0-232).

7.2.4.4 Social support

The Self-Evaluation and Social Support Schedule (O'Connor & Brown, 1984)

This social support schedule is derived from the theories of Brown & Harris (1978). These propose that the most important source of support in mitigating the deleterious effects of stressful life events is provided within a close confiding relationship (usually with the spouse or boyfriend). The schedule consists of a semi-structured interview, a shortened version of which is employed in the current study.

The pre-operative interview elicits information regarding two confiding relationships. This includes details of the relationship with the confidante, frequency of contact and the extent of confiding in general. Information regarding the practical, emotional and extent of confiding concerns regarding the breast cancer with each of these confidantes is gathered at each of the assessments. Additional information about the negative aspects of the relationship as well as the perceived helpfulness of the support is also elicited (appendix 12).

Each aspect of support from each specified confidante is rated on a 4 point scale ranging from 'marked' to 'little or none'. Some of these aspects of support are combined into an overall category of 'positive support' for analysis. Brown and Harris (1978) suggest that positive social support can act as a buffer from the negative effects of a severe life event, particularly if it is provided by a close confidante. 'Positive social support' is defined as receipt of 'marked' or 'moderate' levels of confiding and active emotional support, with 'little or no' negative responses such as critical comments.

7.3 RESULTS

The results section is organised according to the aims outlined in chapter 5, beginning with an exploration and description of the data from each of the measures at each assessment, followed by the results from cross-sectional analyses. These examine the relationship between measures which were assessed at the same time point. The final section describes the results of the longitudinal analyses which examine the relationship between measures assessed at different time points in an attempt to determine the direction of causality. All analyses were performed using the Statistical Package for Social Scientists (Norusis, 1992).

7.3.1 EXPLORATION AND DESCRIPTION

7.3.1.1 Attrition from the study

One hundred and eight women were approached for the first interview and only one woman refused to participate. The overall rate of attrition throughout the course of the three assessments was 10.1% (that is 88.9% of the women first approached completed all three assessments), although a minority of women failed to return some of their final questionnaires after having completed their last interview. The details of the overall drop-out rate at each assessment is presented in table 7.1 below.

TABLE 7.1: Rate of attrition at each assessment.

1st Assessment (Pre-operative)	2nd Assessment (3 months post-operative)	3rd Assessment (12 months post-operative)
107 (99.1%)	100 (92.6%)	96 (88.9%)

Seven women refused further interviews, the main reasons being a lack of time and a reluctance to answer "any more questions". Four women were missed because they did not attend their outpatient appointments when one of their interviews was scheduled but were willing to participate in other interviews. A comparison of these women with those women who completed all three interviews demonstrated non-significant differences for all socio-demographic variables and coping responses elicited in the first interview. There were no significant differences between the levels of anxiety and depression as measured by the HAD scale (table 7.2) or mood as assessed by the Profile of Mood

States, with the exception of the confusion sub-scale (table 7.3). Those women who did not complete all three interviews were significantly more confused, giving positive answers to questions such as 'unable to concentrate' and 'forgetful'.

Table 7.2: Comparison of HAD scale scores for completers and non-completers of all three interviews

HAD Scale:	Women who completed all three interviews (N=96)	Women who did not complete all three interviews (N=11)	Statistical comparison
HAD Anxiety: Mean score (SD) {Mean rank score}	7.73 (4.90) {52.8}	9.91 (6.33) {(64.5)}	T-test P=0.18 (Mann W-U P=0.23)
Observed number scoring ≥ 8 /Total number scoring ≥ 8 (expected number scoring ≥ 8)	43/49 (44.0)	6/49 (5.0)	X ² P=0.54
HAD Depression: Mean score (SD) {Mean rank score}	2.94 (2.96) {52.19}	4.64 (3.04) {(69.82)}	T-test P=0.07 (Mann W-U P=0.0)
Observed number scoring ≥ 8 /Total number scoring ≥ 8 (expected number scoring ≥ 8)	9/10 (9.0)	1/10 (1.0)	X ² P=0.98

Table 7.3: Comparison of POMS scores for completers and non-completers of all three interviews

Profile of Mood States:	Women who completed all three interviews (N=96)	Women who did not complete all three interviews (N=11)	Statistical comparisons T-test ((Mann W-U))
Tension: Mean score (SD) ((Mean rank score))	13.80 (9.26) ((53.55))	15.36 (10.98) ((57.91))	P=0.60 ((P=0.66))
Depression: Mean score (SD) ((Mean rank score))	10.49 (10.63) ((53.32))	15.45 (16.78) ((59.91))	P=0.36 ((P=0.50))
Anger: Mean score (SD) ((Mean rank score))	7.13 (6.29) ((54.56))	8.36 (12.20) ((49.14))	P=0.75 ((P=0.58))
Vigour: Mean score (SD) ((Mean rank score))	14.09 (7.32) ((52.93))	16.36 (7.50) ((63.32))	P=0.33 ((P=0.29))
Fatigue: Mean score (SD) ((Mean rank score))	6.26 (6.56) ((52.28))	10.00 (8.70) ((69.00))	P=0.09 ((P=0.09))
Confusion: Mean score (SD) ((Mean rank score))	6.27 (5.69) ((51.87))	11.09 (7.80) ((72.59))	P=0.01 ((P=0.04))
POMS Total score: Mean score (SD) ((Mean rank score))	58.02 (37.96) ((52.94))	76.64 (54.68) ((63.27))	P=0.15 ((P=0.30))

Completers and non-completers were also found to be significantly different in their receipt of social support with non-completers reporting a lower level of positive support from husbands or friends (6/11 non-completers received no positive support from husband/friend, Fisher's Exact Test $P=0.03$).

Analyses of physical and pathological data showed no significant differences between those women who completed all three interviews and those who did not, with the exception of adjuvant treatment.

Of the seven women who received post-operative ovarian irradiation, three did not complete all of the interviews (table 7.4, $X^2 P=0.02$). This finding was independent of age, which was not significantly different between completers and non-completers (mean age 54.25 vs 50.18 years, T-test $P=0.23$).

Table 7.4: Comparison of adjuvant treatment between completers and non-completers of all three interviews.

Adjuvant treatment:	Women who completed all three interviews (N=96)	Women who did not complete all three interviews (N=11)
None	39/41 (36.8)	2/41 (4.2)
Chemotherapy	10/11 (9.9)	1/11 (1.1)
Ovarian irradiation	4/7 (6.3)	3/11 (0.7)
Tamoxifen	43/48 (43.1)	5/48 (1.9)

7.3.1.2 Sociodemographic and treatment data for all patients

Psychosocial and demographic data of the patients are presented in table 7.5. The majority of women were married or co-habiting (69.2%). Their ages ranged from 24-69 years (the upper age limit for inclusion in the study) with a mean age of 53.8 years. Around one third had children still living at home, five women had children aged under six. Approximately 40% had received treatment from either their General Practitioner or a Psychiatrist for past psychological difficulties such as anxiety or depression.

TABLE 7.5: Psychosocial and demographic data

N=107	n	(%)
MARITAL STATUS: Married/cohabiting	74	(69.2)
Widowed	16	(15.0)
Separated/divorced	11	(10.3)
Single	6	(5.6)
AGE: Range	24 - 69	
Mean (SD)	53.8	(10.6)
Median	55	
SOCIAL CLASS*: I	7	(6.5)
II	14	(13.1)
III	69	(64.5)
IV	8	(7.5)
V	9	(8.4)
LIFE STAGE: Woman aged <35 years, no children at home	4	(3.7)
Youngest child <6 years old, at home	5	(4.7)
Youngest child aged 6-14 years, at home	13	(12.1)
Youngest child aged >15 years, at home	18	(16.8)
Woman aged >35 years, no children at home	67	(62.6)
COUNTRY OF BIRTH: United Kingdom	98	(91.6)
West Indies	2	(1.9)
Asia	1	(0.9)
Orient	1	(0.9)
Other	5	(4.7)
RELIGION: Church of England	68	(63.6)
Roman Catholic	13	(12.1)
Other Christian	10	(9.3)
Other Protestant	2	(1.9)
Moslem	1	(0.9)
None	13	(12.1)
FORMAL PRACTICE OF RELIGION:		
No	89	(83.2)
Yes	18	(16.8)
PREVIOUS HISTORY OF PSYCHIATRIC DISORDER:		
None	65	(59.8)
Received treatment from G.P.	31	(29.9)
Received treatment from Psychiatrist	11	(10.3)

* Office of Population Censuses and Surveys (1980). Women are classified under their husband's occupation if married. Single women are classified under their own occupation.

TABLE 7.6: Clinical and pathological data.

N=107	n	(%)
PRIMARY OPERATION:		
Mastectomy	46	(43.0)
Conservation procedure	61	(57.0)
ADJUVANT TREATMENT:		
None	41	(38.3)
Cytotoxic chemotherapy	11	(10.3)
Tamoxifen +/- prednisolone	48	(44.9)
Ovarian irradiation +/- pred.	7	(6.5)
TUMOUR SIZE:		
T0	2	(1.9)
T1	32	(29.9)
T2	73	(68.2)
NUMBER OF AFFECTED LYMPH NODES:		
0	56	(52.3)
1-3	35	(32.7)
≥ 4	16	(15.0)
TUMOUR HISTOLOGY:		
Ductal grade I	14	(13.1)
Ductal grade II	41	(38.3)
Ductal grade III	33	(30.8)
Lobular	13	(12.1)
Other	5	(4.7)
Not known	1	(0.9)
RECURRENCE OF DISEASE IN 1ST POST-OPERATIVE YEAR		
No recurrence	101	(94.4)
Local recurrence	4	(3.7)
Distant recurrence	2	(1.9)
DELAY IN PRESENTATION OF SYMPTOMS TO DOCTOR (IN DAYS)		
Range	3 - 56	
Mean (SD)	16.6 (10.7)	
Median	15.0	
MENOPAUSAL STATUS:		
Pre-menopausal	52	(48.6)
Post-menopausal	54	(50.5)
Not known	1	(0.9)

Clinical and pathological data are presented in table 7.6. More women received a conservative surgical treatment as opposed to mastectomy (57% versus 43%). Around 40% did not require any further treatment and a similar number were given adjuvant tamoxifen (44.9%). Eleven women (10.3%) required cytotoxic chemotherapy and seven (6.5 %) underwent ovarian irradiation. The average delay between first noticing symptoms of breast disease and reporting them to a doctor was 16.6 days, according to the women's own estimation. The range in delay in presentation was from 3 to 56 days. Data collected at the end of the first post-operative year indicated that 6 women (5.6%) had experienced a local or distant recurrence of their cancer.

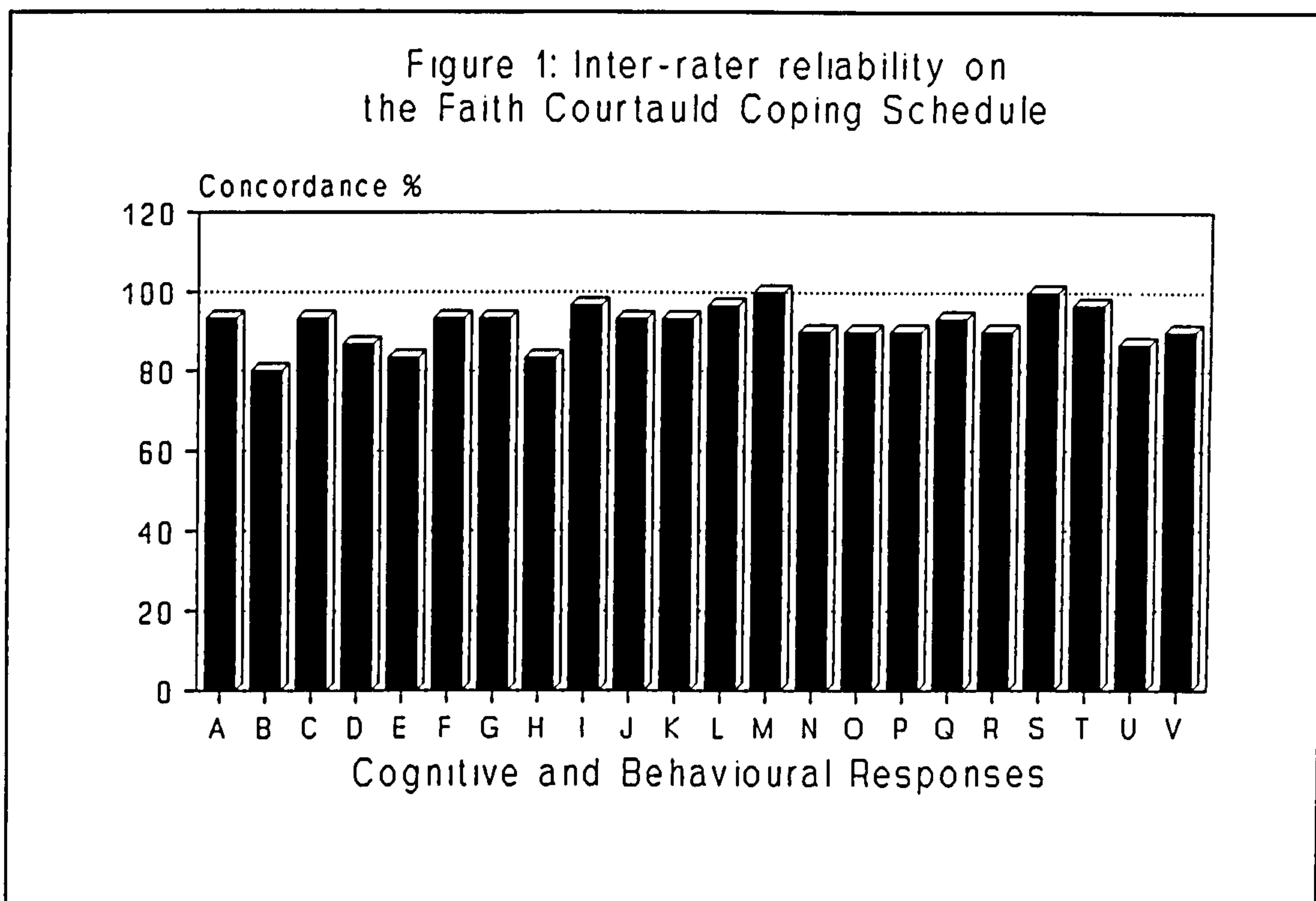
7.3.1.3 Cognitive and behavioural coping responses

Faith Courtauld Schedule for Coping with Cancer.

The transcripts from the semi-structured interviews conducted at each assessment were rated by two individuals according to the revised manual and procedure described in chapter six. In order to determine the inter-rater reliability, thirty of the transcripts (28%) were double rated. Calculation of inter-rater reliability was problematic as the distribution of responses in each category was found to be skewed, with some items employed by almost the whole sample whilst other items were rarely used. Cohen's kappa has been shown to produce a smaller picture of agreement within a skewed distribution even when there is a high agreement on ratings (Feinstein & Cichetti, 1990). Consequently, concordance levels between the two raters were used to assess inter-rater reliability (details of concordance and Cohen's kappa are in appendix 13). These were found to be high, with concordance ranging from 80-100% for each category (figure 1).

The skewed distribution of the cognitive and behavioural responses elicited by the Faith Courtauld Schedule of Coping with Cancer at all three assessments is displayed in figure 2 (raw data in appendix 14). The responses are presented in descending order of frequency at the first assessment. Beliefs about the prognosis and control over disease outcome (coded Q - V) were only elicited at the second and third interviews.

Over three quarters of the women expressed fear of their diagnosis and half were concerned about treatment prior to operation. These fears and concerns had reduced significantly at both post-operative assessments (McNemar's test for significance of change $P \leq 0.01$).

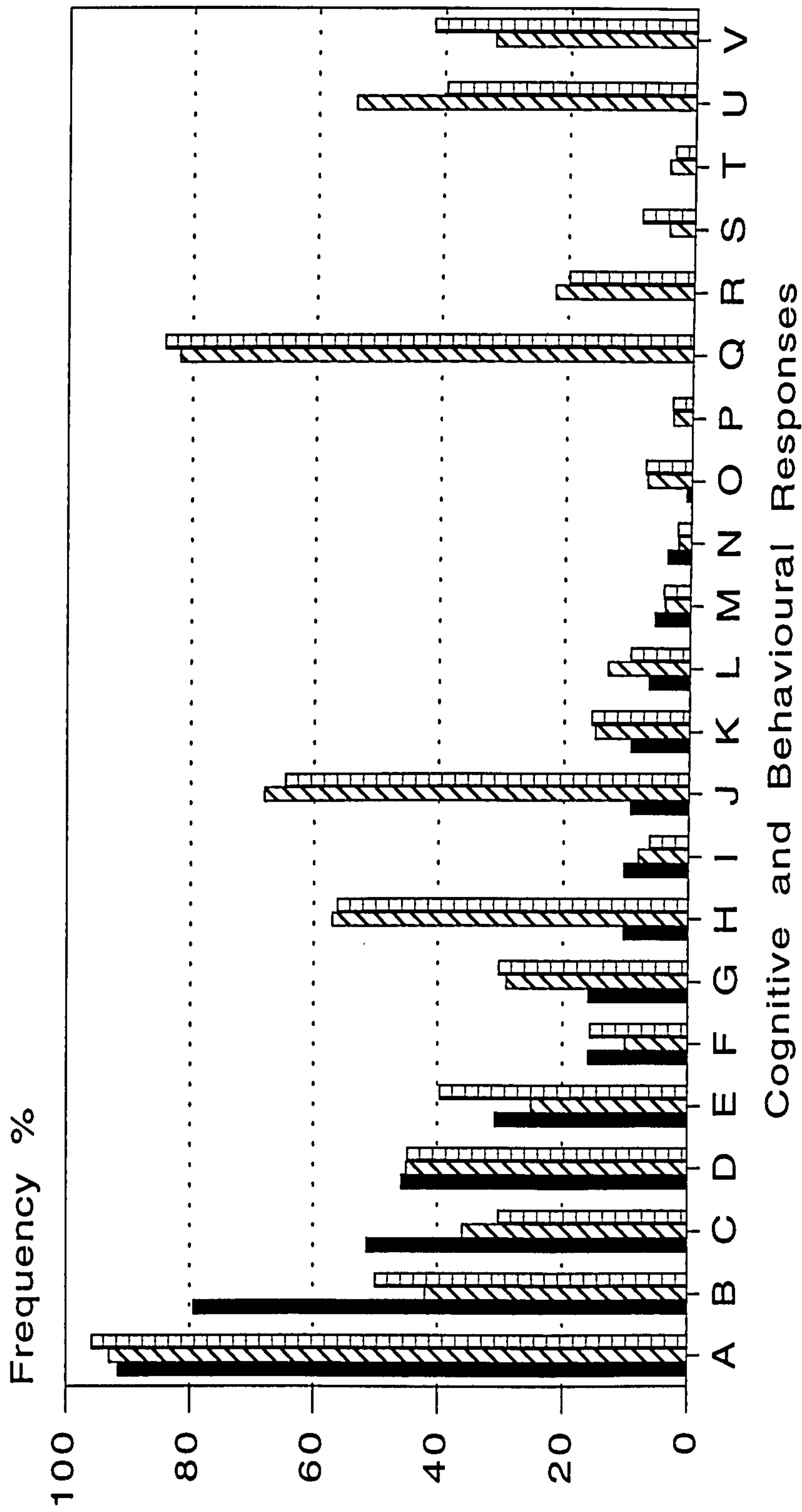


KEY:

- | | | |
|---------------------------------|---------------------------------------|-----------------------------------|
| A Cognitive avoidance | I Use of religion | P Social avoidance |
| B Fear of diagnosis | J Positive appraisal of life | Q Uncertain re prognosis |
| C Concern re treatment | K Avoidance of information | R Believes in good prognosis |
| D Positive appraisal of disease | L Neutral pre-occupation with disease | S Believes in poor prognosis |
| E Acceptance of disease | M Anger | T Not considered prognosis |
| F Seeking social support | N Use of humour | U Feels some control over outcome |
| G Seeking information | O Behaviours to aid recovery | V Feels no control over outcome |
| H Attempts to return to normal | | |

The most frequently stated response was cognitive avoidance, expressed by over 90% of the women at all three assessments. This involved responses which avoided thinking about the threat of the disease and its implications such as "I keep myself busy" or "I take each day as it comes"

Figure 2: Frequency of Responses from the Faith Courtauld Coping Schedule



■ 1st Assessment ▨ 2nd Assessment ▩ 3rd Assessment

- KEY:
- | | | | | | |
|---------------------------------|---------------------------------|----------------------------------|------------------------------|------------------------------|------------------------------------|
| A Cognitive avoidance | E* Acceptance of disease | I Use of religion | M Anger | Q Uncertain re prognosis | U* Feels some control over outcome |
| B* Fear of diagnosis | F Seeking social support | J* Positive appraisal of disease | N Use of humour | R Believes in good prognosis | V Feels no control over outcome |
| C* Concern re treatment | G* Seeking information | K Avoidance of information | O Behaviours to aid recovery | S Believes in poor prognosis | |
| D Positive appraisal of disease | H* Attempts to return to normal | L Pre-occupation with disease | P Social avoidance | T Not considered prognosis | |

* = McNemar's test for significance of change $P \geq 0.01$

Over 40% emphasised the positive aspects of their disease prior to operation such as "I don't mind losing my breast at my age, it would be terrible if I were younger". This frequency did not change significantly over time. Statements concerning positive changes in the perception of life in general such as "I don't take things for granted any more, I enjoy each day" were only expressed by around 10% of women at the 1st assessment (prior to operation). This increased significantly to around 60% post-operatively with many women stating that the disease had marked a turning point from which their priorities had changed and life had improved (McNemar's test for significance of change $P \leq 0.01$).

One third had accepted their disease prior to operation, with statements such as "I've come to terms with it" or "what will be will be". Acceptance had fallen significantly at the 2nd assessment (3 months after operation - McNemar's test, $P \leq 0.01$) but had risen again at one year after operation. The number of women reporting active attempts to return to normal increased significantly after operation (McNemar's test, $P \leq 0.01$).

The percentage of women who stated that they sought social support throughout the assessments did not change significantly (from 10% to 16%). The number of women who actively sought information about cancer increased significantly after operation (McNemar's test, $P \leq 0.01$), whilst a consistently small proportion of women stated that they deliberately avoided information about their disease across all three assessments. Strategies which were rarely stated included; a neutral pre-occupation with the disease, expressions of anger, using humour by dismissing the threat of the disease with a joke, social avoidance and behaviours to aid recovery such as trying alternative diets or therapies.

Beliefs about the disease prognosis and feelings of control over the prognosis were only elicited at the 2nd and 3rd assessments. These remained stable over time and demonstrated the concurrent expression of apparently conflicting beliefs. For example, over 80% felt uncertain about the prognosis of their disease, but almost one quarter of the women stated that they were almost certainly cured. This was due to the expression by some women of both beliefs in the same interview. A minority of women (between

4% and 9%) believed that the cancer would probably return and even fewer said that they had not thought about the prognosis at all.

At the second assessment almost one third of the women (32%) felt that they had no control over the outcome of their disease. A greater percentage (54%) said that they had some control over the possibility of recurrence by adopting a healthy lifestyle or believing in "mind over matter". This number had fallen significantly to around 40% at the final assessment.

The change in the overall number of responses used by each woman was also analysed. This involved the summation of the number of coping responses reported by each woman at each assessment. Outcome beliefs were excluded from this analysis since they were only collected at the post-operative interviews. The number of responses used was normally distributed and Levene's test for homogeneity of variance was non-significant. Therefore the parametric test of analysis of variance was used to analyse the change in the number of responses reported over the first post-operative year. The mean number

of responses reported at each assessment is given in table 7.7. Scheffe's post hoc test demonstrated that there was a significant increase in number of coping responses reported between the first and the third interviews only.

Table 7.7: Number of coping responses reported on the Faith Courtauld Coping Interview (excluding outcome beliefs)

Pre-op interview			3 months post-op			12 months post-op			ANOVA
Range	Mean	(SD)	Range	Mean	(SD)	Range	Mean	(SD)	F ratio
2 - 9	4.38	(1.45)	1 - 9	4.82	(1.55)	2 - 10	5.22	(1.75)	7.10 P=0.001

Ways of Coping Questionnaire (WCQ).

The WCQ was given at the 2nd and 3rd assessments only, as described in the procedure. It was the last questionnaire to be given in the assessment and consequently a number of women took it home to complete. Unfortunately, this meant that some of the questionnaires were not returned and although 100 and 96 women respectively completed the 2nd and 3rd assessments, only 94 and 84 women returned their respective Ways of Coping Questionnaire.

A frequency analysis of the WCQ showed that distribution of responses was uneven with some responses frequently employed whilst other responses were rarely used (see figure 3). The responses which were used most (by over 50% of women) mainly reflected cognitive avoidance, positive reappraisal of their situation and control of emotional expression (table 7.8). There were also a number of responses which the majority ($\geq 90\%$) reported as not used or used 'occasionally'. These mainly reflected blaming self or others and wishful thinking (table 7.8).

Whilst the overall distribution of responses to the WCQ items remained similar across both assessments, there appeared to be a decrease in the number of women responding positively to the WCQ items at the final assessment. Change in the use of individual coping items from 3 months to one year after operation was analysed using Wilcoxon's matched-pairs signed-ranks test for those women who completed the WCQ at both the 2nd and 3rd assessments (n=80). A significant change was found for only four items and these were all used by fewer women at the 3rd assessment than the 2nd. These items were:

'I accept sympathy and understanding from someone'	P=0.05
'I don't let it get to me; I refuse to think too much about it'	P=0.05
'I talk to someone about how I am feeling'	P=0.04
'I wish the situation would go away or somehow be over with'	P=0.05

Because of the large number of analyses performed, it is possible that some significance might have occurred by chance. Bonferonni's correction for this would result in none of these items reaching the necessary level of significance.

Figure 3: Distribution of responses on the WCQ Q's answered "quite a bit" or "alot"

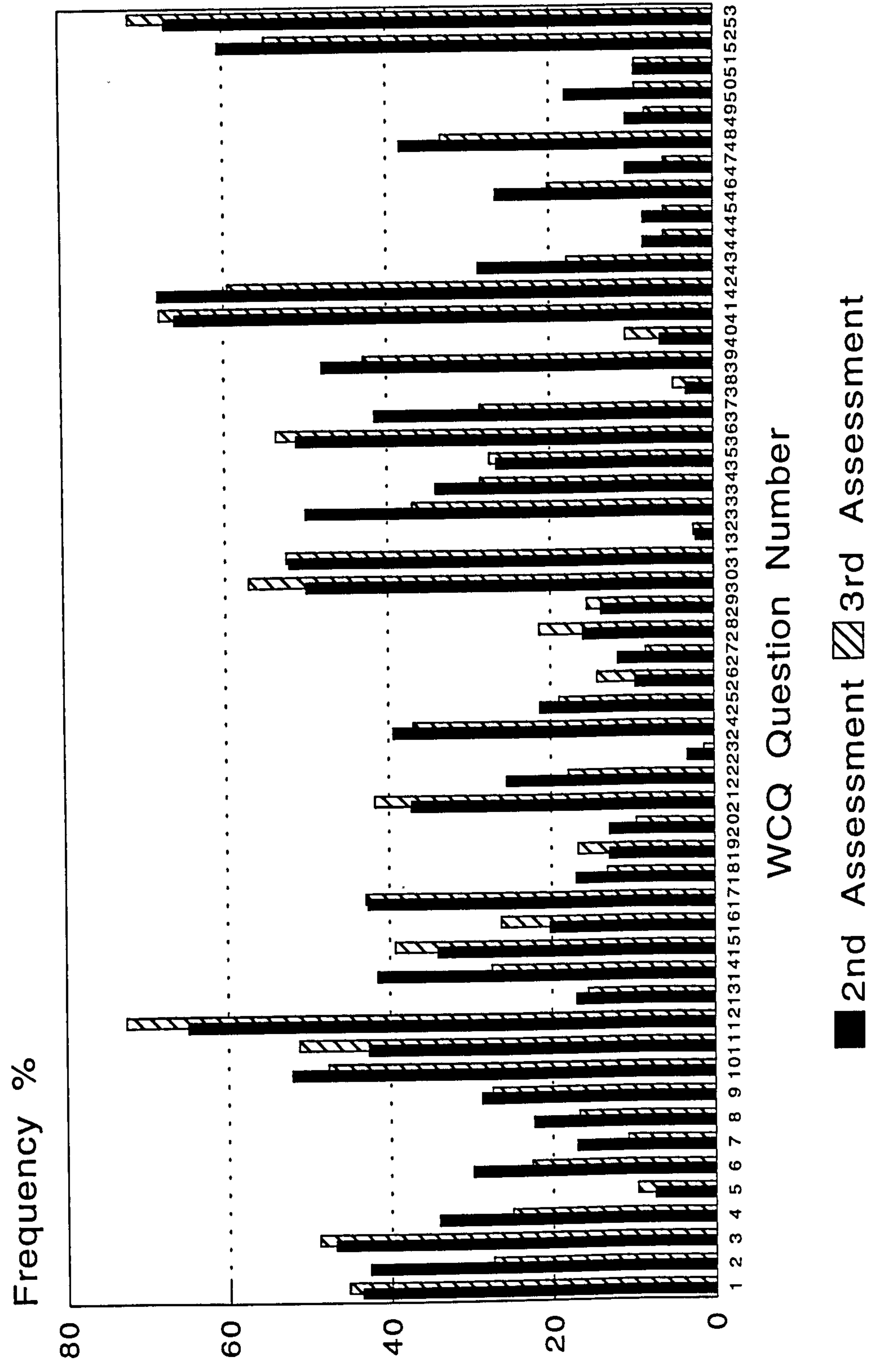


TABLE 7.8: Most frequently used items on WCQ

WCQ items to which over 50% of women responded as used <u>'quite a bit'</u> or <u>'a lot'</u>	3 months post-op Frequency %	12 months post-op Frequency %
'I maintain my pride and keep a stiff upper lip'	50.0	57.1
'I don't let it get to me; Refuse to think too much about it'	50.0	
'I make light of the situation; Refuse to get too serious about it'	51.1	53.6
'I go on as if nothing has happened'	52.1	
'I try to rediscover what is important in life'	52.1	52.4
'I remind myself how much worse things could be'	60.6	54.8
'I look for the silver lining; try to look on the bright side'	64.9	72.6
'I accept the situation, focus on other aspects of my life'	66.0	67.9
'I try to improve my general health'	67.0	71.4
'I try to keep my feelings from interfering too much'	68.1	59.5
'I try to keep my feelings to myself'		51.2

TABLE 7.9: Least frequently used items on WCQ

WCQ items to which over 90% of women responded <u>'not used'</u> or <u>'used occasionally'</u>	3 months post-op Frequency %	12 months post-op Frequency %
'I refuse to believe it has happened'	91.5	
'I do something which I don't think will work, but at least I am doing something'	92.6	90.5
'I think I brought the problem on myself'	93.6	97.6
'I take it out on other people'	93.6	94.0
'I generally avoid being with people'	95.7	97.6
'I try to make myself feel better by eating, drinking, etc'		90.5
'I have fantasies or wishes about how things may turn out'		90.5
'I daydream or imagine a better time or place than the one I am in'		91.7

In addition, two other items ('I talk to someone to find out more about the situation' and 'I accept the situation and focus on other aspects of my life') showed a trend towards lower use at the 3rd assessment but these were not significant ($P=0.09$).

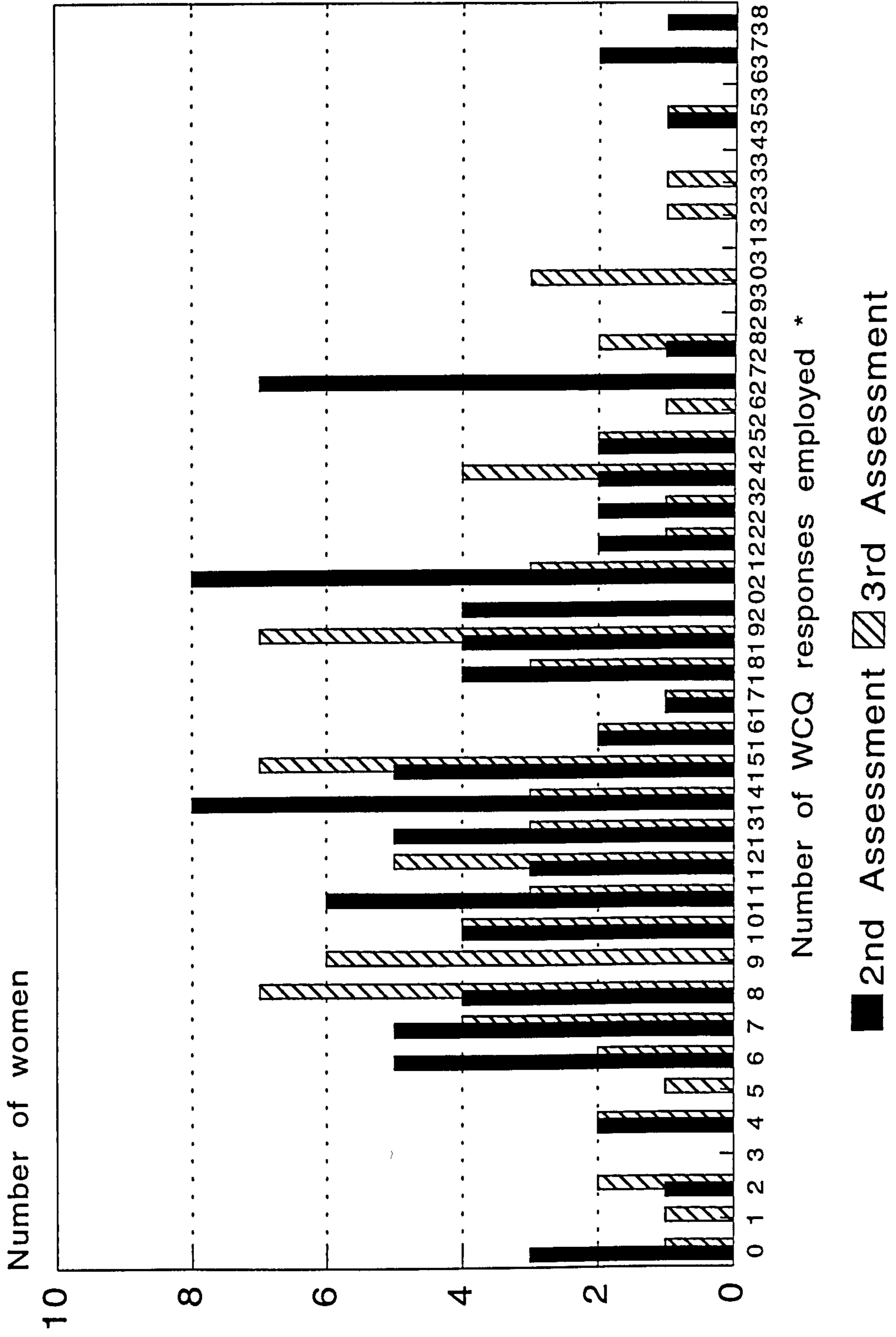
An analysis of the size of the repertoire of responses used by each woman at each assessment (i.e. the number of responses marked as used 'quite a bit' or 'a lot') showed a similar decrease in the overall number of responses employed (figure 4). The median number of responses answered positively fell significantly from the second to the third assessment (Wilcoxon's matched-pairs signed-ranks test $P=0.04$ - table 7.10).

TABLE 7.10: Number of WCQ responses answered as used 'quite a bit' or 'a lot' for women with complete WCQ data (n=80)

	2nd Assessment	3rd Assessment	Wilcoxon's Test
Range	0 - 38	0 - 35	
Mean (SD)	15.94 (8.21)	14.87 (7.96)	
Median	15.0	14.0	$P=0.04$

A group of women were identified who used very few coping responses on the second WCQ. Sixteen women answered fewer than seven items positively which corresponded to one standard deviation below the average number of responses employed. The items which these women did use (answered 'used quite a bit' or 'used a lot') corresponded with the responses used by over 50% of all of the women (see table 7.8), with the addition of the response "I try to forget the whole thing". A similar group was identified on the final WCQ, although only two women were in both groups. Nine women responded to less than 6 items on the 3rd WCQ as used 'quite a bit' or 'a lot'. Of the items which they did report using, one item "I try to improve my general health", was used by 3 of the 9 women. No other item was used consistently.

Figure 4: Repertoire of WCQ responses
 (* Responses answered as used
 'quite a bit' or 'a lot')



Examination of these data also identified a group of women who employed a wide repertoire of responses on the 2nd and 3rd WCQ. More than 25 items were answered as used 'quite a bit' or 'a lot' by fourteen women on the 2nd WCQ. This is equal to 1 SD or more above the mean number of responses employed. Similarly, sixteen women responded positively to more than 23 items on the final WCQ. Seven women were found to be in both groups. There was no consistent pattern for the items which these women did not use.

Overall, the WCQ demonstrated a similar pattern of responses to the interview. Since previous attempts to group the WCQ items into meaningful factors for subsequent analyses had been problematic (see chapter 6), it was decided that the interview alone would be employed in the cross-sectional and longitudinal analysis of relationships with psychological outcome. Individual analyses of the separate items from the WCQ would have meant the inclusion of a very large number of independent variables.

7.3.1.4 Measures of mood

The Hospital Anxiety and Depression Scale

The distribution of scores was different on the anxiety and depression sub-scales of the HAD scale as demonstrated by figures 5 & 6. Scores on both sub-scales decreased sharply after operation, the mean score for both sub-scales being approximately halved by the 2nd assessment and they remained around these levels (table 7.11).

A cut off of eleven on either sub-scale (scores may range from 0 to 21) was suggested by the authors as indicating the probable presence of clinically significant mood disorder (Zigmond & Snaith, 1983). This includes a low false positive rate. However, a cut-off of eight is suggested for inclusion of all possible cases of clinical mood disorder, with a low proportion of false negatives. Almost one third of the women (30.8%) had a score equal to or above the cut-off of eleven on the anxiety sub-scale of the pre-operative HAD scale as opposed to only 2 women (1.9%) on the depression sub-scale (table 7.11). The lower cut-off of eight, which includes the borderline examples of mood disorder, increased these levels so that almost half of the women (45.8%) experienced

Figure 5: Distribution of Scores on HAD Anxiety Sub-scale

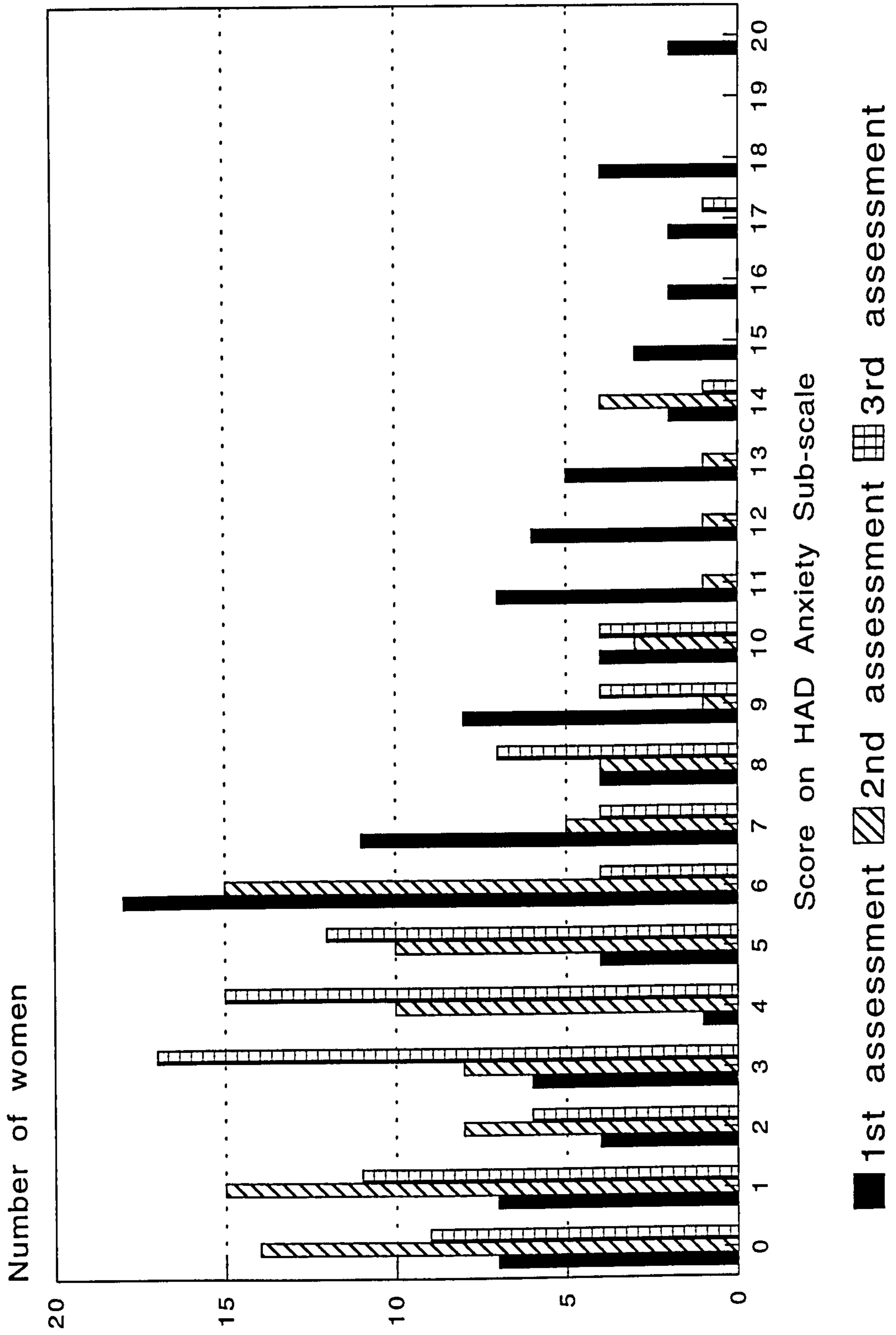
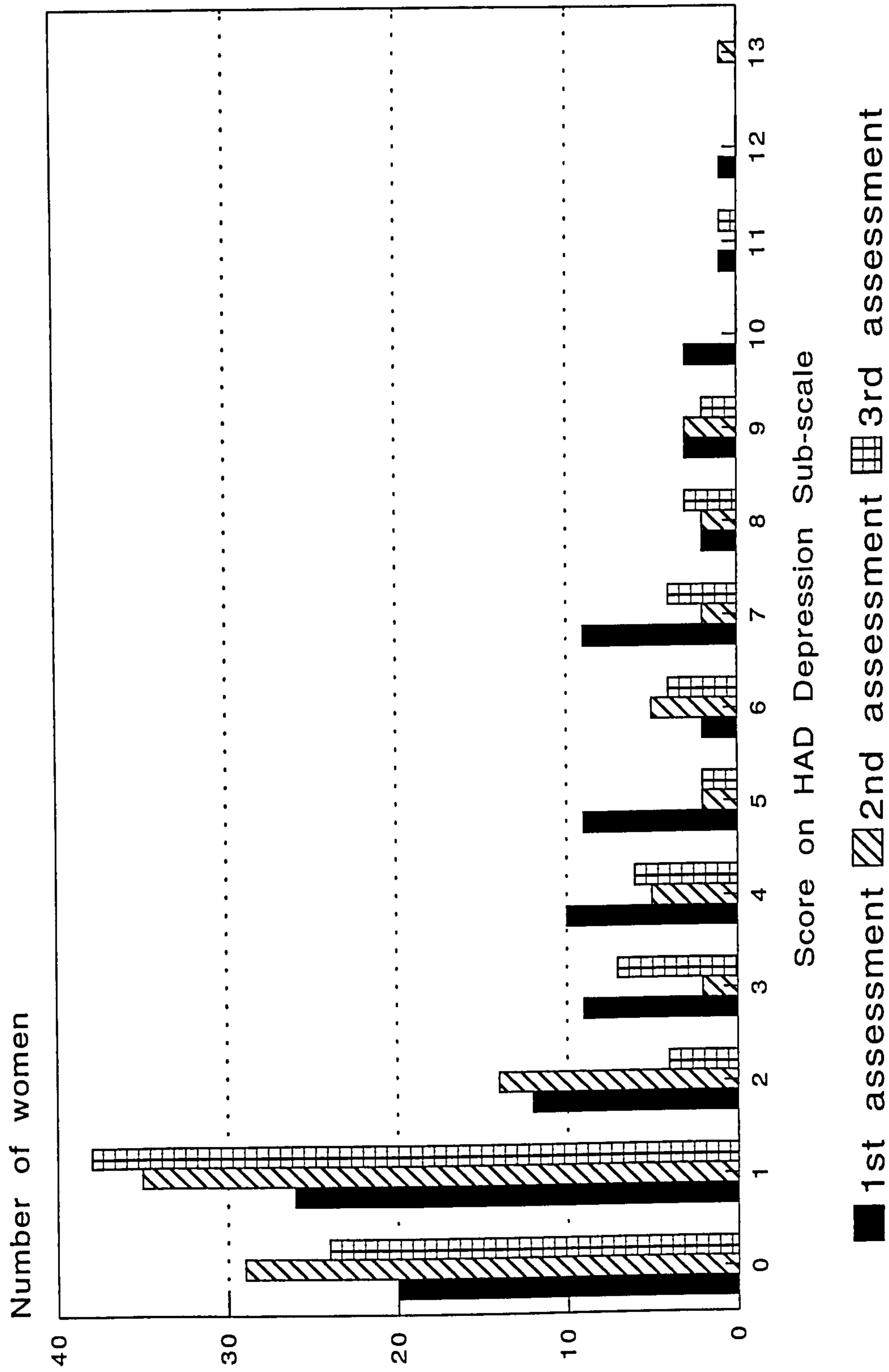


Figure 6: Distribution of Scores on
HAD Depression Sub-scale



pre-operative anxiety. The pre-operative levels of depression were similarly increased, rising to around 10%. Anxiety and depression, according to both cut-off points, fell sharply after operation.

TABLE 7.11: Prevalence of clinical mood disorder during the year after diagnosis using the HAD scale.

	ANXIETY				DEPRESSION			
	Mean (SD)	Median	N scoring \geq 11 (%)	N scoring \geq 8 (%)	Mean (SD)	Median	N scoring \geq 11 (%)	N scoring \geq 8 (%)
Pre-operative (N=107)	8.0 (5.1)	7.0	33 (30.8)	49 (45.8)	3.1 (3.0)	2.0	2 (1.9)	10 (9.3)
3 months post-op (N=100)	4.3 (3.6)	4.0	7 (7.0)	15 (15.0)	2.0 (2.6)	1.0	1 (1.0)	6 (6.0)
12 months post-op (N=95)	4.3 (3.2)	4.0	2 (2.1)	17 (17.9)	2.2 (2.6)	1.0	1 (1.1)	6 (6.3)

Figures 5 and 6 demonstrate that the scores for both sub-scales were not normally distributed, therefore a non-parametric test was used to test for the significance of change in the scores. A Kruskal-Wallis one-way analysis of variance by ranks demonstrated an overall significant fall in both sub-scale scores, although it was more significant for the anxiety sub-scale (H adjusted for ties = 36.37, $P \leq 0.01$) than for depression (H adjusted for ties = 8.86, $P \leq 0.05$). The Wilcoxon matched-pairs signed-ranks test confirmed that scores on both pre-operative sub-scales were significantly higher than on both post-operative assessments. There was no change in median scores between the 2nd and 3rd assessments (table 7.11).

The change in mood disturbance on the HAD scale was also examined in terms of the change from case (score ≥ 8) to non-case (score ≤ 7) over the course of the first post-operative year. Data from the 95 women who completed all three assessments are represented in tables 7.12 and 7.13.

Table 7.12 presents the change for case/non-case for anxiety; the 53 women who were non-cases for anxiety are presented in the first part of the table, with the 42 women who were cases of anxiety presented in the second part. Fifty women were non-cases at all three assessments, whilst 9 women were cases of anxiety at all three assessments. Table 7.13 represents a similar presentation of the data for cases/non-case of depression from the HAD scale. A greater number of women (80) were non-cases of depression at all three assessments, with only one woman remaining a case of depression over the first post-operative year.

TABLE 7.12: Changes in case/non-case of anxiety from the HAD scale over the first post-operative year.

i) Women who were non-cases of anxiety on the pre-operative HAD scale N = 53		12 months post-operative assessment	
		Non-case anxiety (score ≤ 7)	Case anxiety (score ≥ 8)
3 months post-operative assessment	Non-case anxiety (score ≤ 7)	50	1
	Case anxiety (score ≥ 8)	2	

ii) Women who were cases of anxiety on the pre-operative HAD scale N = 42		12 months post-operative assessment	
		Non-case anxiety (score ≤ 7)	Case anxiety (score ≥ 8)
3 months post-operative assessment	Non-case anxiety (score ≤ 7)	25	7
	Case anxiety (score ≥ 8)	1	9

TABLE 7.13: Changes in case/non-case of depression from the HAD scale over the first post-operative year.

i) Women who were non-cases of depression on the pre-operative HAD scale N = 86		12 months post-operative assessment	
		Non-case depression (score ≤ 7)	Case depression (score ≥ 8)
3 months post-operative assessment	Non-case depression (score ≤ 7)	80	3
	Case depression (score ≥ 8)	3	

ii) Women who were cases of depression on the pre-operative HAD scale N = 9		12 months post-operative assessment	
		Non-case depression (score ≤ 7)	Case depression (score ≥ 8)
3 months post-operative assessment	Non-case depression (score ≤ 7)	6	2
	Case depression (score ≥ 8)		1

The Profile of Mood States

Scores on the POMS showed a similar distribution to the HAD scale, with higher levels of tension than depression and an overall fall in disturbed mood after operation. The POMS included normative data for comparisons from psychiatric outpatients and college students (McNair, Lorr & Droppleman, 1981). Neither group was applicable for comparison with a population of women with breast cancer; consequently the scores were not converted to normative scores, and details of the raw scores are presented in table

7.14. The mean scores from the raw data were consistently lower than those of the psychiatric outpatient sample described by the authors of the POMS, with the exception of the vigour scale where the cancer patients scored higher. This was due to reverse scoring of the POMS vigour subscale in the current study in order that increased scores on all subscales would indicate increased mood disturbance. The outpatient sample included patients who were diagnosed as having no disorder. These also scored higher on the POMS sub-scales (except vigour) than the sample from the current study.

TABLE 7.14: Data from the Profile of Mood States.

	Preoperative N=107 Mean (SD) Median	3 Months Post-op N=100 Mean (SD) Median	12 Months Post-op N=95 Mean (SD) Median
Tension (Range 0 - 36)	14.0 (0.9) 11.0	6.6 (0.6) 5.0	6.4 (0.7) 4.0
Depression (Range 0 - 60)	11.0 (1.0) 6.0	5.0 (0.7) 2.0	5.1 (0.8) 2.0
Anger (Range 0 - 48)	7.3 (0.7) 5.0	4.8 (0.5) 4.0	5.0 (0.6) 3.0
Vigour (Range 0 - 32)	14.3 (0.7) 15.0	12.6 (0.7) 12.0	13.2 (0.7) 13.0
Fatigue (Range 0 - 28)	6.6 (0.7) 4.0	5.6 (0.6) 4.0	6.3 (0.7) 5.0
Confusion (Range 0 - 28)	6.8 (0.6) 5.0	4.4 (0.4) 3.5	4.1 (0.4) 3.0
Total score (Range 0 - 232)	60.0 (3.9) 52.0	38.9 (2.8) 31.0	39.6 (3.1) 32.0

The scores on the POMS sub-scales (with the exception of vigour again) were not normally distributed, and tended to be clustered at the lower end of the scale (see appendix 15). A non-parametric test, the Kruskal-Wallis one-way analysis of variance by ranks, was used to test for the significance of change in scores over all three assessments. This demonstrated a significant change in the scores for tension, depression, anger and confusion as well as the total score for mood disturbance (table 7.15). The Wilcoxon matched-pairs signed-ranks test confirmed that the pre-operative scores were significantly higher than scores on both post-operative assessments. The overall changes in the scores on vigour and fatigue across the three assessments were not significant, but the Wilcoxon's test demonstrated a significant fall in the scores on the vigour sub-scale from the first to the second assessment only.

TABLE 7.15: Analyses of the change in scores on the POMS sub-scales across all three assessments.

POMS sub-scale	Kruskal-Wallis analysis H adjusted for ties (P value)	Wilcoxon's test 1st POMS -> 2nd POMS Wilcoxon's statistic (P value)	Wilcoxon's test 1st POMS -> 3rd POMS Wilcoxon's statistic (P value)	Wilcoxon's test 2nd POMS -> 3rd POMS Wilcoxon's statistic (P value)
Tension	45.22 (P<0.01)	3652.0 (P=0.000)	3729.0 (P=0.000)	1832.5 (P=0.546)
Depression	25.36 (P<0.01)	3001.0 (P=0.000)	3050.0 (P=0.000)	1204.0 (P=0.852)
Anger	9.81 (P<0.01)	2642.0 (P=0.000)	2516.5 (P=0.001)	1622.0 (P=0.994)
Vigour	2.80 (P>0.05)	2592.5 (P=0.016)	2360.5 (P=0.094)	1428.5 (P=0.360)
Fatigue	1.18 (P>0.05)	1728.5 (P=0.350)	1638.0 (P=0.408)	1157.0 (P=0.056)
Confusion	8.72 (P<0.05)	2695.5 (P=0.000)	2496.5 (P=0.000)	1621.0 (P=0.690)
POMS Total Score	19.20 (P<0.01)	3828.5 (P=0.000)	3669.0 (P=0.000)	2089.0 (P=0.989)

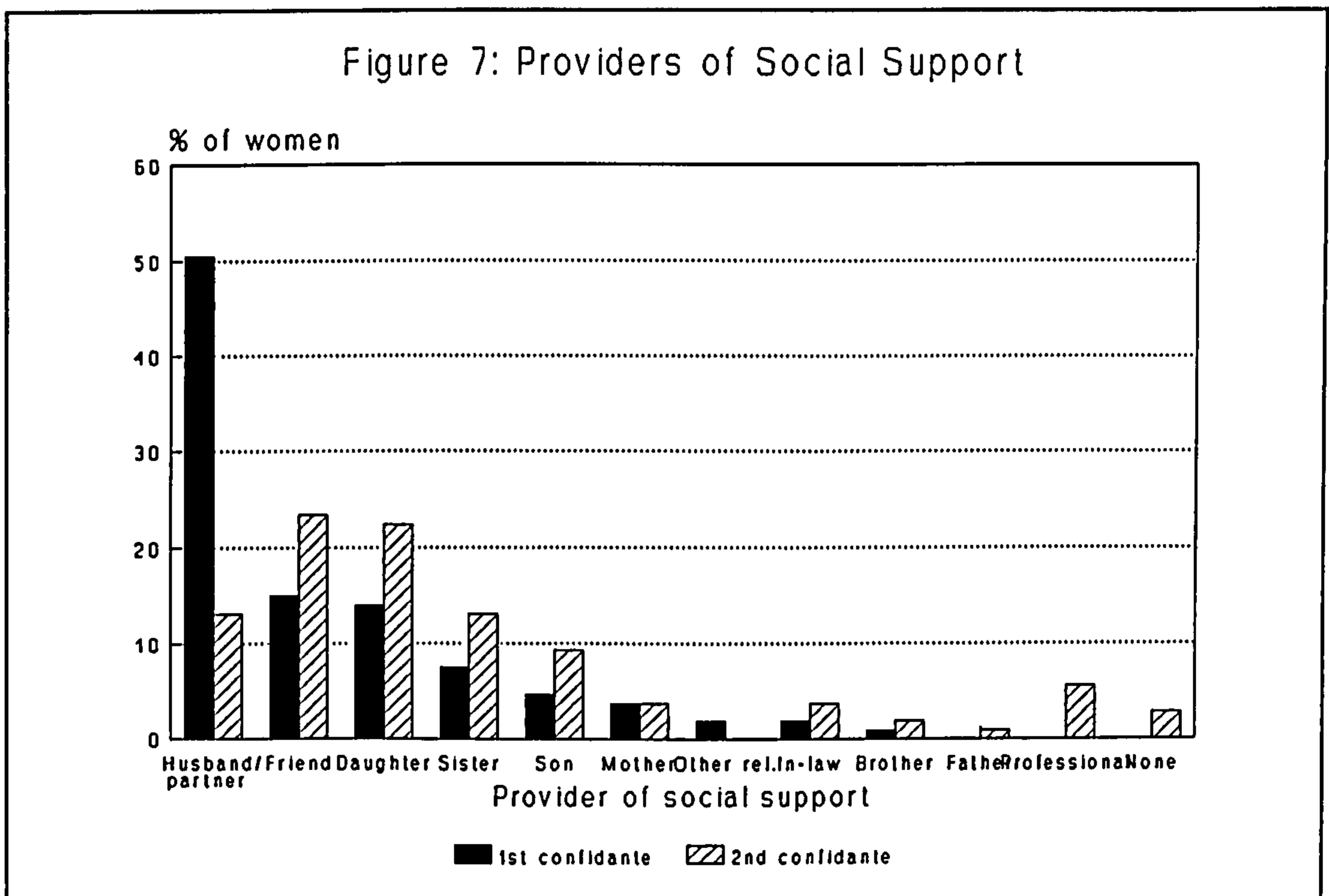
7.3.1.5 Measure of social support

The Self-Evaluation and Social Support Schedule (SESS)

Information collected at the pre-operative interview on the providers of social support

demonstrated that half of the women would turn to their husband or partner as the first person they seek support from (figure 7). Almost one third (29%) reported that they would initially seek support from a friend or their daughter (15% and 14% respectively). In addition, friends and daughters were most frequently sought as second confidantes. No one reported that they did not have anyone they could ask for support.

The majority of the women (79.4%) stated that the support they received from their first confidante was close and intimate and they felt able to confide any concern they wished (table 7.16). A smaller majority (60%) felt close to their second confidante and able to discuss anything which was worrying them. Four women did not feel close to their first source of support and were not able to discuss their worries. A larger number expressed similar difficulties with their second source of support (8.4%). Three women reported that they only had one confidante.



Brown and Harris (1978) suggested that women can be buffered from the deleterious effects of stressful life events if they are in receipt of 'positive social support', particularly if it is provided by a husband or partner. They define 'positive social support' as moderate or high levels of confiding and active emotional support with little or no negative or critical responses from a confidante. According to this definition, less than half of the women were in receipt of positive support from their partner, although this percentage increased to around three quarters of the women with the inclusion of positive support from other confidantes (table 7.17). Consequently, between one quarter and one third of the women with breast cancer did not receive this important form of support in their first pre-operative year.

TABLE 7.16: Data on social support derived from the Social Evaluation and Social Support Schedule.

Quality of confiding:	First confidante		Second confidante	
	N	(%)	N	(%)
Close, intimate and confiding	85	(79.4)	65	(60.7)
Impossible to discuss some topics	18	(16.8)	30	(28.0)
Not very close	4	(3.7)	9	(8.4)
Non-applicable	0	(0)	3	(2.8)

TABLE 7.17: Data on positive social support derived from the Social Evaluation and Social Support Schedule:

	Pre-operative N=107		3 Months post-op N=100		12 Months post-op N=96	
	N	(%)	N	(%)	N	(%)
Positive support from spouse or partner	48	(44.9)	42	(42.0)	35	(36.5)
Positive support from first confidante (not spouse/partner)	32	(29.9)	25	(25.0)	32	(33.3)
No positive support	27	(25.2)	33	(33.0)	29	(30.2)

These data can be further examined in relation to the changes in positive support over time for the 95 women who completed all three assessments (table 7.18). Table 7.18 is subdivided according to the support received by these women at the pre-operative assessment. Thus, those women who received no support prior to operation are in table 7.18i). This also contains details of the support they subsequently received at both post operative assessments.

It can be seen that eight women did not receive positive support from anyone at any of three assessments. Alternatively, thirty women reported receiving positive support from their spouse/partner at all assessments, and a further seventeen women received positive support from either their partner or another first confidante at all of the assessments.

TABLE 7.18: Changes in the receipt of positive support over the first post-operative year.

i) Women who received no positive support at pre-operative assessment N = 21		12 months post-operative assessment		
		No positive support	Positive support from 1st confidante	Positive support from spouse/partner
3 months post-op assessment	No positive support	8	6	1
	Positive support from first confidante (not spouse/partner)	2	4	
	Positive support from spouse/partner			

ii) Women who received positive support from first confidante (not spouse/partner) at pre-operative assessment N = 29		12 months post-operative assessment		
		No positive support	Positive support from first confidante	Positive support from spouse/partner
3 months post-op assessment	No positive support	7	2	
	Positive support from first confidante (not spouse/partner)	4	11	
	Positive support from spouse/partner	2	2	1

iii) Women who received positive support from spouse/partner at pre-operative assessment N = 45		12 months post-operative assessment		
		No positive support	Positive support from first confidante	Positive support from spouse/partner
3 months post-op assessment	No positive support	3	1	2
	Positive support from first confidante (not spouse/partner)		1	1
	Positive support from spouse/partner	3	4	30

TABLE 7.19: Data on negative social support derived from the Social Evaluation and Social Support Schedule.

	Pre-operative N=107		3 Months post-op N=100		12 Months post-op N=96	
	N	(%)	N	(%)	N	(%)
Some/moderate/marked negative support from spouse or partner	4	(3.7)	2	(2.0)	5	(5.2)
Some/moderate/marked negative support from first confidante (not spouse/partner)	1	(0.9)	2	(2.0)	0	
Little or no negative support	102	(95.3)	96	(96.0)	91	(94.8)

The receipt of negative support has also been associated with poor psychological outcome (see chapter 3). The Social Evaluation and Social Support Schedule enables the collection of these data which are presented in table 7.19. Few women reported receiving any negative support or criticisms from their first confidante. Of these women, only one received negative support on more than one occasion. She reported receiving moderate negative support from her husband at three months after operation and marked negative support at one year.

7.3.2 CROSS-SECTIONAL ANALYSES

These analyses examine the relationships between variables which were assessed at the same time point; for example, pre-operative social support was analysed in relation to pre-operative measures of mood. Although the variables do not all conform to a normal distribution, statistical advice suggested that parametric tests should be employed in order to ensure compatibility with the final multivariate analyses.

The anxiety and depression sub-scales of the HAD scale were analysed both as continuous measures of mood disturbance as well as a dichotomous scale of case (score ≥ 8) and non-case (score ≤ 7). The sub-scales on the POMS were measured as continuous scores where a higher score represented a greater degree of mood disturbance (scoring for the vigour scale was reversed in order to conform to this pattern).

7.3.2.1 Cognitive and behavioral coping responses and measures of mood

Cognitive and behavioural coping variables were coded either 'yes' or 'no' depending on whether they were reported in the interviews. The number of times a response was reported was not included in the analyses as this may have represented the amount the woman spoke rather than the degree to which each response was used. These responses were analysed in relation to all measures of mood using t-tests for independent samples. In addition, the HAD scale was analysed as a dichotomous scale for cases and non-cases using the chi-square (or Fisher exact probability test for smaller numbers).

Significant associations were found with many of the cognitive and behavioural responses (table 7.20). The performance of a large number of analyses increases the probability of significant associations being found by chance, which can be controlled for by applying Bonferonni's correction. This was used to reduce the probability of finding a false positive result to $P=0.05$ for each coping response from the Faith Courtauld Coping Schedule. Thus, since each coping response was analysed in relation to eleven different measures of mood (HAD anxiety and depression sub-scales analysed as continuous and

dichotomous data, the six sub-scales and the total score on the POMS), Bonferroni's correction requires a significance of less than $^{0.05}/_{11}=0.005$ (significant results ≤ 0.005 in italics in table 7.20). Correlations between the measures of mood means that Bonferroni's correction is a conservative method of controlling for spurious results.

Using this criterion, one response, fear of diagnosis, was found to be significantly associated (i.e. ≤ 0.005) with almost all measures of mood at all three time points, which meant that women who perceived the diagnosis as a threat at any time in the first post-operative year had significantly higher mood disturbance. A pre-occupation with thoughts of the disease was also significantly related to increased mood disturbance on almost all measures of mood but only at the twelve month post-operative assessment. Conversely, cognitive attempts to avoid thinking about the disease or threat of the diagnosis was associated with lower mood disturbance on most measures of mood at the pre-operative assessment. Attempts to return to normal life and routine were also associated with lower scores on the POMS sub-scales for fatigue and confusion before the operation.

Three months after operation, those women who expressed pessimism about their prognosis, believing that the disease would almost certainly recur had raised scores for anxiety on the HAD scale as well as depression and total score on the POMS. One year after operation, active attempts to aid recovery from the disease were associated with decreased anger on the POMS, whilst concern about the treatment of the disease was associated with lower reported vigour on the POMS.

Table 7.20: Cognitive and behavioural responses from the coping interview which were significantly associated with mood disturbance measured at the same time point during the first post-operative year.

Category from coping interview	Pre-operative assessment	3 months post-operation	12 months post-operation
Fear of diagnosis	<p>* Yes = 85 No = 22</p> <p>Case HAD anxiety $p < 0.005$ $X^2 = 8.51$ (45/85 vs 4/22)</p> <p>Mean HAD anxiety $p < 0.005$ $t = -3.03$ *8.68 (5.12) vs 5.14 (3.82)</p> <p>Mean POMS tension $p < 0.001$ $t = -4.42$ *15.42 (9.63) vs 8.32 (5.73)</p> <p>Mean POMS depression $p < 0.001$ $t = -4.08$ *12.52 (12.01) vs 5.14 (5.88)</p> <p>Mean POMS vigour $p \leq 0.001$ $t = -3.58$ *15.55 (7.06) vs 9.59 (6.55)</p> <p>Mean POMS fatigue $p \leq 0.005$ $t = -2.91$ *7.40 (7.15) vs 3.73 (4.66)</p> <p>Mean POMS confusion $p \leq 0.001$ $t = -3.50$ *7.49 (6.40) vs 3.95 (3.44)</p> <p>Mean POMS Total $p < 0.001$ $t = -4.20$ *65.75 (41.48) vs 37.45 (23.57)</p>	<p>Yes = 42 No = 58</p> <p>Case HAD anxiety $p < 0.001$ $X^2 = 19.09$ (14/42 vs 1/58)</p> <p>Case HAD depression $p < 0.005$ Fishers Exact Test (6/42 vs 0/58)</p> <p>Mean HAD anxiety $p < 0.005$ $t = -3.02$ *5.67 (4.49) vs 3.36 (2.43)</p> <p>Mean HAD depression $p < 0.01$ $t = -2.72$ *2.86 (3.23) vs 1.36 (1.77)</p> <p>Mean POMS tension $p \leq 0.01$ $t = -2.61$ *8.57 (7.72) vs 5.10 (4.48)</p> <p>Mean POMS depression $p < 0.005$ $t = -3.24$ *7.67 (8.62) vs 2.98 (4.34)</p> <p>Mean POMS vigour $p < 0.01$ $t = -2.72$ *14.60 (6.09) vs 11.08 (6.58)</p> <p>Mean POMS confusion $p < 0.01$ $t = -2.85$ *5.90 (5.36) vs 3.29 (3.00)</p> <p>Mean POMS Total $p < 0.005$ $t = -2.96$ 49.12 (35.05) vs 31.45 (19.24)</p>	<p>Yes = 47 No = 48</p> <p>Case HAD anxiety $p < 0.001$ $X^2 = 16.51$ (16/47 vs 1/48)</p> <p>Mean HAD anxiety $p < 0.001$ $t = -4.71$ *5.72 (3.56) vs 2.92 (2.04)</p> <p>Mean HAD depression $p < 0.005$ $t = -3.23$ *3.00 (2.96) vs 1.35 (1.87)</p> <p>Mean POMS tension $p < 0.001$ $t = -4.55$ *9.15 (7.32) vs 3.67 (3.86)</p> <p>Mean POMS depression $p \leq 0.01$ $t = -2.65$ *7.13 (9.11) vs 3.13 (4.98)</p> <p>Mean POMS vigour $p < 0.005$ $t = -3.22$ *15.38 (6.44) vs 11.00 (6.82)</p> <p>Mean POMS fatigue $p < 0.05$ $t = -2.06$ *7.68 (7.46) vs 5.02 (4.86)</p> <p>Mean POMS confusion $p < 0.001$ $t = -4.16$ *5.60 (4.42) vs 2.63 (2.12)</p> <p>Mean POMS Total $p \leq 0.001$ $t = -3.50$ 50.32 (33.56) vs 29.79 (22.29)</p>
Concern re treatment		<p>Yes = 36 No = 64</p> <p>Mean POMS tension $p < 0.05$ $t = -2.27$ *8.42 (6.99) vs 5.52 (5.60)</p>	<p>Yes = 29 No = 66</p> <p>Mean POMS tension $p < 0.05$ $t = -2.34$ *8.66 (7.12) vs 5.38 (5.88)</p> <p>Mean POMS anger $p \leq 0.05$ $t = -2.00$ *7.00 (7.14) vs 4.08 (5.07)</p> <p>Mean POMS vigour $p < 0.005$ $t = -3.08$ *16.34 (6.42) vs 11.77 (6.77)</p> <p>Mean POMS Total $p < 0.05$ $t = -2.32$ 50.52 (33.56) vs 35.30 (27.45)</p>

* Yes = Number of women using coping response; No = Number of women not using coping response

*(Number of women using coping response who are distressed vs number of women not using coping response who are distressed)

*Mean score (SD) of women using coping response vs mean score (SD) of women not using coping response

Table 7.20 (contd.): Cognitive and behavioural responses from the coping interview which were significantly associated with mood disturbance measured at the same time point during the first post-operative year.

Category from coping interview	Pre-operative assessment	3 months post-operation	12 months post-operation
Pre-occupation with disease		<p>*Yes = 13 No = 87</p> <p>Case HAD anxiety $p < 0.02$ Fisher Exact Test *(5/13 v 10/87)</p> <p>Case HAD depression $p < 0.03$ Fishers Exact Test *(3/13 v 3/87)</p>	<p>Yes = 9 No = 86</p> <p>Case HAD anxiety $p < 0.01$ Fishers Exact test *(5/9 vs 12/86)</p> <p>Case HAD depression $P \leq 0.01$ Fishers Exact Test *(3/9 vs 3/86)</p> <p><i>Mean HAD anxiety $p < 0.001$</i> <i>$t = -4.32$</i> <i>*8.33 (4.15) vs 3.88 (2.80)</i></p> <p><i>Mean HAD depression $p < 0.001$</i> <i>$t = -5.09$</i> <i>*5.89 (2.71) vs 1.78 (2.26)</i></p> <p><i>Mean POMS tension $p < 0.001$</i> <i>$t = -4.17$</i> <i>*14.22 (6.59) vs 5.56 (5.86)</i></p> <p><i>Mean POM depression $p \leq 0.001$</i> <i>$t = -3.59$</i> <i>*13.22 (8.47) vs 4.26 (6.98)</i></p> <p>Mean POMS anger $p < 0.05$ $t = -2.25$ <i>*7.92 (8.18) vs 4.36 (4.80)</i></p> <p><i>Mean POMS vigour $P \leq 0.005$</i> <i>$t = -2.89$</i> <i>*17.31 (6.12) vs 11.85 (6.38)</i></p> <p>Mean POMS fatigue $p < 0.001$ $t = -5.79$ <i>*16.44 (6.43) vs 5.28 (5.41)</i></p> <p>Mean POMS confusion $p < 0.01$ $t = -3.44$ <i>*9.78 (5.38) vs 3.5 (3.01)</i></p> <p>Mean POMS Total $p < 0.001$ $t = -5.55$ <i>*86.11 (25.43) vs 35.12 (26.30)</i></p>
Acceptance of the disease	<p>Yes = 33 No = 74</p> <p>Mean HAD anxiety $p < 0.01$ $t = 2.65$ <i>*6.06 (4.51) vs 8.80 (5.1)</i></p> <p>Mean POMS tension $p < 0.05$ $t = 2.15$ <i>*11.09 (8.65) vs 15.24 (9.49)</i></p> <p>Mean POMS confusion $p < 0.05$ $t = 2.17$ <i>*5.21 (3.90) vs 7.46 (6.74)</i></p>	<p>Yes = 25 No = 75</p> <p>Mean POMS confusion $p < 0.05$ $t = 2.44$ <i>*2.6 (2.66) vs 4.99 (4.63)</i></p>	

Yes = Number of women using coping response; No = Number of women not using coping response

*(Number of women using coping response who are distressed vs number of women not using coping response who are distressed)

*Mean score (SD) of women using coping response vs mean score (SD) of women not using coping response

Table 7.20 (contd.):

Category from coping interview	Pre-operative assessment	3 months post-operation	12 months post-operation
Avoiding thinking about the threat of diagnosis	Yes = 86 No = 21 Mean POMS vigour $p < 0.05$ $t = 2.16$ *13.58 (7.35) vs 17.38 (6.61)		
Cognitive action to change meaning of diagnosis	Yes = 3 No = 104 Mean POMS tension $p \leq 0.005$ $t = 3.71$ *9.33 (1.53) vs 14.10 (9.50)		
Difficulties assimilating threat of diagnosis	#Yes = 41 No = 66 Mean POM confusion $p < 0.05$ $t = -2.04$ *8.39 (7.23) vs 5.76 (5.04)		
Not thinking/not worried about diagnosis	Yes = 23 No = 84 Case HAD anxiety $p < 0.005$ $X^2 = 9.52$ *(4/23 vs 45/84) Mean HAD anxiety $p \leq 0.001$ $t = 3.40$ *4.91 (3.52) vs 8.79 (5.13) Mean POMS tension $p < 0.001$ $t = 4.09$ *8.61 (6.21) vs 15.43 (9.62) Mean POM depression $p < 0.001$ $t = 5.04$ *4.48 (4.77) vs 12.79 (12.05) Mean POMS fatigue $p < 0.05$ $t = 2.23$ *4.39 (4.87) vs 7.26 (7.21) Mean POM confusion $p < 0.001$ $t = 3.87$ *4.09 (2.47) vs 7.50 (6.56) Mean POMS Total $p < 0.001$ $t = 4.31$ *38.39 (21.13) vs 65.83 (42.05)	Yes = 39 No = 64 Mean POMS depression $p < 0.05$ $t = 2.13$ *3.33 (4.56) vs 5.98 (7.85) Mean POMS anger $p < 0.05$ $t = 2.35$ *3.26 (3.77) vs 5.82 (6.10) Mean POMS confusion $p \leq 0.05$ $t = 1.98$ *3.33 (3.57) vs 5.07 (4.66)	
Avoidance of relevant information	Yes = 10 No = 97 Mean POMS tension $p \leq 0.05$ $t = -1.98$ *19.5 (7.44) vs 13.39 (9.43)	Yes = 15 No = 85 Mean POMS depression $p < 0.05$ $t = -2.33$ *8.67 (7.93) vs 4.29 (6.48) Mean POMS Total $p \leq 0.05$ $t = -1.97$ *51.93 (25.79) vs 36.56 (28.19)	

* Yes = Number of women using coping response; No = Number of women not using coping response

*(Number of women using coping response who are distressed vs number of women not using coping response who are distressed)

+Mean score (SD) of women using coping response vs mean score (SD) of women not using coping response

Table 7.20 (contd.):

Category from coping interview	Pre-operative assessment	3 months post-operation	12 months post-operation
Use of humour regarding diagnosis/treatment	<p>Yes = 4 No = 103</p> <p>Mean HAD anxiety $p < 0.05$ $t = 2.23$ $^*2.5 (2.08) vs 8.17 (5.04)$</p> <p>Mean HAD depression $p < 0.001$ $t = 6.32$ $^*0.75 (0.5) vs 3.20 (3.02)$</p> <p>Mean POMS tension $p < 0.01$ $t = 4.47$ $^*4.75 (3.86) vs 14.32 (9.38)$</p>		
Positive appraisal of the disease			<p>Yes = 43 No = 52</p> <p>Mean POMS vigour $p < 0.05$ $t = 2.37$ $^*11.35 (7.01) vs 14.67 (6.61)$</p> <p>Mean POMS confusion $p < 0.01$ $t = 2.73$ $^*3.02 (2.56) vs 4.98 (4.33)$</p>
Positive appraisal of life in general	<p>Yes = 10 No = 97</p> <p>Mean POMS confusion $p < 0.05$ $t = 2.43$ $^*4.5 (2.55) vs 7.0 (6.29)$</p>	<p>Yes = 58 No = 42</p> <p>Mean POMS anger $p \leq 0.01$ $t = -2.62$ $^*5.91 (6.25) vs 3.31 (3.63)$</p>	<p>Yes = 61 No = 34</p> <p>Case HAD depression $p < 0.05$ Fisher Exact Test $^*(1/61 vs 5/34)$</p>
Use of religion		<p>[†]Yes = 8 No = 92</p> <p>Mean POMS fatigue $p \leq 0.01$ $t = -2.64$ $^*11.0 (5.88) vs 5.12 (6.07)$</p> <p>Mean POMS Total $p < 0.05$ $t = -2.28$ $^*59.63 (44.89) vs 37.07 (25.93)$</p>	<p>Yes = 6 No = 89</p> <p>Mean HAD depression $p < 0.05$ $t = -2.91$ $^*0.83 (0.98) vs 2.26 (2.64)$</p>
Seeking social support			<p>Yes = 15 No = 80</p> <p>Mean POMS anger $p < 0.05$ $t = -2.06$ $^*7.8 (6.86) vs 4.44 (5.59)$</p>
Behaviours to aid recovery		<p>Yes = 7 No = 93</p> <p>Mean POMS fatigue $p < 0.05$ $t = 2.77$ $^*3.0 (2.0) vs 5.78 (6.4)$</p>	<p>Yes = 7 No = 88</p> <p>Mean POMS anger $p < 0.005$ $t = 3.17$ $^*2.29 (1.70) vs 5.18 (6.06)$</p>

[†] Yes = Number of women using coping response; No = Number of women not using coping response

^{*}(Number of women using coping response who are distressed vs number of women not using coping response who are distressed)

⁺Mean score (SD) of women using coping response vs mean score (SD) of women not using coping response

Table 7.20 (contd.):

Coping interview	Pre-operative assessment	3 months post-operation	12 months post-operation
Returning to normal	<p>Yes = 11 No = 96 Mean POMS tension $p < 0.05$ $t = 2.23$ *8.09 (9.53) vs 14.64 (9.20)</p> <p>Mean POMS vigour $p < 0.05$ $t = 2.56$ *9.09 (7.97) vs 14.93 (7.06)</p> <p><i>Mean POMS fatigue $p < 0.001$</i> $t = 4.24$ *2.55 (2.66) vs 7.11 (7.04)</p> <p><i>Mean POMS confusion $p < 0.001$</i> $t = 5.42$ *2.27 (2.24) vs 7.28 (6.17)</p> <p>Mean POMS Total $p < 0.05$ $t = 2.47$ *35.18 (34.52) vs 62.77 (39.84)</p>		
Belief in a good prognosis		<p>*Yes = 22 No = 78 Mean POMS vigour $p < 0.05$ $t = 2.34$ *9.73 (6.54) vs 13.36 (6.41)</p>	
Uncertainty regarding prognosis		<p>Yes = 82 No = 18 Mean POMS fatigue $p < 0.05$ $t = 2.01$ *5.01 (5.69) vs 8.22 (7.95)</p>	
Not considered prognosis at all		<p>Yes = 4 No = 96 Mean POMS vigour $p < 0.05$ $t = -2.03$ *19.0 (8.45) vs 12.29 (6.41)</p>	
Belief in a poor prognosis		<p>*Yes = 4 No = 96 Mean HAD anxiety $p < 0.005$ $t = -3.20$ *9.75 (4.43) vs 4.10 (3.42)</p> <p><i>Mean POMS depression</i> $p < 0.001$ $t = -4.11$ *17.75 (8.54) vs 4.42 (6.28)</p> <p>Mean POMS anger $p < 0.05$ $t = -2.17$ *10.5 (7.05) vs 4.58 (5.28)</p> <p>Mean POMS fatigue $p < 0.05$ $t = -2.40$ *12.75 (9.07) vs 5.29 (5.97)</p> <p>Mean POMS confusion $p < 0.05$ $t = -1.96$ *8.5 (7.72) vs 4.22 (4.12)</p> <p><i>Mean POMS Total $p < 0.005$</i> $t = -3.22$ *81.50 (40.84) vs 37.09 (26.45)</p>	<p>Yes = 8 No = 87</p> <p>Mean POMS vigour $p < 0.05$ $t = -2.03$ *17.88 (7.68) vs 12.74 (6.77)</p>

* Yes = Number of women using coping response; No = Number of women not using coping response

*(Number of women using coping response who are distressed vs number of women not using coping response who are distressed)

*Mean score (SD) of women using coping response vs mean score (SD) of women not using coping response

Table 7.20 (contd.):

Category from coping interview	Pre-operative assessment	3 months post-operation	12 months post-operation
Believes in some control over disease outcome		Yes = 54 No = 46 Case IIAD depression $p < 0.01$ Fisher Exact Test [*] (0/54 v 6/46)	Yes = 38 No = 57 Mean IIAD anxiety $p < 0.05$ $t = -2.03$ [*] 3.5 (2.74) vs 4.84 (3.40)
Believes in little control over disease outcome		Yes = 32 No = 68 Mean IIAD anxiety $p \leq 0.05$ $t = -2.01$ [*] 5.53 (4.52) vs 3.76 (2.97)	Yes = 39 No = 56 Mean IIAD depression $p \leq 0.01$ $t = -2.60$ [*] 3.0 (2.8) vs 1.59 (2.29)

^{*} Yes = Number of women using coping response; No = Number of women not using coping response

^{*}(Number of women using coping response who are distressed vs number of women not using coping response who are distressed)

^{*}Mean score (SD) of women using coping response vs mean score (SD) of women not using coping response

The number of cognitive and behavioural responses used (i.e. the repertoire of coping responses) was also examined in relation to mood disturbance assessed at the same time point. Correlations between the number of coping strategies and mood scores demonstrated significant associations at the post-operative assessments only (in italics in table 7.21). The greater the number of coping strategies employed, the higher the levels of mood disturbance, with more significant associations at one year after operation than at 3 months. No significant associations were found between repertoire of coping responses and mood using dichotomous scoring on the HAD scale (case and non-case) using t-tests for independent samples.

Table 7.21: Correlations between the number of coping strategies used and the continuous measures of mood disturbance.

Measure of mood	Pre-operative		3 months post-operative		1 year post-operative	
	Correlation	p	Correlation	p	Correlation	p
HAD anxiety	-0.072	p=0.463	<i>0.205</i>	<i>p=0.041</i>	<i>0.220</i>	<i>p=0.032</i>
HAD depression	-0.007	p=0.944	0.055	p=0.587	0.167	p=0.106
POMS tension	-0.076	p=0.438	<i>0.227</i>	<i>p=0.023</i>	<i>0.218</i>	<i>p=0.034</i>
POMS depression	-0.021	p=0.830	0.125	p=0.217	0.100	p=0.333
POMS anger	-0.037	p=0.709	<i>0.239</i>	<i>p=0.017</i>	0.137	p=0.184
POMS vigour	-0.095	p=0.332	0.138	p=0.172	<i>0.222</i>	<i>p=0.030</i>
POMS fatigue	-.0122	p=0.210	0.079	p=0.436	<i>0.210</i>	<i>p=0.041</i>
POMS confusion	-0.081	p=0.408	0.148	p=0.142	<i>0.219</i>	<i>p=0.033</i>
POMS Total score	-0.081	p=0.408	<i>0.199</i>	<i>p=0.048</i>	<i>0.216</i>	<i>p=0.036</i>

7.3.2.2 Social and demographic variables and measures of mood

Similar analyses to those employed with cognitive and behavioural coping responses were used to analyse social and demographic variables in relation to all measures of mood at the three assessments. Dichotomous data were analysed using independent T-tests or chi-square when the dependent variables were also dichotomous (e.g. HAD scale case/non-case). One-way analysis of variance was employed in the analyses of variables with more than two factors in relation to dependent variables with continuous data. In addition, continuous variables such as age were analysed using Pearson's Product Moment Correlation co-efficient. Age was also analysed as a dichotomous variable using a median cut-off to divide the sample into those women aged 54 years or less and women older than 55 years. Significant results are presented in table 7.22.

The majority of significant associations was found with measures of mood from the pre-operative assessment. Application of Bonferroni's correction ($P \leq 0.005$ in italics in table 7.22) greatly reduces the number of significant associations. Of those remaining, increased mood disturbance from both the HAD scale and the POMS were found with younger age (looking at age as both a continuous variable and a dichotomous split according to median age) and a history of previous psychiatric treatment from either a G.P. or Psychiatrist. Women who had a child aged under 6 years had increased scores for depression on the HAD scale, although this may be confounded with the age of the women. Interestingly, the association with age was reversed at the third assessment where women who scored ≥ 8 on the HAD depression sub-scale were found to be significantly older than non-cases.

A further unexpected association was found with those women who said that they actively practised their religion, such as by attending church. They were found to have decreased anger on the POMS at the pre-operative interview, but this reversed after operation. The practising of religion was associated with lower reports of vigour on the POMS.

Table 7.22: Significant associations between social and demographic variables and measures of mood in the first post-operative year

Social and demographic variables	Pre-operative assessment	3 months post-op	12 months post-operation
Age (range 24-69 years)	<p><i>Case HAD anxiety</i> $p < 0.005$ $t = 3.21$ ¹56.74 (9.48) vs 50.39 (11.02)</p> <p><i>Mean HAD anxiety</i> $p < 0.001$ Correlation = 0.381</p> <p>Mean HAD depression $p < 0.05$ Correlation = -0.243</p> <p><i>Mean POMS tension</i> $p \leq 0.005$ Correlation = -0.270</p> <p><i>Mean POMS depression</i> $p \leq 0.001$ Correlation = -0.309</p> <p>Mean POMS anger $p < 0.05$ Correlation = -0.238</p> <p>Mean POMS fatigue $p < 0.05$ Correlation = -0.194</p> <p><i>Mean POMS confusion</i> $p < 0.001$ Correlation = -0.343</p> <p><i>Mean POMS Total</i> $p < 0.005$ Correlation = -0.287</p>		<p><i>Case HAD depression</i> $p < 0.005$ $t = -4.50$ ¹53.70 (10.71) vs 64.33 (5.09)</p>
Age: median split ≤ 54 years vs ≥ 55 years	<p>N ≤ 54 yrs = 52 N ≥ 55 yrs = 55</p> <p><i>Case HAD anxiety</i> $p < 0.05$ $\chi^2 = 5.77^2$ (30/52 vs 19/55)</p> <p><i>Mean HAD anxiety</i> $p \leq 0.001$ $t = 3.27$ ⁴9.54 (5.32) vs 6.45 (4.37)</p> <p>Mean HAD depression $p \leq 0.05$ $t = 1.97$ ⁴3.69 (3.23) vs 2.56 (2.67)</p> <p>Mean POMS tension $p \leq 0.05$ $t = 1.96$ ⁴15.77 (10.03) vs 12.25 (8.5)</p> <p>Mean POMS depression $p \leq 0.01$ $t = 2.55$ ⁴13.85 (12.59) vs 8.31 (9.52)</p> <p>Mean POMS anger $p < 0.05$ $t = 2.32$ ⁴8.85 (7.94) vs 5.75 (5.75)</p> <p>Mean POMS fatigue $p < 0.05$ $t = 2.54$ ⁴8.35 (7.49) vs 5.04 (5.83)</p> <p><i>Mean POMS confusion</i> $p \leq 0.001$ $t = 3.33$ ⁴8.71 (7.05) vs 4.93 (4.29)</p> <p>Mean POMS Total $p \leq 0.01$ $t = 2.59$ ⁴70.06 (44.53) vs 50.36 (32.98)</p>		<p>N ≤ 54 yrs = 43 N ≥ 55 yrs = 52</p> <p><i>Case HAD depression</i> $p < 0.05$ Fisher Exact Test ²(0/43 vs 6/52)</p>

¹ Mean age of women with HAD score ≤ 7 vs mean age of women with HAD score ≥ 8

² (Number of distressed women aged ≤ 54 years vs number of distressed women aged ≥ 55 years)

³ (Number of distressed women answering 'yes' for socio-demographic variable vs number of distressed women answering 'no' for socio-demographic variable)

⁴ Sub-scale score (SD) for women answering 'yes' for socio-demographic variable vs sub-scale score (SD) for women answering 'no' for socio-demographic variable

Significant difference on sub-scale score using Scheffe's test

Table 7.22 (contd.): Significant associations between social and demographic variables and measures of mood in the first post-operative year

Sociodemographic variables	Pre-operative assessment	3 months post-operation	12 months post-operation
<p>Marital status: MS0 = Single MS1 = Married/co-habiting MS2 = Separated/divorced MS3 = Widowed</p>	<p>⁵MS0=6 MS1=74 MS2=11 MS3=16</p> <p>Mean POMS anger $p \leq 0.05$ F=2.74 (ANOVA) MS0=7.8 MS1=7.3 MS2=11.6* MS3=3.9</p>		
<p>Life stage: LS0= <35 years, no child at home LS1=child <6 years at home LS2=child 6-14 years at home LS3=child 15+ years at home LS4= >35 years, no child at home</p>	<p>⁵LS0=4 LS1=5 LS2=13 LS3=18 LS4=67</p> <p>Case HAD anxiety $p < 0.05$ $X^2=10.65$ (Sig. greater anxiety in LS1)</p> <p>Case HAD depression $p \leq 0.001$ $X^2=19.62$ (Sig. greater depression in LS1)</p> <p>Mean HAD anxiety $p < 0.05$ F=3.21 (ANOVA) LS0=7.5 LS1=15.0* LS2=9.3 LS3=7.6 LS4=7.3</p> <p>Mean POMS tension $p < 0.05$ F=2.60 (ANOVA) LS0=15.0 LS1=26.6* LS2=14.4 LS3=13.1 LS4=13.1</p> <p>Mean POMS depression $p < 0.05$ F=2.84 (ANOVA) LS0=13.0 LS1=26.6* LS2=11.2 LS3=8.4 LS4=10.4</p>	<p>⁵LS0=4 LS1=5 LS2=12 LS3=16 LS4=63</p> <p>Case HAD anxiety $p \leq 0.05$ $X^2=9.50$ (Sig. greater anxiety in LS1)</p>	

¹ Mean age of women with HAD score ≤ 7 vs mean age (SD) of women with HAD score ≥ 8

²(Number of distressed women aged ≤ 54 years vs number of distressed women aged ≥ 55 years)

³(Number of distressed women answering 'yes' for socio-demographic variable vs number of distressed women answering 'no' for socio-demographic variable)

⁴Sub-scale score (SD) for women answering 'yes' for socio-demographic variable vs sub-scale score (SD) for women answering 'no' for socio-demographic variable

⁵ Number of women in each socio-demographic group

*Significant difference on sub-scale score using Scheffe's test

Table 7.22 (contd.):

Sociodemographic variables	Pre-operative assessment	3 months post-operation	12 months post-operation
<p>Previous psychiatric history: PPH0 = none PPH1 = GP/Psychiatrist</p>	<p>⁵PPH0=64 PPH1=43</p> <p><i>Case HAD anxiety</i> $p \leq 0.001$ ²$2^{-10.11}$ (28/43 vs 21/64)</p> <p><i>Mean HAD anxiety</i> $p < 0.005$ $t = -3.20$ ⁴9.79 (5.07) vs 6.78 (4.72)</p> <p><i>Mean HAD depression</i> $p < 0.01$ $t = -2.72$ ⁴4.05 (3.09) vs 2.48 (2.79)</p> <p><i>Mean POMS tension</i> $p < 0.01$ $t = -2.78$ ⁴16.95 (9.65) vs 11.95 (8.74)</p> <p><i>Mean POMS depression</i> $p \leq 0.01$ $t = -2.59$ ⁴14.40 (12.35) vs 8.72 (10.21)</p> <p><i>Mean POMS fatigue</i> $p < 0.01$ $t = -2.85$ ⁴8.98 (7.58) vs 5.08 (5.89)</p> <p><i>Mean POMS confusion</i> $p < 0.01$ $t = -2.84$ ⁴8.86 (7.0) vs 5.36 (4.95)</p> <p><i>Mean POMS total</i> $p < 0.01$ $t = -2.81$ ⁴72.81 (42.72) vs 51.28 (35.99)</p>		<p>⁵PPH0=57 PPH1=38</p> <p><i>Case HAD anxiety</i> $p < 0.05$ $X^2 = 5.27$ ³(11/38 vs 6/57)</p>
<p>Religion: R0 = non-practising R1 = practising</p>	<p>⁵R00=89 R01=18</p> <p><i>Mean POMS anger</i> $p < 0.005$ $t = 3.29$ ⁴4.39 (2.89) vs 7.83 (7.49)</p>	<p>⁵R00=82 R01=18</p> <p><i>Case HAD anxiety</i> $p < 0.05$ Fisher Exact ³(6/18 v 9/82)</p>	<p>⁵R00=78 R01=17</p> <p><i>Mean POMS tension</i> $p < 0.01$ $t = -2.74$ ⁴10.12 (7.76) vs 5.56 (5.84)</p> <p><i>Mean POMS vigour</i> $p < 0.005$ $t = -3.19$ ⁴17.82 (7.85) vs 12.15 (6.36)</p> <p><i>Mean POMS fatigue</i> $p < 0.05$ $t = -2.33$ ⁴9.53 (7.63) vs 5.64 (5.92)</p> <p><i>Mean POMS Total</i> $p < 0.05$ $t = -2.26$ ⁴54.59 (33.87) vs 36.76 (28.46)</p>

¹ Mean age of women with HAD score ≤ 7 vs mean age (SD) of women with HAD score ≥ 8

²(Number of distressed women aged ≤ 54 years vs number of distressed women aged ≥ 55 years)

³(Number of distressed women answering 'yes' for socio-demographic variable vs number of distressed women answering 'no' for socio-demographic variable)

⁴ Sub-scale score (SD) for women answering 'yes' for socio-demographic variable vs sub-scale score (SD) for women answering 'no' for socio-demographic variable

⁵ Number of women in each socio-demographic group

^{*}Significant difference on sub-scale score using Scheffe's test

7.3.2.3 Physical and pathological variables and measures of mood

Significant associations between physical and pathological variables and measures of mood, after applying Bonferroni's correction ($p \leq 0.005$ in italics in table 7.23) were found with pre-operative measures of mood only. Women who were due to have a local excision of their tumour had significantly greater mood disturbance than women who were having a mastectomy. This may again be confounded with age as local excision of the tumour was often offered to younger women, whilst older women were offered mastectomy. Age may be similarly associated with menopausal status, where pre-menopausal women had significantly higher scores on the HAD anxiety sub-scale and POMS depression than peri- or post-menopausal women.

Table 7.23: Significant associations between physical and pathological variables and measures of mood at all three time points

Physical & pathological variables	Pre-operative assessment	3 months post-operation	12 months post-operation
Type of operation: Mastectomy vs Local Excision	¹ M=46 LE=61 <i>Mean HAD anxiety $p < 0.005$</i> <i>$t = -3.03$</i> <i>M=6.30 (4.46) vs LE=9.20 (5.18)</i> <i>Mean POMS confusion $p \leq 0.001$</i> <i>$t = -3.27$</i> <i>M=4.76 (4.30) vs LE=8.28 (6.78)</i>		¹ M=43 LE=52 Mean HAD anxiety $p < 0.05$ <i>$t = 2.03$</i> M=2.77 (2.93) vs LE=1.67 (2.19)
Adjuvant treatment: AT0 = None/Tamoxifen AT1 = Chemotherapy AT2 = Ovarian irradiation	¹ AT0=89 AT1=11 AT2=7 Case HAD depression $p < 0.01$ $\chi^2 = 9.99$ (Sig. greater depression in AT2) Mean HAD anxiety $p < 0.01$ F=5.26 (ANOVA) AT0=7.3 AT1=11.9* AT2=10.3 Mean POMS confusion $p < 0.05$ F=3.28 (ANOVA) AT0=6.2 AT1=10.9* AT2=8.0		
Delay in presentation: DP0 = ≤ 3 months DP1 = ≥ 4 months		¹ DP0=95 DP1=5 Mean POMS vigour $p < 0.05$ <i>$t = -2.77$</i> DP0=12.39 (6.69) vs DP1=15.80 (2.28)	

¹ Number of women in each physical/pathological group

* Significant difference on sub-scale score using Scheffe's test

Table 7.23 (contd.):

Physical & pathological variables	Pre-operative assessment	3 months post-operation	12 months post-operation
Menopausal status: MS0 = Pre-menopausal MS1 = Peri/post-menopausal	<p>¹MS0=41 MS1=65 (Missing=1)</p> <p>Case HAD anxiety $p < 0.05$ $X^2=8.81$ (Sig. greater anxiety in MS0)</p> <p><i>Mean HAD anxiety $p < 0.005$</i> <i>$t=3.23$ MS0=9.3 (5.21) vs</i> <i>MS1=6.82 (4.59)</i></p> <p>Mean HAD depression $p < 0.05$ $t=2.29$ MS0=4.0 (3.37) vs MS1=2.58 (2.63)</p> <p>Mean POMS tension $p < 0.05$ $t=2.15$ MS0=16.49 (10.2) vs MS1=12.52 (8.58)</p> <p><i>Mean POMS depression $p \leq 0.005$</i> <i>$t=2.93$ MS0=15.29 (12.84) vs</i> <i>MS1=8.45 (9.62)</i></p> <p>Mean POMS anger $p < 0.05$ $t=2.46$ MS0=9.39 (6.96) vs MS1=6.02 (6.83)</p> <p>Mean POMS fatigue $p < 0.01$ $t=2.70$ MS0=9.05 (7.82) vs MS1=5.23 (5.77)</p> <p>Mean POMS confusion $p \leq 0.01$ $t=2.54$ MS0=8.78 (6.92) vs MS1=5.58 (5.17)</p> <p>Mean POMS Total $p \leq 0.01$ $t=2.59$ MS0=73.44 (44.53) vs MS1=52.23 (34.62)</p>		
Recurrence: R0 = None R1 = Local recurrence R2 = Distant recurrence			<p>¹R0=89 R1=4 R2=2</p> <p>Mean HAD anxiety $p \leq 0.01$ $F=4.55$ (ANOVA) R0=4.2 R1=2.8 R2=10.5[*]</p> <p>Mean POM confusion $p < 0.01$ $F=5.08$ (ANOVA) R0=4.0 R1=3.0 R2=12.0[*]</p>
Family history of breast disease: FH0 = none FH1 = family history	<p>¹FH0=69 FH1=20 (Missing=18)</p> <p>Mean POMS vigour $p \leq 0.01$ $t=-2.65$ FH0=13.19 (7.24) vs FH1=17.90 (6.14)</p>	<p>¹FH0=65 FH1=19 (Missing=16)</p> <p>Mean HAD anxiety $p < 0.05$ $t=-2.23$ FH0=3.88 (3.20) vs FH1=6.00 (4.74)</p> <p>Mean POMS vigour $p < 0.05$ $t=-2.05$ FH0=12.03 (6.57) vs FH1=15.47 (6.0)</p>	
Personal history of breast disease: PH0 = none PH1 = personal history		<p>¹PH0=54 PH1=23 (Missing=23)</p> <p>Mean POMS tension $p < 0.05$ $t=-2.31$ PH0=5.31 (4.88) vs PH1=9.50 (7.89)</p>	

¹ Number of women in each physical/pathological group

* Significant difference on sub-scale score using Scheffe's test

7.2.2.4 Social support and measures of mood

The receipt of positive and negative social support was analysed in relation to all measures of mood using t-tests for independent samples for the continuous measures, and the chi-square (or Fisher exact probability test for smaller numbers) for case/non-case on the HAD scale.

No significant associations were found between measures of positive social support and mood disturbance at any of the three assessments, but significant results were found in the analyses of negative support. The mood scores of those women who reported receiving some negative support from their first confidante (either spouse or other relative/friend) were compared with those women who received little or no negative support. No significant associations were found at the pre-operative assessment, but increased mood disturbance was associated with negative support at both three and twelve months after operation (table 7.24).

7.3.3 LONGITUDINAL ANALYSES

This section builds upon the results of the previous section where a number of factors, including coping, physical, social and demographic variables, were found to be significantly associated with concurrent assessments of mood. The longitudinal analyses examine whether these associations remain significant over time and across assessments. Thus the measures of mood at three months after operation were examined in relation to variables assessed pre-operatively, and mood at one year post-operation was analysed in relation to variables assessed both pre-operatively and at three months after operation.

Multiple regression analyses were used to predict the values of the measures of mood disturbance using the coping, physical, social and demographic factors which had been found to have significant associations ($P \leq 0.05$) with concurrent mood. It was assumed that any variable which did not have a significant correlation with measures of concurrent mood would also be unrelated to subsequent mood. This decision enabled the overall

number of independent variables in the regression analyses to be reduced by approximately ten (for mood at three months post-op) or twenty variables (for mood at one year post-op). The factors which were included as independent variables in the regression analyses are listed in appendix 16.

Linear multiple regression was employed where the measures of mood consisted of continuous data (all of the POMS sub-scales as well as the HAD anxiety and depression sub-scales where a cut-off was not used). Logistic regression was used to estimate regression models for dichotomous dependent variables (HAD anxiety and depression sub-scales using a case/non-case division of scores). The use of the Statistical Package for Social Scientists enabled the independent variables to be entered in pre-defined blocks of variables which could be analysed in a specified order. As the cognitive and behavioural ways of coping were the main focus of the study, these were entered first, followed by the physical, social and demographic factors.

Previous measures of mood were entered last as it was expected that they would provide the greatest degree of prediction of subsequent mood. Entering all the variables together would have meant that the previous mood scores would have been selected first in the regression analysis, with few other factors being added. Thus, it was possible to see the contribution of the independent variables (first column of data in table 7.24) as well as the results after including previous mood scores (second column of data in table 7.24).

A stepwise method of inclusion was used to enter independent variables in the regression equation. The stepping method criterion used the probability of the F value for the entry and removal of variables. Thus, independent variables were entered if the significance level of F was less than 0.05 and removed if the significance level of F was less than 0.10.

7.3.3.1 Prediction of mood at three months after operation

Overall, the independent variables explained between one third and a half of the variance in the dependent variables, of which approximately half was accounted for by pre-operative mood scores. Several socio-demographic variables were also found to be predictive of mood at three months (before the inclusion of pre-operative mood scores) and these tended to be associated with more than one measure of mood disturbance which might suggest a stronger connection. Specifically, a family history of malignant breast disease, separation or divorce, formal practice of religion and having a child under 6 years old at home were all significantly associated with more than three measures of mood disturbance. Of these, the first three continued to be significantly associated with mood, even after the inclusion of prior mood scores and explained a maximum of between seven and nine percent of the variance. Thus, those women who had a family member who had been diagnosed with malignant breast disease were significantly more likely to have raised mood scores on the HAD anxiety ($P=0.002$), HAD depression ($P=0.05$), POMS tension ($P=0.02$) and POMS fatigue sub-scales ($P=0.04$) three months after operation. Women who were separated or divorced had higher scores on the POMS fatigue sub-scale ($P=0.02$) and women who reported that they regularly practised their religion had higher scores on the HAD depression sub-scale ($P=0.01$) at three months after operation.

Only three of the cognitive and behavioural coping responses were significantly associated with subsequent mood scores. However all of these associations remained significant even after the inclusion of prior mood scores. Pre-operative behaviours aimed at aiding recovery from the disease were predictive of higher scores on the POMS tension sub-scale at three months ($P=0.01$), and a pre-occupation with thoughts about the disease prior to operation was related to higher scores on the POMS confusion sub-scale ($P=0.005$). The inclusion of pre-operative scores for the POMS anger sub-scale resulted in the loss of significance of the contribution of having a child aged under 6 years at home, but increased the significance of a positive appraisal of life. Unexpectedly, those women who reported that their disease had a positive effect on their lives before operation were significantly more likely to have higher anger scores three months later.

Table 7.24: Results from multiple linear regression analyses to predict mood (measured as continuous variables) at three months after operation.

Dependent variable	Independent variables	¹ % Variance	B (SE B) (without including prior mood)	B (SE B) (including prior mood scores)
HAD anxiety (3 months post-op)	Apprehension re diagnosis (pre-operative) Family history of malignant disease Life stage: child under 6 years at home Personal history of benign breast disease HAD anxiety (pre-operative)	7.0 7.7 3.9 3.3 19.3	Total Variance (%) = 21.9 2.16 (0.87) P=0.02 2.65 (0.84) P=0.002 4.55 (1.85) P=0.02 1.19 (0.58) P=0.05	Total Variance (%) = 41.3 1.17 (0.78) P=0.14 2.34 (0.73) P=0.002 2.23 (1.67) P=0.19 0.57 (0.52) P=0.28 0.38 (0.08) P=0.0000
HAD depression (3 months post-op)	Formal practice of religion Life stage: child aged 15+ at home Family history of malignant disease HAD depression (pre-operative)	8.4 3.8 3.5 21.5	% Variance = 15.7 2.41 (0.76) P=0.002 -1.61 (0.79) P=0.05 1.33 (0.66) P=0.05	% Variance = 37.2 1.71 (0.67) P=0.01 -0.98 (0.69) P=0.16 1.14 (0.57) P=0.05 0.45 (0.09) P=0.0000
POMS tension (3 months post-op)	Behaviours to aid recovery (pre-operative) Family history of malignant disease Life stage: child aged under 6 years at home Personal history of benign breast disease POMS tension (pre-operative)	6.4 5.0 4.4 4.9 29.5	% Variance = 20.7 13.12 (5.19) P=0.01 3.71 (1.39) P=0.01 7.94 (3.03) P=0.01 2.29 (0.97) P=0.02	% Variance = 50.1 10.34 (4.14) P=0.01 2.75 (1.11) P=0.02 4.05 (2.48) P=0.11 1.32 (0.79) P=0.10 0.38 (0.06) P=0.0000
POMS depression (3 months post-op)	Life stage: child aged under 6 years at home POMS depression (pre-operative)	10.4 32.8	% Variance = 10.4 12.84 (4.08) P=0.002	% Variance = 43.2 6.10 (3.40) P=0.08 0.45 (0.07) P=0.0000
POMS anger (3 months post-op)	Positive appraisal of life (pre-operative) Life stage: child aged under 6 years at home POMS anger (pre-operative)	3.8 7.8 25.4	% Variance = 11.6 3.28 (1.94) P=0.09 8.96 (3.22) P=0.007	% Variance = 37.0 3.75 (1.64) P=0.03 4.75 (2.82) P=0.10 0.49 (0.09) P=0.0000

¹% Variance derived from adjusted R square

Table 7.24 (contd): Results from multiple linear regression analyses to predict mood (measured as continuous variables) at three months after operation.

Dependent variable	Independent variables	1% Variance	B (SE B) (without including prior mood)	B (SE B) (including prior mood scores)
POMS vigour (3 months post-op)	Negative support (pre-operative) Use of religion (pre-operative) Family history of malignant disease Formal practice of religion Marital status: separated/divorced POMS vigour (pre-operative)	6.0 3.9 4.9 4.8 3.8 24.3	% Variance = 23.4 7.50 (2.98) P=0.01 2.65 (2.68) P=0.32 4.22 (1.54) P=0.008 5.25 (2.05) P=0.01 5.49 (2.18) P=0.01	% Variance = 47.7 3.68 (2.60) P=0.16 3.48 (2.26) P=0.13 1.86 (1.37) P=0.18 2.42 (1.80) P=0.18 4.12 (1.86) P=0.03 0.48 (0.09) P=0.0000
POMS fatigue (3 months post-op)	Marital status: separated/divorced Family history of malignant disease POMS fatigue (pre-operative)	9.4 6.5 19.3	% Variance = 15.9 6.97 (2.10) P=0.001 3.96 (1.51) P=0.01	% Variance = 35.2 4.67 (1.90) P=0.02 2.86 (1.35) P=0.04 0.45 (0.09) P=0.0000
POMS confusion (3 months post-op)	Pre-occupation with disease (pre-operative) Marital status: separated/divorced Formal practice of religion Life stage: child aged under 6 years at home POMS confusion (pre-operative)	4.8 6.9 4.3 4.3 21.7	% Variance = 20.3 6.04 (2.07) P=0.005 3.33 (1.52) P=0.03 3.15 (1.27) P=0.02 5.35 (2.40) P=0.03	% Variance = 42.0 5.16 (1.77) P=0.005 1.41 (1.35) P=0.30 1.99 (1.11) P=0.08 3.26 (2.08) P=0.12 0.43 (0.08) P=0.0000
POMS total score (3 months post-op)	Family history of malignant disease Marital status: separated/divorced Life stage: child aged under 6 years at home POMS total score (pre-operative)	5.9 5.8 3.6 38.5	% Variance = 15.3 19.03 (7.26) P=0.01 21.88 (10.19) P=0.04 32.76 (16.04) P=0.05	% Variance = 53.8 10.08 (5.48) P=0.07 4.98 (7.82) P=0.53 13.94 (12.08) P=0.25 0.55 (0.07) P=0.0000

1% Variance derived from adjusted R square

Logistic regression analyses were similarly performed for the dependent variables of case (score ≥ 8) or non-case (score ≤ 7) on the HAD scale (see table 7.25). Only one variable was significantly associated with HAD anxiety at three months in the final regression equation. Thus, the odds of being a clinical 'case' of anxiety on the HAD scale were almost seven times higher in women who had a family history of malignant disease ($P=0.05$). This result should be treated with caution, since the confidence intervals for this odds ratio ranged from less than one to over forty-seven. This means that these women may have had exactly the same odds (one times the likelihood) of being a case of anxiety as women who did not have a history of malignant disease.

The association between a family history of malignant disease and subsequent mood disturbance was demonstrated again in relation to depression on the HAD scale. This time the association was stronger. The odds for being cases of depression at three months after operation were fourteen times higher for these women. The confidence intervals for this odds ratio extended from almost four to over fifty, suggesting that at the most conservative estimate, women who had a family history of malignant disease were at least four times as likely to be a case on the HAD depression subscale as those women who did not have this history. In addition, women who reported that they regularly practised their religion were almost six times as likely to be cases of depression at three months after operation. However, the numbers involved were very small due to the exclusion of women with missing data. This meant that the regression equation was seeking to predict only four cases of HAD depression at three months after operation. Inclusion of the variables of a family history of malignant breast disease and formal practice of religion only predicted one woman.

It is interesting to note that a pre-operative score of greater than eight on either the HAD anxiety or depression subscales did not significantly predict a similar score three months later.

Table 7.25: Results from multiple logistic regression analyses to predict mood (measured as a dichotomous outcome variable) at three months after operation.

Dependent variable	Independent variables	B (SE B)	Exp(B)	P	* (CI)	
HAD anxiety: case (score ≥ 8) non-case (score ≤ 7) (3 months post-op)	Pos. appraisal of life (pre-op)	-9.71 (44.9)	0.0001	P=0.83		
	Behav to aid recovery (pre-op)	23.21 (274.5)	1.21E+10	P=0.93		
	Life stage: <35 years, no children	-1.19 (150.5)	0.30	P=0.99		
	Child <6 years at home	11.28 (48.1)	79177	P=0.81		
	Child aged 6-14 years at home	-9.55 (73.3)	0.0001	P=0.90		
	Child age 15+ years at home	0.18 (43.7)	1.2	P=1.00		
	Family history of malignant disease	1.90 (0.98)	6.7	P=0.05	(0.94, 47.5)	
	HAD depression: case (score ≥ 8) non-case (score ≤ 7) (3 months post-op)	Family history of malignant disease	2.63 (1.4)	13.9	P=0.05	(3.60, 53.5)
		Formal practice of religion	3.16 (1.4)	23.5	P=0.03	(5.70, 97.5)

* Confidence intervals for odds ratio of significant variables only

7.3.3.2 Prediction of mood at one year after operation

The independent variables used to predict the levels of mood disturbance at one year after operation were similarly entered in blocks. The coping and mood variables were further sub-divided into pre-operative and three months post-operative assessments, with the most recent data (from three months post-op) entered first, followed by the pre-operative assessment variables. Accordingly, the independent variables were entered in the following order: Cognitive and behavioural coping responses assessed at three months after operation; pre-operative cognitive and behavioural coping responses; physical, social and demographic variables; mood assessed at three months post-op; pre-operative mood. This again enabled the separate examination of the contribution of psychosocial and demographic variables (first column of data in table 7.26) before the inclusion of prior mood scores (second column of data in table 7.26).

A larger percentage of the variance in mood scores at one year after operation was explained by the independent variables which account for between 46%-72% of variance. In addition, a greater number of cognitive and behavioural coping responses was found to be significantly associated with mood scores at one year after operation than at three months, and six of these remained significant even after including both pre-operative and three months post-operative mood scores in the regression equation. With one exception (pre-operative behaviours to aid recovery), these all comprised coping responses reported at three months after operation. In particular, a pre-occupation with thoughts about the disease at three months post-op was predictive of increased mood scores on all of the measures of mood before the levels of previous mood were entered. This remained significantly associated with HAD scale anxiety ($P=0.03$), POMS tension ($P=0.002$) and POMS confusion ($P=0.007$) after prior mood was taken into account and explained up to sixteen percent of the variance.

Table 7.26: Results from multiple linear regression analyses to predict mood (measured as continuous variables) at one year after operation.

Dependent Variable	Independent Variables	¹ % Variance	B (SE B) (without including prior mood)	B (SE B) (including prior mood scores)	
HAD anxiety (1 year post-op)			Total Variance (%) = 27.2	Total Variance (%) = 46.9	
	Pre-occupation with disease (3 months post-op)	10.1	3.84 (0.92) P=0.0001	1.94 (0.87) P=0.03	
	Negative support (3 months post-op)	3.6	7.44 (2.12) P=0.0008	3.59 (1.96) P=0.07	
	Behaviours to aid recovery (3 months post-op)	5.5	-4.29 (1.73) P=0.02	-2.21 (1.54) P=0.16	
	Avoidance of relevant information (pre-operative)	3.5	2.73 (1.08) P=0.01	1.07 (0.98) P=0.28	
	Positive appraisal of disease (pre-operative)	4.5	-1.48 (0.63) P=0.02	-0.62 (0.56) P=0.27	
	HAD anxiety (3 months post-op)	15.8		0.29 (0.10) P=0.003	
	HAD anxiety (pre-operative)	3.9		0.19 (0.08) P=0.01	
				% Variance = 26.7	% Variance = 53.6
		Pre-occupation with disease (3 months post-op)	9.2	1.02 (0.87) P=0.244	0.11 (0.71) P=0.88
HAD depression (1 year post-op)			% Variance = 26.7	% Variance = 53.6	
	Pre-occupation with disease (3 months post-op)	9.2	1.02 (0.87) P=0.244	0.11 (0.71) P=0.88	
	Apprehension re diagnosis (3 months post-op)	4.5	1.39 (0.56) P=0.016	0.66 (0.46) P=0.16	
	Not considered prognosis (3 months post-op)	5.5	3.83 (1.39) P=0.007	0.97 (1.19) P=0.42	
	Behaviours to aid recovery (pre-operative)	7.5	7.23 (2.47) P=0.005	7.07 (1.96) P=0.0006	
	HAD depression (3 months post-op)	26.9		0.61 (0.09) P=0.0000	
				% Variance = 34.9	% Variance = 54.2
		Pre-occupation with disease (3 months post-op)	13.6	9.28 (1.80) P=0.0000	5.45 (1.66) P=0.002
		Negative support (3 months post-op)	5.0	17.80 (4.34) P=0.0001	8.59 (4.01) P=0.04
		Use of religion (3 months post-op)	4.7	5.74 (2.19) P=0.01	3.68 (1.90) P=0.06
	Behaviours to aid recovery (3 months post-op)	4.1	-8.02 (3.32) P=0.02	-3.49 (2.90) P=0.23	
	Avoidance of relevant information (pre-operative)	4.7	5.28 (2.06) P=0.01	1.72 (1.88) P=0.36	
	Life stage: Child under 6 at home	2.8	1.27 (0.63) P=0.05	0.78 (0.54) P=0.15	
	POMS tension (3 months post-op)	15.3		0.31 (0.12) P=0.01	
	POMS tension (pre-operative)	4.0		0.22 (0.08) P=0.01	
			% Variance = 25.6	% Variance = 60.3	
POMS depression (1 year post-op)			% Variance = 25.6	% Variance = 60.3	
	Pre-occupation with disease (3 months post-op)	10.2	7.14 (2.45) P=0.005	1.37 (1.99) P=0.49	
	Negative support (3 months post-op)	6.2	13.77 (4.93) P=0.007	2.30 (3.87) P=0.55	
	Positive appraisal of life (3 months post-op)	3.4	-3.73 (1.58) P=0.02	-2.60 (1.17) P=0.03	
	Behaviours to aid recovery (pre-operative)	5.8	18.99 (7.28) P=0.01	11.42 (5.55) P=0.04	
	POMS depression (3 months post-op)	28.8		0.44 (0.11) P=0.0002	
	POMS depression (pre-operative)	5.9		0.28 (0.08) P=0.001	

¹ % Variance derived from adjusted R square

Table 7.26 (contd.):

Dependent Variable	Independent Variables	¹ % Variance	B (SE B) (without including prior mood)	B (SE B) (including prior mood scores)
POMS anger (1 year post-op)	Negative support (3 months post-op) Belief in a good prognosis (3 months post-op) Pre-occupation with disease (3 months post-op) Apprehension re diagnosis (3 months post-op) Life stage: Child under 6 at home POMS anger (3 months post-op)	13.9 6.2 6.9 2.9 3.0 27.2	% Variance = 32.9 18.83 (3.79) P=0.0000 5.51 (1.50) P=0.0004 4.62 (1.75) P=0.01 2.53 (1.19) P=0.04 1.23 (0.59) P=0.04	% Variance = 60.1 8.04 (3.30) P=0.02 3.47 (1.19) P=0.005 1.57 (1.42) P=0.27 1.59 (0.93) P=0.09 0.90 (0.46) P=0.06 0.62 (0.09) P=0.0000
POMS vigour (1 year post-op)	Pre-occupation with disease (3 months post-op) Avoidance of relevant information (3 months post-op) Use of humour (3 months post-op) Positive appraisal of life (3 months post-op) Formal practice of religion POMS vigour (3 months post-op) POMS vigour (pre-operative)	7.7 7.4 5.0 4.4 3.9 26.5 5.3	% Variance = 28.4 4.71 (2.07) P=0.03 8.06 (2.25) P=0.0006 -10.74 (4.33) P=0.02 -3.43 (1.36) P=0.01 4.28 (1.92) P=0.03	% Variance = 60.2 0.59 (1.64) P=0.72 4.31 (1.75) P=0.02 -9.44 (3.24) P=0.005 -2.33 (1.03) P=0.03 1.02 (1.50) P=0.50 0.43 (0.11) P=0.0001 0.30 (0.09) P=0.002
POMS fatigue (1 year post-op)	Uncertain re prognosis (3 months post-op) Use of religion (3 months post-op) Pre-occupation with disease (3 months post-op) Marital status: separated/divorced POMS fatigue (3 months post-op) POMS fatigue (pre-operative)	6.0 5.3 3.8 4.3 40.9 5.9	Total Variance (%) = 19.4 -4.94 (1.89) P=0.01 5.34 (2.37) P=0.03 3.53 (1.90) P=0.07 4.65 (2.10) P=0.03	Total Variance (%) = 66.2 -0.36 (1.30) P=0.78 1.42 (1.59) P=0.38 0.43 (1.27) P=0.74 -0.11 (1.44) P=0.94 0.61 (0.09) P=0.0000 0.29 (0.08) P=0.0004
POMS confusion (1 year post-op)	Pre-occupation with disease (3 months post-op) Negative support (3 months post-op) Behaviours to aid recovery (3 months post-op) Life stage: Child under 6 at home POMS confusion (3 months post-op) POMS confusion (pre-operative)	16.2 7.2 6.6 4.2 22.4 4.7	% Variance = 34.2 6.09 (1.12) P=0.0000 12.47 (2.70) P=0.0000 -6.24 (2.07) P=0.004 0.94 (0.39) P=0.02	% Variance = 61.3 2.72 (0.97) P=0.007 5.08 (2.34) P=0.03 -3.39 (1.68) P=0.05 0.40 (0.31) P=0.20 0.35 (0.08) P=0.0001 0.22 (0.07) P=0.003
POMS total score (1 year post-op)	Pre-occupation with disease (3 months post-op) Negative support (3 months post-op) Positive appraisal of disease (3 months post-op) Life stage: Child under 6 at home POMS total score (3 months post-op) POMS total score (pre-operative)	13.0 5.1 3.9 3.6 37.4 8.9	% Variance = 25.6 41.25 (9.10) P=0.0000 65.53 (20.5) P=0.002 -13.57 (6.00) P=0.03 6.87 (3.21) P=0.04	% Variance = 71.9 9.97 (6.38) P=0.12 10.48 (13.6) P=0.44 -5.53 (3.81) P=0.15 2.48 (2.02) P=0.22 0.43 (0.10) P=0.0001 0.37 (0.08) P=0.0000

¹ % Variance derived from adjusted R square

The effect of a positive appraisal of life was reversed in these analyses compared to mood at three months after operation, such that those women who reported that their disease had resulted in their appraising their life more positively at three months after operation had significantly *lower* scores on the POMS depression and vigour sub-scales at a year ($P=0.03$). Decreased levels of mood disturbance were also predicted by the use of humour in coping with the disease at three months after operation (POMS vigour, $P=0.005$).

Pre-operative behaviours aimed at aiding recovery were again predictive of increased mood disturbance (POMS depression $P=0.04$). However, such behaviours when reported at three months after operation were associated with *decreased* mood disturbance at one year after operation (POMS confusion, $P=0.05$). In addition, avoidance of information relevant to the disease and a belief that the disease would not recur reported at three months after operation were both significantly associated with increased mood disturbance at one year after operation (POMS vigour, $P=0.005$; POMS anger, $P=0.005$ respectively).

No psychosocial or physical variables remained significantly associated with mood disturbance at the one year post-operative assessment, after previous mood scores were included in the analyses. However, those women who reported receiving negative or critical comments from their confidant at three months after their operation were significantly more likely to have higher scores on the POMS tension, anger and confusion sub-scales at one year after operation ($P=0.04$, $P=0.02$ & $P=0.03$ respectively).

Logistic regression analyses were again performed in order to determine which independent variables were significantly associated with scores greater than or equal to eight ('caseness') on the HAD anxiety and depression subscales 12 months post-operatively (table 7.27). Previous cases of HAD anxiety were the only significant predictors of case anxiety at one year after operation such that women who scored greater than eight on their pre-operative or 3 months post-operative HAD scales had an odds ratio for scoring greater than eight on the 12 month assessment of 1:17 and 1:21 respectively. A conservative estimate of these odds, taken from the lowest range of the

Table 7.27: Results from multiple logistic regression analyses to predict mood (measured as a dichotomous outcome variable) at one year after operation.

Dependent variable	Independent variables	B (SE B)	Exp(B)	P	* (CI)
HAD anxiety case (score ≥ 8) non-case (score ≤ 7) (one year post-op)	Pre-occupation with disease (3 months)	0.67 (1.31)	1.95	P=0.61	
	Avoidance of info (pre-op)	1.79 (1.06)	6.01	P=0.09	
	Personal history of benign breast disease	1.39 (0.79)	4.0	P=0.08	
	Case HAD anxiety (3 months post-op)	3.05 (1.17)	21.16	P=0.009	(2.03, 219.2)
	Case HAD anxiety (pre-op)	2.84 (1.18)	17.04	P=0.02	(1.62, 181.3)
HAD depression case (score ≥ 8) non-case (score ≤ 7) (one year post-op)	Not considered prognosis at all (3 months post-op)	2.95 (1.47)	19.06	P=0.04	(1.01, 361.4)
	Behav to aid recovery (pre-op)	12.76 (60.5)	347454	P=0.83	
	Age	0.25 (0.14)	1.28	P=0.08	

* Confidence intervals for odds ratio of significant variables only

confidence interval, meant that these women had at least twice the odds of being cases of HAD anxiety at one year. Although other independent variables were no longer significant after the inclusion of prior mood, a personal history of benign breast disease, pre-operative avoidance of information and a pre-occupation with the disease at 3 months after operation, when combined with prior mood, helped identify eight of the fourteen cases of anxiety (57.1%) at the one year assessment. Only one non-case was misclassified according to this combination of variables.

The same pattern was not repeated for case HAD depression at one year after operation. Previous high scores on the depression subscale did not predict subsequent high scores. Only one independent variable, not thinking about the prognosis, was significant in the final regression equation. Thus, the odds of being a case of HAD depression at one year after operation were nineteen times greater for women who reported that they had not considered their prognosis at all at three months. Caution should again be used when considering this result since the lowest range of the confidence intervals for the odds ratio was approximately one, meaning that the women who reported this coping response may have been no more likely to be cases of HAD depression than those women who did not report this response.

CHAPTER 8: DISCUSSION

This study aimed to describe and explore the cognitive and behavioural responses used to cope with early breast cancer and psychological adjustment. In addition, it was intended to examine the association between psychosocial variables (including coping responses), physical variables and measures of mood at concurrent and subsequent assessments. The discussion is structured according to the hypotheses in chapter five. Thus, each hypothesis will be considered sequentially, in the light of the results found in the current study as well as other research. Results which were not covered in any of the hypotheses will be discussed at the end.

Hypotheses 5.2.1 Cognitive and behavioural responses

'Active coping responses such as cognitive reappraisal and seeking information will be associated with lower levels of mood disturbance'

This hypothesis was assessed by exploring the relationship between cognitive and behavioural coping responses from the Faith Courtauld Coping Schedule and scores on the two measures of mood. Coping was examined in relation to current mood using cross-sectional univariate analyses. Those coping responses which showed a significant relationship with concurrent mood were then entered into multiple regression analyses to examine the relationship between cognitive and behavioural responses and subsequent levels of mood.

Lower levels of mood disturbance were significantly associated with a number of coping strategies in both the cross-sectional and longitudinal analyses. These are illustrated in table 8.1 in order to make the associations clearer. Some of these associations were not consistent, such that positive appraisal of life and behaviours to aid recovery reported prior to operation were additionally associated with **increased** mood disturbance three months later in the linear regression analysis. A belief in a good prognosis expressed at three months after operation was also significantly associated with increased levels of anger on the POMS at one year after operation.

Table 8.1: Coping variables which were significantly associated with lower levels of mood disturbance

	3 months post-op Assessment	12 months post-op Assessment
Acceptance of disease	Acceptance of disease	
Cognitive Avoidance: -Avoiding thinking about the threat of the disease	Cognitive Avoidance:	
-*Changing the meaning of the diagnosis		
-*Not thinking about the disease (without describing specific strategies of avoidance)	-Not thinking about the disease (without describing specific strategies of avoidance)	
*#Use of humour		#Positive appraisal of disease
#Positive appraisal of life	#Positive appraisal of life	Positive appraisal of life
	#Behaviours to aid recovery	*Behaviours to aid recovery
*Returning to normal		
	Belief in a good prognosis	
	Uncertain about the prognosis	
	Belief in some control over outcome	Belief in some control over outcome

* $P \leq 0.005$ (Significant after applying Bonferroni's correction)

Coping variables (assessed at three months after operation) which also have a significant independent effect on mood scores at one year after operation (after controlling for prior mood scores).

Overall, it appears that reduced levels of mood disturbance were most strongly related to attempts to carry on the rest of life in as normal a fashion as possible, trying not to think too much about the disease and looking instead for positive aspects of either the disease or life in general. Behaviours to actively aid recovery, a sense of some control over outcome as well as an acceptance of the uncertainty regarding the prognosis were only associated with decreased mood disturbance after the operation. Further support for these results is provided by the associations between coping strategies and increased mood disturbance which show a relationship between a pre-occupation with thoughts of the disease and difficulties in assimilating the threat of the diagnosis (see next hypothesis).

These results are similar to those described in the study by Morris (1984) which used the Faith Courtauld Coping Schedule to assess coping in breast cancer and lymphoma patients. Lower scores for anxiety and depression were associated with a strategy of 'selective ignoring', which included avoiding reminders of the diagnosis, focusing instead on positive aspects of life or the disease. Dunkel-Schetter and colleagues (1992), found decreased mood disturbance was associated with similar strategies using the Ways of Coping Questionnaire. Lower emotional distress was related to coping by focusing on the positive (e.g. "I rediscovered what was important in life") and distancing (e.g. "I went on as if nothing had happened"). Similarly, Heim (1991) concluded that diverting activities and finding meaning in the event were associated with beneficial effects in the first phase after surgery for breast cancer.

The use of different measures of coping and descriptions of coping strategies can sometimes make comparisons with other research difficult. For example, Filip and co-workers (1990) describe a strategy of "threat minimisation" as being effective in the regulation of well-being. On further examination, 'threat minimisation' again appears similar to 'selective ignoring' such that it includes avoidance and self-instruction regarding positive thinking. These were found to be associated with lower levels of distress over time, after controlling for prior levels of well-being. Orr and Meyer (1990) also found that minimising the threat of the disease led to better social adjustment.

Heim attempted to overcome the problem of the use of different descriptions of coping

in his review of fifteen prospective studies of coping with cancer, published between 1983 and 1990 (Heim, 1991). Heim translated the results of these studies into the descriptions of coping from the Bernese Coping Modes interview (Heim, et al., 1987). Whilst he recognised the pitfalls of this procedure, such as misclassifying modes of coping, it enabled a comparison of research in terms of coping responses related to 'good' or 'bad' psychological outcomes. Over one third of these studies found a positive psychological outcome to be related to: Attention and care (e.g. the need to speak and be heard, "there has always been someone who listened/understood"); tackling (e.g. searching for information, seeking help, co-operating with treatment); problem analysis (e.g. cognitive analysis of the diagnosis, "I'm trying to explain to myself what is happening"); and dissimulation (e.g. playing down the illness, "it's really not so bad - actually I'm feeling quite well"). This supports the results from the current study that decreased mood disturbance is related to attempts to understand and accept the diagnosis, change its meaning in order that it does not appear so threatening and maintain a positive outlook. This research did not find that seeking information or understanding and support from others were significantly related to an improved psychological outcome.

With such overwhelming support for the hypothesis that positive appraisal is related to a better psychological outcome, the inconsistency in its relationship with mood in the current study is surprising. The relationship between pre-operative positive appraisal of life and increased POMS anger at three months after operation was not very strong. It only accounted for approximately four percent of the variance, although this was significant after controlling for prior anger scores. Likewise, Stanton and Snider (1993) found that women who coped through focusing on the positive prior to their biopsy showed lower levels of POMS vigour afterwards. This relationship was no longer apparent after surgery for breast cancer. They conclude that maintaining a positive focus may affect mood when faced with a disconfirming outcome such as the diagnosis of breast cancer. They suggest that this association is short-lived as people search for benefits in their disease experience or life in general. In the current sample, an early adoption of a positive approach to life may be contradicted by the stress of the surgical treatment. This may also apply to the employment of behaviours to aid recovery prior to operation which were also associated with increased mood disturbance after operation.

In the conclusion from his detailed analysis of coping with breast cancer over the first two years after operation, Heim (1991) suggests that the beneficial effects of methods of coping vary according to the stage of disease and recovery from treatment.

Support for the finding that the use of humour and acceptance of the disease are associated with lower levels of mood disturbance is provided by Carver and colleagues (1993). They reported that theirs was one of the few studies where acceptance and humour had been shown to have a beneficial prospective effect on subjective well-being. It is proposed that this may be due to the measurement of coping, where few measures include assessments of acceptance and the use of humour. This illustrates the importance of assessing a range of coping responses, rather than limiting assessments to a restricted number of coping styles.

Further support for the beneficial effects of humour is provided by the literature on laughter therapy. Laughter in therapy has been suggested as a positive indicator of change. It might signal a more positive self-perspective, energy, openness, awareness, acceptance or emotional catharsis (Mahrer & Gervaise, 1984). Laughter is also suggested as a therapeutic tool to place events and emotions in perspective and may have beneficial physiological effects (Shaughnessy, 1984). A review of these claims concludes that whilst there is some evidence for humour having salutary effects on positive physical and psychological well-being, there is a need for further careful "clinical trial" research (Saper, 1988). A recent review of the effects of laughter therapy for patients with cancer concluded that it has a place in helping alleviate the distress associated with the disease (Erdman, 1993). Thus, in the present study, those women who already cope by using humour may have significantly reduced scores for disturbed mood because they are able to view their disease from a different perspective and reduce its threat.

Previous research examining the relationship between perceived control over outcome and psychological adjustment has been inconsistent. Morris (1984) found that lower mood disturbance was related to a feeling of little responsibility or control over the disease ("outcome lies in the hands of others"), Stanton and Snider (1993) found no association whilst the research of Ell and colleagues (1988) concurred with the findings of the current

study such that a greater sense of control over outcome was related to improved psychological adjustment. A sense of control over outcome is often associated with the nature of the stressor, that is whether it is one which is open to change or immutable. Collins and colleagues (1983), in research with people living near 3-mile island, concluded that the most adaptive form of coping with such a chronic, immutable stress involved reappraisal and management of emotions. Similarly, Forsythe and Compas (1987) demonstrated that emotion-focused strategies of coping were more adaptive in situations where perceived control was low, whilst fewer symptoms of distress were associated with the use of problem-focused strategies where perceived control was high. The current study did not assess the impact of perceived control in relation to the use of other coping strategies. It is possible that those women who believed that they had some control over the outcome of their disease might also have been employing problem-focused strategies such as seeking information or engaging in behaviours to aid their recovery.

Aldwin and Revenson (1987) examined the effects of problem versus emotion-focused coping on psychological outcome in a longitudinal community survey. They suggested their results showed that the difference in effects of problem versus emotion-focused coping reflected the relative importance of personality and situational factors. Thus, the management of the emotional aspects of a stressful situation were a function of the individual's personality, whilst the use of problem solving strategies was more likely to be a function of the environmental factors in the situation. These situational factors may vary over the course of a chronic stressor such as the diagnosis and treatment of breast cancer. During active treatment, a belief in some control over outcome may be adaptive in terms of encouraging compliance with medical procedures. Alternatively, attempts to affect the course of the disease may result in symptoms of depression when faced with a recurrence. This is similar to the cognitive theory of learned helplessness where depressive symptoms are viewed as resulting from active attempts to deal with an uncontrollable situation (Seligman, 1975). Thus, some of the inconsistent results with regard to the adaptiveness of perceived control in women with cancer may be related to their disease stage. In the present study, the association between a belief in some control over outcome and psychological adjustment may have been related to the fact that the

women were in the initial phases of breast cancer. Further research, with a longer follow-up period, would be required to clarify this issue.

In summary, coping through acceptance of the diagnosis, attempts to carry on with life, trying not to think too much about the disease, thinking instead about positive aspects of life and the use of humour are associated with lower levels of mood disturbance. These findings concur with the results from previous studies. Previous research on the effects of perceived control over outcome has been equivocal. Whilst related to a better psychological outcome in the current study, this may be associated with the concurrent use of other problem or emotion-focused strategies or the phase of the disease. Overall, these findings in part support the hypothesis that active coping with the threat of the disease is beneficial in terms of psychological outcome, although some passive strategies such as the acceptance of the diagnosis and its associated uncertainty as well as avoidance also appear to play a role in decreasing mood disturbance.

'Passive coping responses such as resignation, social withdrawal and pre-occupation with thoughts of the disease will be associated with increased mood disturbance'

Univariate and multivariate analyses similar to those employed in the first hypothesis were used to examine the relationship of coping strategies with concurrent and subsequent mood. Those coping variables which were significantly associated with increased mood disturbance are illustrated in table 8.2.

Overall, increased mood disturbance is most strongly associated with a pre-occupation with thoughts about the diagnosis after surgical intervention. This is the opposite of avoiding distressing thoughts which were related to an improved psychological outcome (discussed in relation to the previous hypothesis). This relationship remained consistent, even after previous mood scores had been taken into account. A resigned attitude was also associated with increased mood disturbance. This comprises a fatalistic approach in the belief that the disease would probably recur plus a perception of little control. It is considered as different from an attitude of acceptance of the diagnosis in the current

Table 8.2: Coping variables which were significantly associated with increased levels of mood disturbance

Pre-operative Assessment	3 months post-op Assessment	12 months post-op Assessment
<p>*Fear of diagnosis</p> <p>Cognitive avoidance: -Difficulty assimilating the threat of the diagnosis</p> <p>+Avoidance of relevant information</p>	<p>*Fear of diagnosis</p> <p>Concern re treatment</p> <p>*#+Pre-occupation with thoughts of the disease</p> <p>+Avoidance of relevant information</p> <p>#Positive appraisal of life</p> <p>Use of religion</p> <p>+Not considered prognosis at all</p> <p>*Belief in a poor prognosis</p> <p>Belief in little/no control over outcome</p>	<p>*Fear of diagnosis</p> <p>*Concern re treatment</p> <p>*#+Pre-occupation with thoughts of the disease</p> <p>Seeking social support</p> <p>Belief in a poor prognosis</p> <p>Belief in little/no control over outcome</p>

* $P \leq 0.005$ (Significant after applying Bonferroni's correction)

Significant association on the longitudinal analyses between pre-operative coping variable and mood scores at three months after operation (after controlling for prior mood scores).

+ Significant association on the longitudinal analyses between coping variable assessed at three months after operation and mood scores at one years after operation (after controlling for prior mood scores).

study, where the reality of the disease and uncertainty concerning prognosis is acknowledged.

In addition, responses which attempt to avoid the reality of the diagnosis, such as avoidance of relevant information and a refusal to consider the prognosis, are also significantly related to increased mood disturbance. These might be considered as examples of 'denial', that is not accepting the reality of the disease, as opposed to avoidance, where the life-threatening nature of the diagnosis is recognised but is subsequently not dwelt upon.

It is interesting that one of the strategies of cognitive avoidance from the adapted Faith Courtauld Coping Schedule, that of difficulties assimilating the threat of the diagnosis, is related to increased mood disturbance, whilst the remaining three avoidance strategies were related to decreased distress. The former strategy appears to describe a response similar to denial where the threat of the disease is not recognised. This might explain why the individual responses of cognitive avoidance were significantly associated with psychological outcome, whilst an overall strategy of 'cognitive avoidance', which consisted of a combination of all four responses, did not show such a significant relationship. The inclusion of difficulties in assimilating or believing the threat of the disease might have counteracted the effects of the other components.

Reports of fearful responses to the diagnosis and treatment appeared to be expressions of current anxiety rather than a method of coping, since these were highly correlated with concurrent distress but were not predictive of subsequent mood in the longitudinal analyses.

These results concur with two recent prospective studies of coping with breast cancer and psychological outcome (Filipp, Klauer, Freudenberg & Ferring, 1990; Heim, 1991). Both were based on transactional models of coping although they employed different measures. Filip and co-workers found that 'rumination' (similar to 'pre-occupation' in the current study) was consistently negatively related to subjective well-being. Further analyses to determine the direction of causality demonstrated that rumination was

influenced by previously low levels of well-being. Heim (1991) also found that rumination was associated with negative mood. In addition, denying or avoiding reality and resignation/fatalism were related to increased mood disturbance. These equate with the responses of difficulties assimilating the threat of the diagnosis, not considering the prognosis and a belief that the prognosis is poor as assessed in the current study. Resignation/fatalism was also found to be associated with a poorer psychological outcome by almost half of the prospective studies of coping in cancer reviewed by Heim (1991).

Further support is provided by a study which employed the Mental Adjustment to Cancer Scale (Watson, et al., 1991). Anxious pre-occupation with thoughts of the diagnosis, a fatalistic attitude and helplessness/hopelessness (which are similar to beliefs in a poor prognosis and little or no control over outcome in the current study) were associated with greater negative affect. A previous study by Watson and colleagues, using a semi-structured interview specifically to measure denial, appear to contradict these findings (Watson, Greer, Blake & Shrapnell, 1984). Denial was found to be associated with the best psychological outcome, whilst increased mood disturbance was associated with an attitude of acceptance. This illustrates the problems inherent in the definition and subsequent measurement of denial and its association with measures of avoidance. These will be discussed in relation to the next hypothesis.

The relationship between the use of religion and increased mood disturbance seems surprising as research on coping through religion in the general population has indicated that it is an adaptive strategy (Park, Cohen & Herb, 1990; Rothbaum, Weisz & Snyder, 1982). A large longitudinal study of cancer patients also found that "religiosity" was protective in the face of stress (Dunkel-Schetter, Feinstein, Taylor & Falke, 1992), although three other longitudinal studies with cancer patients found no association between coping through religion and psychological outcome (Carver, et al., 1993; Filipp, et al., 1990; Heim, 1991). The significance of the associations with mood disturbance in the current study are small and should be interpreted with caution due to the large number of analyses performed and the possibility that some significant associations may occur due to chance. However, this result was supported by the additional finding that women who reported that they attended church in the pre-operative interview had

significantly raised scores of depression on the HAD scale at three months after operation. Rather than being comforted by their belief, these women may have felt angry and let down by their religion, which had not protected them from developing breast cancer.

With the exception of seeking social support, the results from the current study supported the hypothesis that passive strategies such as resignation and pre-occupation with thoughts of the disease are associated with increased mood disturbance. Resignation was defined as a fatalistic, hopeless attitude as opposed to an acceptance of the disease which was associated with an improved psychological outcome. Social withdrawal was not found to be related to distress in the current study. In fact, active seeking of social support was associated with increased mood disturbance. This will be discussed in more detail in the hypotheses concerning social support.

'Initial avoidance of the stressful aspects of the diagnosis will be associated with decreased mood disturbance'

Strategies to avoid thinking about the diagnosis and treatment of breast cancer were the most frequently reported ways of coping at all three assessments in the current study. Over 90% of the women reported using one of the four methods of cognitive avoidance, with this percentage increasing slightly over time. Two of these methods; cognitive action to change the meaning of the diagnosis (e.g. "all the Doctors have been very reassuring so I don't worry too much") and statements of a lack of worry or concern without describing what cognitive processes are used to achieve this (e.g. "I don't really think about it") were significantly associated with decreased mood disturbance in the cross-sectional analyses. Cognitive strategies such as focusing on other concerns, blocking out unpleasant thoughts and focusing on a limited period of time (e.g. "I take each day as it comes") were also related to lower scores on concurrent assessments of mood, although these associations were weaker. One strategy describing difficulties in assimilating the threat of the diagnosis (e.g. "I just couldn't accept it; I keep thinking they must have made a mistake") was related to increased mood disturbance in the

cross-sectional analyses.

The strongest associations between avoidant coping and mood disturbance were found at the pre-operative assessment where initial avoidance (with the exception of difficulties in believing the reality of the diagnosis) was related to decreased mood disturbance. None of these strategies were significantly predictive of subsequent mood in the longitudinal analyses, although the opposite of avoidance, a pre-occupation with thoughts of the diagnosis at three months after operation, was consistently predictive of increased mood disturbance one year post-operation, even after the inclusion of prior mood scores.

The apparently contradictory findings in the current study, where some avoidant strategies promote a positive psychological outcome whilst another is related to a poorer outcome, reflects the contradictory results in the literature on coping and cancer. These difficulties are exacerbated by disagreements on the definition and measurement of avoidance and its confusion with a response of denial or wishful thinking. Carver and colleagues (1993) cite a number of researchers who support their finding that avoidant coping is associated with a negative outcome both concurrently (Aldwin & Revenson, 1987; Billings & Moos, 1984; Cronkite & Moos, 1984; Felton, Revenson & Hinrichson, 1984; Folkman & Lazarus, 1985; Holahan & Moos, 1985; Rohde, Lewinsohn, Tilson & Seeley, 1990) and prospectively (Bolger, 1990; Felton, et al., 1984; Litt, Tennen, Affleck & Klock, 1992; Stanton & Snider, 1993). Avoidant coping was assessed using the denial and behavioural disengagement scales of the COPE. These strategies were respectively defined as a "refusal to believe that the stressor exists" and "reducing one's effort to deal with the stressor" (Carver & Scheier, 1989, p.269-270). The authors concluded that these strategies have a reciprocal influence on coping such that distress promotes responses of denial and behavioral disengagement which produce further distress. These strategies were among the least frequently reported in their study and appear to bear little relation to the frequently reported methods of cognitive avoidance in the current study. The only exception is the description of difficulties assimilating the threat of the diagnosis, which is similar to the aforementioned definition of denial. It would appear, therefore, that although the results seem to be contradictory, the term 'cognitive avoidance' included differing methods of coping. Carver and colleagues conclude from their results that

"*aspects* of avoidance coping.. are problematic" (p.386- italics added). The same study found that self-distraction, another aspect of avoidance assessed by the COPE, was significantly related to a better psychological outcome at six months after operation.

Similar difficulties are encountered when making comparisons with other studies which found avoidant coping to be related to increased distress. For example, Felton, Revenson and Hinrichson (1984) observed that poorer adjustment in a group of chronically ill adults (including cancer patients) was consistently associated with emotional expression, wish-fulfilling fantasy and self-blame as measured by the WCQ. They construed wish-fulfilling fantasy as an avoidant strategy, suggesting that their results disconfirm previous conceptions of avoidance as an adaptive strategy to use when faced with an unalterable stressful situation. However, their results also demonstrate that an approach of threat minimisation, which included avoidant responses such as "didn't let it get to you, refused to think too much about it", was related to better adjustment. More recently, a study by Nelson and colleagues (Nelson, Friedman, Baer, Lane & Smith, 1994) found poorer adjustment to be associated with avoidant coping (Nelson, et al., 1994). Avoidant coping was selected from the Billing and Moos coping scale as one of only two coping responses to be assessed (the other being fighting spirit as assessed by selected items from the Cancer Adjustment Survey which was associated with better adjustment). Avoidant coping was defined as strategies which avoided confronting the problem or indirectly reduced emotional distress such as eating or smoking. This did not include methods of avoiding thoughts about the distressing aspects of the situation. Stanton and Snider (1993) similarly found avoidance, which included wishful thinking, to be associated with increased levels of negative affect after surgery. However they recognise that "the influence of other cognitive avoidance strategies (e.g. active distraction) requires further examination" (p.22).

The importance of the definition and measurement of avoidant responses is illustrated by the research of Dunkel-Schetter and colleagues (1992) using a version of the Way Coping Questionnaire adapted for use with cancer patients. An avoidant response of distancing (e.g. "didn't let it get to me, refused to think too much about it") was associated with lower levels of emotional distress, whilst cognitive and behavioural escape-avoidance

(e.g. "hoped a miracle would happen", "wished the situation would go away or be over with" and "avoided being with people") were related to increased distress. Distancing was found to be the most prevalent way of coping, comprising 26% of the total coping effort and was reported as the primary method of coping by 42% of the participants. Cognitive and behavioural strategies of escape-avoidance were the least frequently used methods of coping. The authors found that distancing was associated with distress in a curvilinear manner (which had been predicted but not found by Meyerowitz, 1983). Accordingly, a response of distancing was found most frequently when distress was at a moderate level and least frequently at low or high levels of distress. They suggest that his finding may account for conflicting results in the past and is best understood if distress is seen as a determinant of coping, as found by Carver and colleagues (1993).

The definition and assessment of avoidance has also proved problematic in studies of coping in the general population. Surtees and Miller (1994) employed the Mental Adjustment to Cancer Scale to assess coping in three groups: people who had been recently bereaved, whose spouse had suffered a non-fatal heart attack and in women entering a women's refuge. Final analysis of the coping data excluded avoidant coping altogether as it contributed less well to a unified scale than the other coping responses. Overall, a response of 'fighting spirit' was related to the best mood outcome.

The measurement of avoidant coping in the current study was not without difficulties. An overall category of cognitive avoidance, involving the combination of all of the strategies which avoided distressing thoughts, did not produce significant correlations with concurrent or subsequent mood scores. This category included those responses which described difficulties in assimilating or believing the threat of the diagnosis, which were subsequently found to be related to mood in an opposite direction to the other strategies of cognitive avoidance, thereby cancelling out any overall associations with mood.

Contradictory findings in relation to the effects of avoidant coping may also be associated with the type of stressor or stage of disease. Previous research on coping has suggested

that specific situations require different ways of coping (Mattlin, Wethington & Kessler, 1990; Pearlin & Schooler, 1978). A meta-analysis examining the relative efficacy of avoidant and non-avoidant coping strategies (Suls & Fletcher, 1985) concluded that avoidance was initially associated with a positive psychological outcome, with non-avoidant strategies associated with a better outcome in the long-term. Many studies on avoidant coping in cancer have employed populations of mixed cancer patients or patients at different stages of their disease. These will have included patients who have had their diagnosis for several years and for whom it may no longer be adaptive to cope with avoidant strategies. Heim (1991) examined the effect on psychological adjustment of 'dissimulation', in which the illness is played down or minimised (e.g. "it's not really so bad - actually I'm feeling quite well" p.233). He found that dissimulation initially had a buffering effect on distress but that this relationship diminished over time until it was no longer significant by 18 and 24 months after operation. He suggests that the concept of denial is complex and that both its meaning as well as its effect as a buffer change over time. Stanton and Snider (1993) suggest that avoidance can have negative effects if it interferes with appropriate action such as regular medical checks. Furthermore, avoidance also requires significant effort which may deplete other psychological resources. Avoidance paradoxically can also intensify negative thoughts (Wegner, Short, Blake & Page, 1990).

Overall, the results from the current study might suggest that cognitive avoidance, specifically defined as conscious or unconscious attempts to avoid thinking about distressing aspects of the disease, is related to a better psychological outcome in the initial period after a diagnosis of operable breast cancer. Responses of denial, defined as difficulties in accepting or believing the diagnosis and including strategies of avoiding relevant information, a refusal to consider the prognosis or a belief that the cancer is cured are associated with a poorer psychological outcome in the first year after diagnosis and treatment.

'The number of women reporting the use of cognitive and behavioural responses to cope with their disease will decrease over the first post-operative year. Post-operative coping responses will show a larger number of associations with concurrent and subsequent measures of mood than pre-operative coping responses'

It was hypothesised that the frequency of reporting the use of the range of cognitive and behavioural responses to cancer would diminish after the initial shock of the diagnosis was assimilated and the surgical procedure completed. It was expected that as women settled into more stable patterns of coping with their disease, differences between those ways of coping which promoted a positive psychological outcome and those which increased mood disturbance would become more apparent.

The pattern of responses on the adapted Faith Courtauld Coping Schedule was variable. Some responses, such as positive appraisal of life, returning to normal and seeking information were used by increasing numbers of women over the first post-operative year. Other responses declined in their reported use; these included fear of the diagnosis, concern regarding treatment, acceptance and a belief in some control over outcome. In addition, the use of positive appraisal of the disease, seeking social support and most of the beliefs about outcome were unchanged over time. Analyses of the change in the number of coping responses reported by each woman in the interviews (excluding outcome beliefs which were only assessed at the second and third interviews) demonstrated an overall gradual increase in the number of responses employed.

The adapted WCQ was only given at three months and one year after operation and could not be used to detect changes in patterns of coping from before the operation. Just four items showed a significant change over the nine months between the post-surgical assessments. These described talking and accepting sympathy, cognitive avoidance and wishful thinking. The number of items marked as used 'quite a bit' or 'a lot' fell significantly from three months to one year after operation.

Methodological difficulties may account for the discrepancy between the use of coping responses from the interview and questionnaire. Several women did not return their

Ways of Coping Questionnaires, despite having completed the rest of the assessments. It is possible that these women were using a greater number of cognitive and behavioural strategies to deal with their disease. They may have been experiencing greater distress and the completion of the questionnaire could have felt like an additional stress. The women who returned their questionnaires may subsequently have been biased towards those who employed fewer strategies. Further analyses of the correlation between the number of responses reported in the interview and levels of mood disturbance for those women who did not return the WCQ might help clarify this issue.

In addition, the interview from the adapted Faith Courtauld Coping Schedule was slightly longer at the second and third interviews (see appendixes 6 & 7) and elicited beliefs about outcome. Whilst outcome beliefs were excluded from the analyses to enable comparison with the pre-operative interview, the greater length of the post-operative interviews may have provided a better opportunity for women to describe the range of their coping responses than at the pre-operative assessment. These methodological issues make it difficult to draw general conclusions about the overall use of cognitive and behavioural responses to cope with breast cancer in the first post-operative year.

The number of associations from the cross-sectional analyses between coping strategies reported on the Faith Courtauld Schedule and mood showed a mixed picture. Whilst the pre-operative coping responses were associated with a greater number of the mood scales than post-operative responses, approximately equal numbers of coping strategies were found to be significantly related to mood at each of the assessments, with two responses associated with mood scores at all three assessments. However, the longitudinal analyses demonstrated an increasing association between methods of coping and subsequent mood. Thus, a greater number of cognitive and behavioural strategies assessed at three months after operation were related to subsequent mood than those assessed prior to operation. Correlations between the number of coping strategies reported in the interview and concurrent mood scores also demonstrated a larger number of associations over time.

Reports on the changing patterns of the use of coping strategies are rare in the literature on coping with cancer. Heim (1991), in his detailed longitudinal study of coping and

adaptation in the first two years after operation, reports the frequency of use of strategies of coping, but these are expressed as mean ranks and do not illustrate changes in the overall frequency of reporting of cognitive and behavioral responses. Variable results, similar to the mixed picture in the current study, have been found by those few studies which describe the change in the use of coping responses. Thus, some strategies decline in frequency whilst others increase. These changes do not always concur with the direction of change for individual strategies in the current study. For example, two studies found an increase in the reporting of acceptance (Burgess, Morris & Pettingale, 1988; Carver, et al., 1993), whilst this decreased significantly in its reported use in the current study. Similarly, cognitive and behavioural avoidance, self-distraction and denial have been found to decrease over time (Carver, et al., 1993; Stanton & Snider, 1993) whilst cognitive avoidance remained consistently high, with a slight increase over time in the current study. However, it is difficult to compare the change in the reporting of individual strategies due to the variety of definitions of responses as discussed previously in relation to avoidance.

Filip and co-workers (1990) found little change in the frequency of the reported use of five coping modes from their coping questionnaire in their one year longitudinal study of cancer patients. However, their population consisted of patients with different primary cancer diagnoses who were at different stages of disease and treatment. Therefore, their results are not comparable with specific changes in methods of coping from the time of diagnosis to one year after operation.

The changes in the strength of association between coping and psychological adaptation over time are also rarely reported, with the exception of the study by Carver and colleagues (1993). They found that associations between strategies of coping and concurrent distress became weaker over the first post-operative year. This pattern was not reproduced in the longitudinal analyses where only one pre-operative coping response predicted subsequent mood whereas three responses assessed at three months after operation were predictive. This association was not sustained as none of the coping responses assessed at six months after operation was significantly related to subsequent mood scores.

In summary, results from the current study were inconsistent, such that analysis of the coping responses from the Faith Courtauld Coping Schedule showed an increase in the number of strategies reported, whilst the WCQ showed a decline. This inconsistency may be a result of methodological difficulties, including the extended length of the post-operative coping interviews and the non-return of some of the questionnaires. Consequently, the first part of the hypothesis cannot be supported.

There is some evidence from the current study and previous research to support the second part of the hypothesis, suggesting that post-operative coping responses have a greater association with mood disturbance than pre-operative coping. A tentative conclusion from these results and those of the current study is that the coping responses employed shortly after operation have the greatest influence on subsequent mood in the first year after operation. This might then be the optimum time to consider implementing a cognitive intervention.

'An indiscriminate use of a wide range of responses will be associated with greater mood disturbance'

This hypothesis was explored using correlations between the number of coping responses reported by each woman on the adapted Faith Courtauld Coping Schedule and concurrent assessments of mood. The number of coping responses employed was also entered as an independent variable in the regression analyses.

The numbers of coping responses reported showed a significant correlation with concurrent assessments of post-operative distress only. A slightly greater number of measures of mood were correlated with the repertoire of responses at the third assessment than at the second, with neither the HAD scale or POMS assessments of depression showing significant associations with the number of responses used at any of the assessments. There were no significant associations between number of coping responses used and mood in the regression analyses.

These results suggest that higher levels of distress might require a wider repertoire of cognitive and behavioural methods of coping, although this does not predict subsequent distress. These findings do not provide evidence to suggest that using several methods of coping lead to heightened levels of mood disturbance.

A wide repertoire of cognitive and behavioural responses has been considered as indicating a flexible approach towards coping with a stressor (Lester, Smart & Baum, 1994). Flexibility in coping has been linked to an improved psychological outcome in chronic illness and alcoholism (Ell, 1986; Sargent & Lieberman, 1985; Shapiro, 1986) as well as in studies of the general population (Lester, et al., 1994), but few studies have examined its effects in breast cancer. Heim and colleagues conducted a detailed analysis of their results from a comprehensive assessment of coping with breast cancer over the first five years after surgery (Heim, Augustiny, Schaffner & Valach, 1993). They found evidence to suggest that there was some stability in coping responses, with a number of responses frequently reported at all assessments. In addition, they demonstrated flexibility in coping as the full range of the coping modes measured by their interview (n=26) were used by their sample at all times, with an average of ten coping modes per patient. These included both the stable modes reported by most of the women plus an additional pattern of responses to meet the demands of the specific disease stage. However, these patterns of flexibility and stability in the use of cognitive and behavioural methods of coping were not analysed in relation to psychological outcome. The authors conclude that their results offer some support for a 'psychosocial phasing' view of coping processes and express an interest in Antonovsky's salutogenic model (1979; 1987). This refers to "those with a broad repertoire and good flexibility being able to adjust to most life challenges better to those with poor repertoires" (p.540).

Carver and colleagues (1993) did attempt to link coping flexibility and psychological outcome in breast cancer using two methods for operationalising flexibility. These both consisted of determining how much each of their coping scales contributed to the overall coping responses reported. If a scale was deemed to have made a significant contribution it was included in the analysis. Flexibility consisted of a summation of these scales but was found to have no association with distress. They suggested that the influence of

those coping scales which were associated individually with a poorer psychological outcome, such as denial and behavioural disengagement, might have cancelled out any overall effects of flexibility. Consequently they repeated the analyses after removing these scales from the calculation of flexibility. One significant result was that previous distress was significantly related to flexibility at three months after operation (i.e. a larger repertoire of coping responses), which in turn was related to subsequent distress at six months after operation.

Methods of counting the number of cognitive and behavioural responses employed to cope with a stressor may not be considered the best method for defining and measuring flexibility. Instead, as is suggested by the current study and the research of Carver and colleagues (1993), this may provide an indication of current or previous distress which requires a greater number of coping resources. Alternatively, this number may represent the length of the interview or verbosity of the interviewee. As previously discussed, the increase in the number of coping responses on the adapted Faith Courtauld Coping Schedule may have been influenced by the greater number of questions in the post-operative interviews, which provided an increased opportunity to describe the coping strategies employed. In addition, the interviews varied in length between participants, which might have depended on their willingness to talk or their current levels of distress. It is possible that those women who were distressed spoke at greater length and thus had more time to report a larger number of coping responses. This issue might be clarified by examining the relationship between the length of interview, number of coping responses reported and their association with psychological outcome.

The results from the current study support the hypothesis that a wider range of responses is associated with greater mood disturbance, but do not provide any evidence regarding whether this reflects an indiscriminate or flexible approach to coping.

Hypotheses 5.2.2 Social support from a confidante

'Positive social support from a confidant will be associated with lower levels of mood disturbance'

Positive support was defined as the receipt of moderate or significant amounts of practical and emotional support, an ability to confide concerns and the absence of negative support from a close confidante (Brown & Harris, 1978). This was examined in relation to concurrent assessment of both measures of mood using univariate analyses.

The majority of the women in the present study reported the receipt of positive support from either their partner/spouse or another confidante. Only eight women reported receiving no positive support at any of the assessments. This support was not found to be significantly related to any of the measures of mood in the cross-sectional analyses; consequently they were not used in the longitudinal analyses. Thus there is no support for this hypothesis in the current study.

This finding contradicts most other research in the field of social support outlined in chapter three. General conclusions from the majority of reviews of the social support literature suggest that people faced with a severe life event, such as the diagnosis of cancer, would manage better if they have good social support. In addition, the reverse was also suggested, such that the absence of social support was associated with a poorer physical and psychological outcome. These were not found in the current study where positive social support did not appear to act as a buffer against the effect of the diagnosis and treatment of cancer in terms of lower levels of mood disturbance, nor was there higher distress in those few women who reported that they did not receive positive support from their confidants. Sutherland and colleagues (Sutherland, Orbach, Dyk & Bard, 1952) reported that one of the fears of patients at an early stage of cancer is the fear of rejection by family and friends. DiMatteo and Hays (1981) also report that patients with cancer may find it difficult to obtain social support because of the stigma and fears associated with the disease. These fears did not appear to be realised in the current study where the majority of women reported receiving positive social support.

One reason for the lack of an association between social support and mood may be due to the lack of variance in the data, with the majority of women in receipt of positive support. It is possible that this group of women was unusual in the level of support they received. They comprised a group of patients being treated at a well-known teaching hospital, and may not have been composed of a random community sample such as might be found in a general hospital. Consequently, the sample may have included women whose social support had enabled them to push for a referral to the hospital, and they may subsequently have received additional support from the specialist health care team, a variable which was not assessed. This means it is difficult to generalise from these results.

In addition, those women who completed all three assessments may have been biased towards those who were in receipt of more positive support from their confidantes. This is supported by the significant difference between completers and non-completers of all three interviews, where non-completers had significantly lower levels of positive support.

An alternative reason for the non-significance of the results may be due to the definition or measurement of social support. In the current study, the definition of social support was taken from the extensive work of Brown and colleagues (Brown & Harris, 1978; Brown & Prudo, 1981), where support is regarded as the woman's perceptions of the support provided by her husband/partner or other close confidant. As previously described, the receipt of good practical support, emotional support and confiding with few negative aspects of support are combined into a single definition of positive support. This definition conforms to the requirements outlined by Wortman (1984), who suggested that a definition of social support should be concise and specific, should conceptualise the different factors of support separately and avoid an effect-based definition, such as defining social support as the receipt of support which is felt to be helpful. A criticism of the current definition and its subsequent measurement might be levelled at the combination of different aspects of support into the single measure of positive support. Practical and emotional support may have different effects on outcome, with emotional support having the greatest significance in cancer (Dunkel-Schetter, 1984; Leppin & Schwarzer, 1990). The combination of these aspects of support might have masked their

separate effects; further investigations might seek to analyse these components of support separately.

The perceived helpfulness of support, assessed in the Self-Evaluation and Social Support Schedule, was not incorporated in the analyses and might possibly have shown a stronger relationship with mood than the definition of positive social support. Bloom (1982) proposed that it was important to assess the perceived support received when measuring social support. However, Wortman (1984) suggested that the helpfulness or adequacy of support will probably show a high correlation with mental health because they are two aspects of the same variable termed 'well-being'. DiMatteo and Hays (1981) suggest that a more objective assessment might be obtained by asking the patient's relatives and doctors to assess the adequacy of support the patient is receiving, although they would be unlikely to criticise their own contribution to the patient's support. Thus it is difficult to make an objective assessment of a subjective variable such as social support.

The importance of focusing on the support provided by the husband/partner or first confidant has been stressed by various researchers working with cancer patients (Abbey, Abramis & Caplan, 1981; Maguire, 1976). Mitchell and Glicksman (1977) found that patients rated the opportunity to confide their feelings as an important aspect of support, with 86% of patients undergoing radiotherapy reporting that they would like the chance to discuss their situation more fully. An advantage of the measure employed in the current study was that it assessed the extent to which patients felt they could confide in their husband/partner or other confidant, as well as emotional support which has been consistently linked with psychological outcome in cancer (Dunkel-Schetter, 1981). A disadvantage was the combination of these various aspects of support as previously discussed.

Winnubst, Couzijn and Ros (1990) review research indicating that the kind of support required by the patient varies according to which phase of disease they are in. For example, clear information from doctors and mutual support from other patients are important on diagnosis and at the time of first recurrence (Dunkel-Schetter, 1984; Vachon, Lyall, Rogers, Chocrane & Freeman, 1982), whilst the support provided at

home and work is important in the post-operative recovery phase (Dunkel-Schetter, 1984). One limitation of restricting the assessment of social support to that provided by close confidantes meant that it was not possible to examine the effects of support provided by alternative sources. Alternative methods used to measure social support in cancer patients have included estimations of the size of the support network, the support provided by the patient's physicians, other members of the health care team or other patients, as well as the extent of information or financial support, none of which were assessed in the present study. The examination of the amount of information received and its perceived helpfulness, as well as the support provided by doctors and other health carers would have made it possible to ascertain whether one of the reasons for the high levels of positive support received was due in part to the backup support provided by the specialist breast cancer unit of the hospital.

A number of researchers have suggested that the receipt of support which is designed to be helpful can sometimes be perceived as not only unhelpful but actually detrimental to psychological well-being. Peters-Golden (1982) compared the attitudes of women with breast cancer with disease-free individuals. The support received by the women with cancer was sometimes felt to be inappropriate, with the focus on their feelings about the loss of the breast and the avoidance of fears about the life-threatening nature of the disease. Attempts to cheer patients up, rated highly by the disease-free individuals, was sometimes perceived as isolating by the patients. DiMatteo and Hays (1981) found that even when support does appear to be appropriate, it can have the effect of undermining patients' self-esteem because they feel they are perceived as an 'impaired person'. This was further supported by Winnubst and colleagues (1990) who suggested that some patients with cancer might experience increased distress as a result of feelings of helplessness and dependency on their relatives. They argue that the inability to reciprocate in a supportive relationship is a source of mood disturbance.

Another reason for the lack of a relationship between social support and mood in the current study may be that the women comprised a mixed group, with some who found the support helpful and others who experienced it as unhelpful. The perceived helpfulness of support was assessed although not incorporated in the final analyses. This

could be used in future analyses to identify those women who were in receipt of positive support, but who found it to be inappropriate or unhelpful, although this may be confounded with measures of mood as previously discussed.

The present study did not assess dependency as defined by Winnubst and co-workers. However the women included were diagnosed with early breast cancer and consequently did not have to rely too much on relatives for physical care. This association may be more clearly demonstrated in women with advanced cancer.

This study included one further assessment of social support in the adapted Faith Courtauld Schedule for coping with cancer (Morris, Blake & Buckley, 1985) which included a question about the seeking of social support. Wortman (1984) suggested that having to seek social support might be indicative of a weakness in the support system. This appears to be supported in the current study with the significant association between the seeking of social support and increased scores on the POMS anger sub-scale at one year after operation. However, this was the only significant finding within a large number of analyses where the application of Bonferroni's correction would render it non-significant. Consequently this result should be interpreted with caution.

'The receipt of negative support from a confidant will be associated with increased mood disturbance'.

The measurement of support in the current study included a question regarding the receipt of negative support, for example in the form of critical comments. Few women reported receiving negative support, but these had significantly increased levels of post-operative mood disturbance. Pre-operatively, the receipt of negative support appeared to have little impact, but its impact increased over time, with the largest number of significant associations at one year after operation. Negative support was particularly strongly associated with POMS tension, depression and total scores with P values of less than 0.002. This suggests that these results were not due to the large number of analyses performed. Consequently, this hypothesis was supported in the present study.

Wortman (1984), in her review of social support and cancer, suggested that the strain of caring for someone with cancer might actually increase negative outbursts, but this does not appear to be substantiated in the current study, where the women were extremely positive about the support they had received. It is possible that this group may not be representative of women with breast cancer, in terms of their levels of social support as outlined above, meaning that it may be difficult to generalise from these results. Alternatively, the women in the current study may have been reluctant to voice criticisms of their relatives and friends in their assessments, although this was not apparent to the interviewer at the time.

Analysis of an individual factor, such as negative support, in the Self-Evaluation and Social Support Schedule meant that the numbers involved were small. However the strength of the significance of the result supports previous research suggesting a link between unpleasant social interactions and psychological morbidity. Two studies in which the positive and negative aspects of support were compared in relation to psychological outcome similarly found a stronger relationship between negative support and mental health than was found with positive support (Fiore, Becker & Coppel, 1983; Henderson, Byrne, Duncan-Jones & al, 1978). Further support for the link between tension, dispute or criticism in interpersonal relationships and a poor psychological outcome might be found in the literature concerning schizophrenia. High levels of expressed emotion, including critical comments and emotional over-involvement, were found to increase the chances of relapse in people with an existing diagnosis of schizophrenia (Tarrier, et al., 1988).

Overall, the current study as well as other research in social support demonstrate that it is a complex variable which cannot be easily simplified or measured as a single concept. Social support can take a number of forms; emotional, practical, informational etc, and can be provided from a number of different sources; close confidant, other patients, medical staff etc. Not all support, whilst well-intentioned, may be perceived as helpful and some aspects of social relationships may be critical or negative. The needs of the patient for support may also vary according to the stage of disease and its treatment. Therefore, the cohort of women employed in the current study may have had different

needs and experiences of support which could not be distinguished by the global measure of positive support and the two assessments of mood. This might account for the absence of a significant relationship between social support and psychological morbidity. This is in contrast with the effects demonstrated by the analysis of specific components of social support, such as negative or critical relationships and the active seeking of support, both of which were related to a poorer psychological outcome.

Hypotheses 5.2.3 Further mediating factors

'High pre-operative levels of mood disturbance will be associated with increased mood disturbance after operation'

Levels of mood disturbance were assessed using both the HAD scale and the POMS. A cut-off of greater than or equal to eight on the HAD scale has been suggested as indicating a level of distress similar to that seen in a psychiatric out-patient population (Zigmond & Snaith, 1983). This enabled comparisons with other studies of psychiatric morbidity in women with breast cancer. The POMS was designed to assess transient mood states (McNair, Lorr & Droppleman, 1981) and is analysed as continuous scores on six subscales of mood. The association between pre-operative and post-operative mood was analysed using multiple regression techniques.

Initial levels of anxiety, as measured by a score of greater than or equal to eight on the HAD scale, were high with almost half of the women assessed as borderline or clinical cases of anxiety. The levels of depression were much lower with only approximately ten percent of women reporting symptoms equivalent to those that might be found in a depressed psychiatric outpatient population. Both of these levels fell significantly after operation to approximately 17% and 6% for anxiety and depression respectively. The distribution of scores on the POMS sub-scales similarly declined significantly after operation, with a rapid fall in scores from the pre-operative assessment to three months afterwards, this lower level was maintained at one year after operation.

These rates of anxiety and depression are lower than those reported in other studies on

women with early breast cancer. For example, Morris and colleagues (1977) found rates of post-operative depression between 17-23%. This was similar to the rates of post-operative anxiety reported by Maguire and co-workers (1978), whilst post-operative depression was found to be higher (21-27%) in their sample. Other researchers have combined anxiety and depression to give overall rates of psychological morbidity. Hughes (1982) reported pre-operative levels of anxiety and depression at approximately 25% for severe distress and 66% for milder mood disturbance. At one year after operation these levels had fallen to 18% for severe anxiety and depression with a further 36% reporting milder levels of distress. Dean (1987) found levels of anxiety and depression at 46.5%, 29% and 26% at pre-operative and three and twelve month post-operative assessments respectively, although she reported that much of this distress was of a minor nature.

One reason for this variation in rates of psychological morbidity might be the use of different methods of assessing mood. One study which also employed the HAD scale, with a cut-off of greater than or equal to eight, found rates of psychological morbidity similar to those in the current study (Watson, et al., 1991). At three months after operation, 16% of the women were classified as cases of anxiety with 6% of the women were cases of depression.

Similar comparisons can be made with studies using the POMS to assess mood disturbance in women with breast cancer. Wolberg and colleagues report detailed results from their assessment of mood using the POMS with women who were treated with either biopsy alone, a conservative surgical procedure or mastectomy. Assessments were performed prior to operation, at between 4-8 months after operation (when adjuvant treatments had been completed) and at 16 months after operation. Comparison of the median scores for each of the POMS sub-scales at all three assessments demonstrates that the women in the current study had generally lower levels of mood disturbance at all three assessments. The median scores were roughly equivalent for pre-operative POMS vigour and post-operative POMS anger.

Comparison of the POMS scores in the current study with the patient normative samples

described by the POMS authors (McNair, et al., 1981) demonstrates that the women with breast cancer had pre-operative scores which were approximately equivalent to the group judged not to be in need of psychiatric treatment, and lower than the scores of the two groups referred for psychotherapy or hospitalisation. The breast cancer sample also had pre-operative scores approximately equivalent to those found in a group of female college students, with the exception of POMS fatigue and confusion where the women with breast cancer had lower scores.

Pre-operative mood for both measures (when scores were analysed as continuous variables) was highly predictive of mood at three months, explaining an additional 20-40% of the variance above that explained by the coping and psychosocial factors in the regression analyses. The analyses of mood at twelve months after operation produced a less consistent picture. Pre-operative mood scores for POMS depression, vigour, fatigue, confusion and total score remained strongly associated with mood a year later. However, pre-operative scores for HAD depression and POMS anger were not selected by the regression equation as they did not show a strong relationship with scores at one year after operation. The scores for all sub-scales on both measures of mood at three months after operation were consistently related to one year post-operative scores, such that higher levels of mood disturbance at three months were predictive of greater mood disturbance nine months later.

Similar associations between pre-operative and post-operative mood scores were found by Morris and colleagues (1977) and Dean (1987) using the Hamilton Rating scale for depression and the General Health Questionnaire respectively. These were employed using a cut-off to denote clinical 'cases' of mood disorder. In the current study, pre-operative mood was less predictive of subsequent mood when a cut-off was employed on the HAD scale to divide borderline/cases (score ≥ 8) from non-cases (score ≤ 7).

Of the forty-two women who were pre-operative cases of HAD anxiety in the current study, only nine remained cases of anxiety at three and twelve months after operation. A further eight women were cases of anxiety at one of the post-operative assessments only. This was reflected in the logistic regression analysis where pre-operative cases of

anxiety were not selected in the regression equation as they did not significantly predict case anxiety at three months after operation. Pre-operative case anxiety was selected when the dependent variable was case anxiety at twelve months after operation. Although the odds ratio was high, with seventeen times the likelihood that a woman who was a pre-operative case of anxiety would also be a case at one year after operation, the confidence intervals were extremely wide. The most conservative estimate of the odds ratio being that she would only be 1.62 times as likely to be a subsequent case. Women whose scores were sufficiently high to be classified as a case of anxiety at three months after operation were much more likely to be cases of anxiety at one year, with an odds ratio of 1:21. The most conservative estimate of the odds ratio (lowest confidence interval) implies that they were at least twice as likely to be subsequent cases of anxiety.

When this cut-off was applied to the HAD depression scale, only one of the nine women who were pre-operative cases of depression was also classified as being a case of depression at both post-operative assessments. Two further women were classified as cases of depression at one post-operative assessment only. Neither pre-operative or three months post-operative cases of depression were predictive of case depression at one year after operation, as demonstrated by the logistic regression analyses. It therefore appears that the HAD scale was more sensitive at predicting subsequent mood when used as a continuous as opposed to a dichotomous measure. Scores on the HAD depression scale were generally low and pre-operative scores on this sub-scale proved problematic in identifying mood disturbance at one year after operation.

These results suggest that the HAD scale could not have been usefully employed for detecting subsequent mood disorder using a case/non-case division of scores. For anxiety, employing a cut-off of greater than or equal to eight on the pre-operative anxiety sub-scale would have correctly identified 17/20 (85%) of the women who were cases of HAD scale anxiety after operation, but at the expense of a false positive rate of 59.5%. On the depression sub-scale, a similar cut-off on the pre-operative assessment correctly identified only 3/9 women who were post-operative cases of depression (33%), with six women incorrectly identified, a false positive rate of 66.7%.

Overall, the degree of mood disturbance in the current study appears to be similar to that found in women with early breast cancer when the same measures are employed, but lower than that reported in studies using different methods of assessing mood. Pre-operative scores on the measures employed were predictive of subsequent mood disturbance when analysed as continuous data, although the three month assessment was better at predicting mood at one year after operation. The HAD depression sub-scale did not perform well in relation to the other scales. Similarly, the use of a cut-off on the HAD scale did not prove useful in predicting subsequent cases of distress. The use of continuous scores on both measures of mood enabled the detection of smaller, but no less important, changes in mood disturbance. However, this approach is limited as it does not facilitate decision making for which women are at risk from subsequent high levels of distress.

'No association will be found between type of surgery and measures of mood'

This hypothesis was investigated using univariate analyses to explore the association between surgical procedure and assessments of mood over the first post-operative year. Type of surgery (e.g. mastectomy or a conservation procedure) was also entered as an independent variable in the regression analyses.

A slightly higher number of women in this study underwent a local excision of their tumour and radiotherapy (57%) compared with mastectomy (43%). Prior to operation, those women about to undergo the conservative surgical procedure had significantly higher scores on the HAD anxiety and POMS confusion scale. No significant associations were found at three months after operation, but at one year the trend was in the opposite direction from the pre-operative assessment, with women who had local excision of their tumour showing slightly lower scores on the HAD anxiety scale. This result should be treated with caution as there was approximately only one point difference in the mean scores of the local excision and mastectomy samples (mean HAD anxiety = 1.7 v 2.8 respectively) and the result is no longer significant after applying Bonferroni's correction criteria. There were no significant associations between type of operation and mood in the longitudinal analyses.

It is interesting to note that the strongest significant relationship between type of surgical procedure and mood was found before the operation was performed. The women in the two surgical groups did not comprise a matched sample and it is therefore possible that other factors may be responsible for these results. The conservative surgical procedure was usually offered to younger, pre-menopausal women, who were also more likely to be offered chemotherapy or ovarian irradiation if they needed adjuvant treatment, as opposed to Tamoxifen which was given to post-menopausal women and has fewer side-effects. These younger women were also more likely to have young children still at home as assessed in the measure of life stage. Younger age, pre-menopausal status, the presence of a child under 6 years still at home and the subsequent receipt of chemotherapy or ovarian irradiation were all significantly associated with increased mood disturbance prior to operation. Only life stage (the presence of a child <6 years at home) demonstrated a significant independent effect on mood in the multivariate analyses which suggests that this factor may explain the apparent association between type of surgery and mood prior to operation.

Despite methodological difficulties, such as retrospective designs, small numbers and a lack of standardised assessments of psychological adjustment, previous research has concluded that there is no consistent relationship between type of surgical procedure and mood (see chapter 1). Two studies with prospective designs found significant associations but in opposite directions. McArdle and colleagues discovered higher levels of anxiety and depression in women who were treated by mastectomy (McArdle, Hughson & McArdle, 1990), whilst Maunsell and her co-workers (Maunsell, Brisson & Deschenes, 1989) found that women who were treated with breast conservation techniques were more anxious and depressed. This last association was found at three months after operation only and the two groups were not analysed according to other variables such as age.

Subsequent studies have concentrated on the offer of choice in the surgical procedure employed. Fallowfield and colleagues (1990) also found no association between the type of operation and subsequent mood disturbance, but significant differences were found between those women who had been offered a choice of surgical procedure, who had

lower levels of psychological morbidity than those women who had no choice. This information was not gathered in the current study.

Overall, the inconsistent results regarding the association between type of surgery and mood disturbance in the current study meant that this hypothesis could be neither confirmed nor rejected.

'Women undergoing adjuvant treatment (chemotherapy/ovarian irradiation) will experience higher levels of mood disturbance than those not undergoing adjuvant treatment'

Similar analyses were used to examine the association between adjuvant treatment and mood disturbance as had been employed in the exploration of the effects of type of surgery. Prior to operation, those women who subsequently received chemotherapy (N=11) had significantly higher levels of anxiety on the HAD scale and confusion on the POMS. Women who subsequently received ovarian irradiation (N=7) comprised three of the ten women who were cases of depression (score ≥ 8) on the pre-operative HAD scale. There were no other significant associations between adjuvant treatment and mood from the univariate or multivariate analyses.

Adjuvant chemotherapy is accompanied by severe physical toxicity, including side effects such as nausea, vomiting and alopecia (Palmer, Walsh, McKinna, Greening, 1980). These have been associated with increased post-operative psychological morbidity, with Maguire and colleagues showing that women receiving mastectomy and combination adjuvant chemotherapy had significantly more psychiatric morbidity than those treated with mastectomy alone or single agent chemotherapy. This was linked with the physical toxicity of the chemotherapy (Maguire, et al., 1980). Hughson and colleagues found significantly more mood disturbance, particularly depression, thirteen months after operation in those women who were treated with chemotherapy compared with women receiving radiotherapy (Hughson, Cooper, McArdle & Smith, 1986). These differences were not apparent at the assessments at one, three, six, eighteen and twenty-four months

after operation.

It is surprising that the only association between adjuvant treatment and psychological morbidity in the current study was found prior to operation when the women were not certain that they would require further treatment. Adjuvant treatment was offered according to the woman's menopausal status and the presence of malignant cells in their lymph nodes, which could only be ascertained after operation. It is possible that some women were aware of the likelihood that they would need adjuvant treatment, particularly if there were obvious physical signs of the involvement of their lymph nodes such as swelling under the arm. This result could also be confounded with other variables such as age, menopausal status and type of operation, since chemotherapy and ovarian irradiation were only offered to younger, pre-menopausal women who were also more likely to be offered local excision of the tumour. These variables were all found to be significantly associated with increased mood disturbance prior to operation.

Of the eleven women who did not complete all three interviews, three comprised women who received ovarian irradiation. Although there were not significant differences between completers and non-completers in terms of pre-operative mood (with the exception of POMS confusion), it is possible that subsequent higher levels of distress associated with their adjuvant treatment may have influenced their decision to discontinue in the study. Their absence also reduced the number of women in the analysis which may have affected the results.

It might be expected that adjuvant treatment would show a greater association with mood after operation when the women were undergoing active treatment. The absence of this result might be accounted for by the timing of the assessments. The interview at three months after operation took place as women were just starting, or about to start, their adjuvant treatment whilst the twelve month post-operative interview occurred a couple of months after treatment had ended. This may mean that the assessments did not coincide with the time of maximum distress. Taylor and colleagues (1985) similarly did not find a significant relationship between adjuvant treatment and psychological outcome, although respondents who were currently on chemotherapy at the time of assessment were

more poorly adjusted. This relationship appeared to be due to the confounding effects of the patients prognosis, such that the relationship was no longer significant when the analyses were controlled for prognosis. In a prospective study of psychiatric morbidity following mastectomy, Dean (1987) found that women who received adjuvant treatment after mastectomy were found to have higher rates of psychiatric morbidity three months after operation but this relationship had disappeared at one year after operation. No information was given regarding the timing of assessments in relation to the receipt of adjuvant treatment.

The lack of a significant association between adjuvant treatment and mood might also be accounted for by the support provided by the specialist oncology staff which was not measured in the current study. Women who were attending the oncology clinic for chemotherapy or ovarian irradiation treatment after their operation had greater contact with specialist oncology staff than those not receiving adjuvant treatment. It is possible that the opportunity to discuss their concerns and the support offered by the staff may have compensated for the additional distress associated with the unpleasant side effects of the adjuvant treatment.

In conclusion, adjuvant treatment was only related to increased mood disturbance before surgery. This may be accounted for by confounding factors such as age and life stage. The absence of a significant association after operation might also have been related to the timing of the assessments, such that the women were not interviewed whilst they were undergoing active treatment. In addition, their distress may have been alleviated by the contact with the specialist staff in the chemotherapy clinic.

'The following psychosocial variables will be associated with increased mood disturbance; i) young age at diagnosis ii) lower social class iii) unmarried (including widowed or divorced) iv) a previous history of psychological treatment'

The psychosocial variables listed in this hypothesis were examined using univariate analyses in relation to both measures of mood at all three assessments. In addition, they

were entered as independent variables in the multivariate regression analyses. The results from the analyses of each psychosocial variable will be considered in turn.

i) Young age at diagnosis

Prior to operation, younger age was significantly correlated with increased scores on the HAD anxiety and POMS tension, depression, confusion scales as well as POMS total score. Analyses using the median age to divide the group of women found that those women who were younger than or aged 54 years also had significantly higher HAD anxiety and POMS confusion scores. These differences were not sustained at three months after operation where there were no significant associations between age and mood, and the trend had been reversed at one year after operation where older women were found to be significantly more likely to be cases of depression on the HAD scale, such that all six cases of depression were aged 55 years or older. Age did not exert a significant independent effect in the longitudinal analyses.

These results are supported by the significant findings in relation to menopausal state, life stage and type or treatment received as previously discussed. Only life stage was found to have a significant independent effect within the multiple regression analyses, although this did not remain significant after including the effect of prior mood scores. It is possible that age has an indirect effect via the stages of life associated with a younger age when these women have the responsibility of young children at home. This was also found to be a significant predictor of depression in Brown and Harris' study of a female community sample (1978). Developmental theorists such as Erikson (Erikson, Erikson & Kivinck, 1986) suggest that different life stages encompass separate developmental tasks. The tasks of early adulthood (20 to 40 years) comprise separating from parents and establishing an independent life in terms of work, intimacy and the start of one's own family. These may be interrupted by the diagnosis of a life-threatening disease and the confrontation with issues of altered body image and mortality which are tasks of middle and late adulthood (age 40 to 60 years and above). However, the effects of age and the variables associated with a younger age in the current study become non-significant after operation, which may indicate that they comprise initial concerns to which the women

subsequently become adjusted.

Previous research on the association between age and psychological adjustment has been inconsistent. Bloom (1982) and Maunsell and colleagues (1989) found no association between age and psychological distress after operation. In the latter study, age was divided into decades for the purpose of analysis which may have masked any associations. Conversely, Funch and Mettlin did find a significant association such that older women reported significantly less negative affect although there was no difference in the reporting of positive affect.

Two studies have suggested that the apparent effects of age might be associated with menopausal status (Dean, 1987; Morris, Greer & White, 1977). Dean found that there was no predictive association between age and subsequent mood, although no information is given on analyses with concurrent mood. Women who were peri-menopausal prior to operation were found to significantly more likely to be cases of psychiatric morbidity at one year after operation. Menopausal status appeared to play a smaller role than life stage in the current study.

The effect of age was reversed at one year after operation in the current study, such that older women were significantly more likely to be cases of depression on the HAD scale in the cross-sectional analyses. This was further supported by the inclusion of age in the regression equation where the dependent variable was case HAD depression at one year after operation, although this just failed to reach significance. This result is difficult to explain using the information from the current study. The increased distress was not associated with a recurrence of disease nor with critical inter-personal relationships or a lack of positive support. It is an area which therefore requires further investigation.

ii) Lower social class

The majority of women in the current study were within social class III (skilled non-manual or manual) with approximately one fifth in social classes I-II and IV-V

respectively. Cross-sectional analyses found no significant associations between social class and the measures of mood and they were subsequently not included in the longitudinal analyses.

Previous research, both in breast cancer and community samples, has shown contradictory results. Dean (1987) found that lower social class was significantly related to increased psychiatric morbidity in a population of 122 women with malignant breast disease. This was supported by similar results from a community sample matched with their breast cancer sample (Surtees, et al., 1983). However, Bloom (1982) found that socio-economic status did not affect psychological adjustment, although it did affect the sense of self-confidence and power. Large scale epidemiological studies have similarly found conflicting results. The Present State Examination psychiatric interview was used by both Brown and Harris (1978) and Bebbington and colleagues (1981), the former finding that increased rates of psychiatric morbidity were found in lower social classes whilst the latter failed to find any significant differences (although different diagnostic criteria were used).

The absence of a significant result in the current study might reflect an overall lack of association between social class and psychological morbidity. Alternatively, these results may be related to the particular sample or outcome measures employed. The sample in the current study comprised few women in the lower social classes (IV & V) and significant results may have been masked by the large number of women who fell into social class three. It is difficult to compare the distribution of socio-economic status with other studies as detailed information regarding classification or sample characteristics are rarely given. A similar classification system was used by Surtees and colleagues (1981) but they divided their sample into middle and working class, with the division of social class III into manual (working class) and non-manual (middle class). This makes comparison difficult.

A number of factors, such as delay in presentation of symptoms, help-seeking behaviours, variable treatment, follow-up and compliance as well as differences of communication patterns with physicians have been suggested as reasons for an association between

socio-economic status and psychological outcome (Hackett, Cassem & Raker, 1973). It is possible that the women classified as social classes IV and V were not representative as they had been referred to a specialist breast unit rather than a district general hospital. In addition, the staff in the breast unit may not have differentiated between women, supplying the same amount of information and support regardless of class. Research by Bloom (1982) suggests that alternative measures of psychological outcome other than mood disturbance, for example analysis of the sense of control or self-confidence, might be more sensitive to differences between socio-economic status.

iii) Unmarried (including widowed or divorced)

As predicted, those women who were separated or divorced had significantly raised levels of mood disturbance, although these results did not apply to women who were single or widowed. Being separated or divorced was associated with increased mood disturbance in both the univariate and multivariate analyses. It explained almost ten percent of the variance in POMS fatigue at three months after operation as well as 4.3% of this variance at one year after operation, although this was not significant after the inclusion of prior mood scores.

These results concur with previous studies which demonstrated increased levels of psychological morbidity in women who were divorced or separated (Northouse & Swain, 1987; Ortmeyer, 1974). The prospective study on coping with breast cancer by Christine Dean (1987) did not find a relationship between separation/divorce and psychological outcome, but her results demonstrated that a poor marital relationship was significantly related to psychiatric case status at three months after operation for breast cancer. In addition, she found that women who were single were significantly less likely to have levels of mood disturbance equivalent to a psychiatric case of anxiety or depression at one year after operation. No relationship between marital status and mood was found by Maunsell and colleagues (1989).

Lower levels of distress were associated with being married in the study by Bloom

(1982), but this did not reach significance. Bloom suggests that this supports the hypothesis that it is the perception of the support provided in a marital relationship which is important, rather than the mere fact of being married. Overall levels of positive support were not significantly associated with mood in the current study, although specific perceptions of support were not analysed individually as previously discussed. However, negative support or criticism was found to be related to increased psychological morbidity. Women who were separated or divorced are more likely to have experienced, or be experiencing, acrimonious relationships and it may be this association between support and marital status which accounts for the increased levels of distress. These factors have also been associated with increased levels of mood disturbance in community samples of women (Brown & Harris, 1978; Surtees, et al., 1983).

iv) A previous history of psychological treatment

Over forty percent of women reported that they had received some treatment in the past for psychological difficulties, these included eleven women who had been treated by a Psychiatrist. A previous history of psychological treatment was strongly associated with almost all of the pre-operative measures of mood but this relationship was not sustained after operation. Only one post-operative measure of mood demonstrated a relationship with previous psychological difficulties, such that at one year after operation, eleven of the thirty eight women who had a previous history of psychological treatment were cases of HAD anxiety. No significant independent effects were found in the regression analyses.

A history of depression or psychological disorder has been associated with increased psychological morbidity after operation for breast cancer in previous research (Dean, 1987; Maguire, 1982; Maunsell, et al., 1989). As in the current study, Dean (1987) found a previous history of psychological treatment to be associated with mood disturbance in the univariate analyses only. Conversely, Maunsell and colleagues found that a history of depression accounted for a significant proportion of the variance in regression analyses, where the dependent variables were psychological distress at three

and eighteen months after surgery. However, they did not include previous mood scores in the regression equation; these were found to account for a substantial proportion of the variance of subsequent levels of mood in the current study.

These results suggest that a previous history of psychological treatment may be an indicator of increased vulnerability to distress when faced with a severe stressful life event. The associated raised levels of mood disturbance are subsequently strongly associated with increased psychological morbidity over the first post-operative year.

Additional results

Family history of malignant disease and personal history of benign breast disease.

Two related variables which had not been included in the hypotheses were found to have a significant relationship with mood. Results from the cross-sectional analyses demonstrated that women who had a family history of malignant disease had significantly raised levels of mood disturbance prior to operation and three months later, while those with a personal history of benign breast disease were more distressed at the three month assessment only. A family history of malignant disease was also associated with increased mood disturbance in the regression analyses. This remained significantly associated with the subscales of HAD anxiety, HAD depression, POMS tension and POMS fatigue after the inclusion of prior mood scores and accounted for between 3.5 and 7.7% of the variance.

This finding supports the results reported from research examining the relationship between attitudes towards cancer and experience with the disease (Berrenberg, 1989). Berrenberg found that people with a history of cancer in their family held the most negative attitudes towards the disease, whilst cancer patients held the most positive attitudes followed by people with minimal experience of cancer. She concluded that her findings support a dual process model such that "those with personal cancer experience will hold the most positive attitudes due to familiarity with the disease and benefits gained from having coped with cancer, while those with familial experience with cancer will

hold the most negative cancer attitudes due to the aversive social interactions they have experienced with the cancer patient" (p.3). Women with a family history of malignant disease may have formed a negative schema regarding cancer as a result of aversive experiences which initially result in heightened levels of psychological morbidity at the time of diagnosis and treatment. The decline in this relationship might be explained by their subsequent personal experience of cancer, leading to a cognitive reappraisal of their attitude towards the disease. This may be accounted for by the diagnosis not having such fearful results as expected, changed perspectives or renewed meaning in life, the encouragement to adopt an optimistic attitude by their support network or the use of denial of the life-threatening nature of the disease as a method of coping.

A history of benign breast disease may have similarly led to an anxious schema regarding malignant disease which is activated on the diagnosis of cancer. This distress may subsequently decline as the experience of cancer allays some of their fears and they find that they are able to cope with it. This is supported by Berrenberg's findings that people with minimal experience of cancer or a family history of malignant disease were significantly more likely to associate the word 'death' with cancer whilst cancer patients were more likely to see it as curable and an opportunity for personal growth.

SUMMARY

The aims of this study included the exploration of the patterns of cognitive and behavioural responses used to cope with the diagnosis and treatment of early breast cancer and it was found that women used a wide repertoire of strategies. These included the expression of apparently conflicting beliefs about outcome which may reflect the uncertainty inherent in the prognosis of cancer. These results provide further support for the argument against measures which limit assessment to a few, mutually exclusive categories of coping.

Patterns of individual coping strategies varied over the first post-operative year. Those strategies which were increasingly reported included positive appraisal of life, attempts

to return to normal and seeking information, whilst reports of fear regarding the diagnosis or treatment, acceptance of the disease and perceptions of control over outcome declined. Other responses, such as cognitive avoidance, seeking social support, positive appraisal of the disease and most beliefs regarding outcome remained unchanged over the period of study. Attempts to avoid thinking about the disease were reported by the majority of women at all three assessments.

A further aim of the study was to examine the association between coping responses and psychological outcome. Positive psychological outcome was related to an overall strategy of 'selective ignoring'. This included attempts to carry on with life in as normal a fashion as possible, trying not to think about the diagnosis and concentrating instead on positive aspects of the disease. In addition, acceptance of the disease and coping through the use of humour were associated with lower mood disturbance. Perceived control over outcome was also related to decreased mood disturbance in the current study. Previous research on this has been inconsistent. The effect of perceived control may depend on the nature of the stressor and the use of problem or emotion focused strategies.

A few strategies varied in their association with mood. Positive appraisal of life and behaviours to aid recovery were associated with increased mood disturbance if expressed before operation, but post-operative use of these strategies was related to decreased mood disturbance.

A poorer psychological outcome was associated with pre-occupation with thoughts of the disease and a fatalistic approach. This comprised beliefs that the disease would probably recur and perceptions of little or no control over outcome. In addition, increased mood disturbance was associated with denial or failure to accept the reality of the disease. This included an avoidance of relevant information, difficulties assimilating the threat of the diagnosis and a refusal to consider the prognosis. The use of religion was also related to increased mood disturbance, but this observation is not supported by previous research.

A composite measure of 'positive social support' from a confidante was unrelated to psychological outcome in the current study. This may reflect the complexity of the

concept of social support which was not fully investigated by an overall rating of positive support. Analyses of specific components of support, such as negative or critical relationships and active seeking of support, were found to be associated with increased mood disturbance.

Examination of psychosocial and physical factors identified several variables which were associated with a poorer psychological outcome. Women who were separated or divorced, had a previous history of psychological treatment, family history of malignant disease or personal history of benign breast disease were significantly more likely to be distressed. Results regarding the effect of surgical procedure were inconclusive. Surprisingly, adjuvant treatment was only associated with pre-operative measures of mood. This might be explained by the timing of the assessments. Alternatively, this result could be confounded with other variables such as age, menopausal status and life stage, which were also associated with increased mood disturbance prior to operation. Only life stage showed a significant independent effect in the multivariate analyses, such that young women with children aged under six years at home were significantly more distressed.

These results have implications for the delivery of care to women with breast cancer. However, the study is not without criticisms. These will be discussed in the final chapter.

CHAPTER 9: CRITIQUE AND IMPLICATIONS

Conclusions drawn from this research will necessarily be limited by the nature of the study. This chapter critically examines the methodology of the study from two perspectives. The first uses criteria developed by Sackett and colleagues (Department of Clinical Epidemiology and Biostatistics, 1981; Sackett, 1979) to critically examine the sample and outcome assessment. Second, further areas such as measurement and analysis are examined, with particular emphasis on the measurement of coping. Finally, the implications of this study for future research as well as practical implications in the care of breast cancer patients will be considered.

9.1 CRITIQUE

9.1.1 Sample and assessment of outcome

Irvine and colleagues (Irvine, Brown, Crooks, Roberts & Browne, 1991) applied the methodological standards developed by Sackett and colleagues to the study of psychosocial adjustment in women with breast cancer. The standards are phrased in the form of a number of questions: '(1) Was an "inception cohort" assembled? (2) Was the referral pattern described? (3) Was complete follow-up achieved? (4) Were objective outcome criteria developed and used? (5) Was the outcome assessment "blind"? (6) Was adjustment for extraneous prognostic factors carried out?' (p.1098). These standards will be used as the structure for examining the sample and assessment of outcome in the current study.

9.1.1.1 Was an inception cohort assembled?

This standard includes the need to specify and, if necessary, control for the disease stage, diagnostic criteria, co-morbidity and demographic variables. This study fulfilled these standards with specific inclusion criteria indicating that the population was homogeneous in terms of a clinical diagnosis of early breast cancer, with no other current or previous malignant disease. The women were identified early and at a uniform point in the disease process, shortly after diagnosis and prior to first operation. This meant that all women were included, regardless of their subsequent adjustment to the disease. The low rate of refusal of first interview might suggest that the sample was not biased in favour of those

women who were less distressed by their diagnosis. Other physical, social and demographic variables were recorded and examined in the analyses.

Whilst such homogeneity in the population studied provided detailed information about how women cope with early breast cancer, it also means that limitations are imposed on the ability to generalise these findings to other groups. It cannot be assumed that the same patterns of responses and psychological outcome would be found in other cancer populations or any other population undergoing similar stress. This might be a direction for future research.

9.1.1.2 Was the referral pattern described?

This is an important question when considering sampling biases. Irvine and colleagues (1991) suggest that despite standardisation of treatment for breast cancer in the Western world, regional differences may still apply. Geographical and financial access to treatment may also reflect the patient's socioeconomic status. Detailed information on the process of referral was not collected in the current study. As mentioned in the previous chapter, it is possible that the women in the current sample were not representative of the general breast cancer population. Some women had travelled long distances to attend the specialist breast unit. This was considered as having a possible relationship with the high levels of support reported by the women. Without detailed information about the referral pattern it is not possible to determine whether these women were a selected group, although comparisons are also limited by the lack of information provided by other studies. The sample did not appear to be biased in terms of socioeconomic status, which was also found to be unrelated to psychological adjustment.

9.1.1.3 Was complete follow-up achieved?

A completion rate of at least 80% is considered acceptable for an adequate follow-up sample. This was achieved in this study where 88.9% of the women completed all three interviews. Details of those women who refused follow-up assessments were subsequently compared with those who were interviewed on all three occasions.

A separate question might consider the length of follow-up. Practical reasons

necessitated the limitation of the follow-up period to one year after operation. This might appear to be vindicated by the relatively low levels of psychological morbidity at three months which were maintained at the one year assessment. Nevertheless, it is possible that a longer follow-up might provide different information.

9.1.1.4 Were objective outcome criteria developed and used?

Both the POMS and the HAD scale, which were used as outcome measures, are widely-used and standardised assessments. They have both been used extensively in research with women with breast cancer. This enabled comparisons with levels of psychological morbidity in other studies. In addition, they both appear to be sensitive to changes in mood disturbance over time, as demonstrated by the similar patterns in scores, which fell significantly from the first to the second assessment and then stabilised. Despite these positive aspects of the POMS and HAD scale, they also have drawbacks.

Hospital Anxiety and Depression Scale

It was notable that scores on the depression subscale of the HAD scale were low. One explanation might be that the sample of women did not experience many depressive symptoms. Substantially higher levels of anxiety than depression were similarly found in a validation study of the HAD scale in patients with cancer (Moorey, Greer, Watson et al., 1991). The authors conclude that this might be a result of studying patients with early breast cancer. They suggest that increased symptoms of depression might be shown by women with advanced breast disease.

An alternative explanation might be that the HAD scale is limited in its application to depressive symptoms. As a result of the exclusion of any physical symptoms which might be effected by illness, symptoms of anhedonia were predominant in the depression scale (Zigmond & Snaith, 1983). Moorey and colleagues (1991) suggest that the lack of other symptoms of depression, such as hopelessness, guilt and low self-esteem, might have a greater effect in outcome studies than screening studies. Several validation studies have recommended the HAD scale as a useful screening instrument for psychological morbidity in physically ill populations (Aylard, Gooding, McKenna & Snaith, 1987;

Barczak, et al., 1988; Wilkinson & Barczak, 1988).

Symptoms of depression are difficult to detect in a medical setting, as they are often confounded with the physical symptoms of the illness (Kutner, Fair & Kutner, 1985). The General Health Questionnaire (Goldberg & Williams, 1988) has been used widely in the study of psychological outcomes in clinical populations, but it has a bias towards assessing physical symptoms (Goldberg, 1986). It has also been shown to be slightly less sensitive than the HAD depression scale in a clinical population (Wilkinson, et al., 1988).

An alternative approach might be to use a measure which has been designed solely to assess symptoms of depression. An example is the CES-D scale (Radloff, 1977), which is the one of the most widely used measures of depressive symptomatology in epidemiological and community studies. This is a 20 item self-report scale for use with a general population. Unlike the HAD scale, it assesses the presence and severity of a wide range of symptoms of depression, including depressed mood, guilt, worthlessness, helplessness/hopelessness, psychomotor retardation, loss of appetite and sleep disturbance.

Profile of Mood States

The POMS was used to measure transient mood states and to provide information on positive outcomes as well as mood disturbance. It was complementary to the HAD scale, supporting some of the relationships found with HAD anxiety and depression as well as picking up some significant associations which would have been missed by the use of the HAD scale alone (particularly in relation to scoring of case/non-case).

In retrospect, the POMS might not have been the best measure to fulfil the aim of assessing positive mood states. The vigour subscale is designed to perform this function, but vigour does not adequately describe psychological well-being and can be confounded with physical variables associated with the disease. Lower scores on the POMS have been considered as indicative of less mood disturbance and consequently greater positive well-being, but again this does not constitute the measurement of positive mood states. Future research might attempt to assess positive well-being more directly. Scales which might be employed include the Bradburn Affect Balance scale (Bradburn, 1969) which

includes separate subscales for positive and negative affect. Alternatively, the Mental Health Index (Viet & Ware, 1983) could be used. This scale provides an index of global mental health but includes subscales of psychological well-being as well as psychological distress. This has previously been used in studies with patients with cancer and other serious illnesses (Cassileth, et al., 1984; Schmale, et al., 1983), although in one study it was necessary to omit some items which were felt to be inappropriate for newly diagnosed cancer patients (Ell, Mantell, Hamovitch & Nishimoto, 1989).

9.1.1.5 Was the outcome assessment blind?

In the current study, the outcome assessment was not blind in that the questionnaires were given by the interviewer who had also assessed coping strategies and was aware of the patient's status regarding other psychosocial variables. However, the outcome assessments of mood were both standardised self-report measures and not readily open to influence by the interviewer.

A greater difficulty might be posed by the use of the interviewer in the rating of the coping interviews. The interviewer was similarly aware of the participant's mood and other psychosocial variables when rating the coping strategies from the interview. This has been suggested as a possible source of bias in research in health psychology (Contrada & Krantz, 1987). This was controlled for in the present study by the use of a second rater and analysis of inter-rater reliability. The rates of agreement on the coding of coping strategies on double-rated interviews were very high. This suggests that the interviewer's knowledge about the participants did not greatly influence the coding procedure. This was helped by the use of a detailed coding manual and the rating of every statement which described a method of coping with the disease and its treatment. Ideally, future investigations might employ separate interviewers and raters in order to ensure that no bias occurs.

9.1.1.6 Was adjustment for extraneous prognostic factors carried out?

This final guideline relates to the need to control for the effect on outcome of variables other than the main ones under examination. This was achieved in the current study by the use of regression analyses in the examination of those variables which have a

significant effect on subsequent levels of mood disturbance. All variables, including coping, social support as well as psychosocial, physical and pathological factors, which had been significantly associated with concurrent assessments of mood were included in these analyses. It is possible that some variables which did not have an association with concurrent mood may have had a significant effect on *subsequent* mood. However, it was necessary to have a criterion with which to limit the number of independent variables to include in the regression equation.

9.1.2 Further areas for critical examination

The guidelines described above were mainly developed for the critical evaluation of studies on prognosis (Department of Clinical Epidemiology and Biostatistics, 1981; Sackett, 1979), although they can be usefully used for research on psychological outcome as described. However, there remain a number of areas which require further consideration. These include the data collection, the choice of measures of the independent variables, in particular the measurement of coping, as well as the choice of analyses. These will each be considered in the following sections.

9.1.2.1 Data collection

The issues which might need to be considered in the collection of data in the current study include where the assessments were carried out, the timing of the assessments in relation to the women's out-patient appointment and the frequency of the follow-up interviews.

The pre-operative interviews were uniformly conducted with the women in a side room on the oncology ward, either the day before or on the day of their surgery. The location of the post-operative interviews was more variable. Some were conducted in a room in the out-patient clinic whilst several women were interviewed in their own home. This occurred when it was not convenient for the women to be interviewed at the same time as their out-patient appointment. This information was not systematically collected and analysed. It is possible that the location of the interview may have affected the women's responses. For example, those women who were interviewed at home may have felt

more able to express increased distress and dissatisfaction regarding their treatment when they were away from the hospital setting. Alternatively, they may have felt less able to express dissatisfaction with the support from their family, especially if their main confidante was in the house during the interview. These factors could be controlled for in future research through the use of a more neutral setting, which was not immediately associated with the oncology department.

The second point concerns the timing of the post-operative interviews in relation to the women's out-patient appointment. Post-operative interviews varied in relation to whether the women had been in to the doctor. It was intended that all women should be seen straight after seeing the doctor, but this was not always possible due to the pressure of time both in the out-patient clinic and the presence of relatives waiting to take women home. Those women who were interviewed at home were always seen after they had been to their out-patient appointments but this may have been up to one week later. Again, a criticism of the study is that this data was not systematically recorded and analysed, although it may have influenced their responses in the assessment. In particular, those women who had not seen the doctor before their interview may have had increased levels of anxiety associated with fears about what the doctor might say in relation to their prognosis. Future research might aim to assess all women at a uniform point in relation to their out-patient appointment in order to control for this source of bias.

The third point about sampling concerns the frequency of the follow-up assessments. The assessments at three and twelve months enabled comparison with several other studies of women with breast cancer which employed similar follow-ups and were achievable within the resource and time constraints of the current study. Heim and co-workers (Heim, Augustiny, Schaffner & Valach, 1993) suggest that adequate assessment of changes in coping and other psychosocial factors over time require an appropriate frequency of observation. They propose that this should include assessments at each of the phases of illness, such as those outlined by Schain (1976). They conclude that most studies fail to meet these criteria, with either too short a follow-up to gather information about coping across the course of the disease, or too long an interval between assessments. This

second issue means fluctuations in coping or mood might be missed by infrequent assessments. This criticism might apply to the current study such that critical changes in coping, support and mood might have occurred in between assessments which were consequently not sampled. In particular, this might account for the lack of an association between adjuvant treatment and mood disturbance as the post-operative assessments did not occur during the time of active treatment. Greater resources in future research might enable more frequent assessments to deal with this issue, but this has to be balanced against the demands imposed on the participants of frequent and lengthy interviews.

9.1.2.2 Measurement of coping

Throughout the literature on coping, the measurement of coping strategies has consistently been discussed as problematic and the current study is no exception. Specific difficulties of the individual questionnaire and interview used will be discussed first. These will then be considered in the light of general methodological issues concerning the measurement of coping. In particular, the debates regarding standardised versus situation-specific assessments, questionnaire versus interviews and quantitative versus qualitative analyses will be examined. Finally, the influence of other factors on strategies of coping will be discussed and an alternative approach to the study of coping will be considered.

The adapted Ways of Coping Questionnaire (WCQ)

There were a number of problems in the use of the WCQ as a measure of coping in the current study. The relative length and complexity of the questionnaire were considerations in the decision to give it to the participants at the post-operative assessments only. Despite the greater time available and reduced distress at these time points, a number of women failed to complete the WCQ, despite having completed the rest of the assessments. Analyses had already proved problematic in the initial study to develop the WCQ for a population of women with breast cancer (chapter 6). The process of revising the questionnaire meant that the advantages of its established psychometric properties were lost. Attempts to replicate the original factor structure developed by the authors (Folkman & Lazarus, 1980) were not successful, nor could a set of factors for this specific population be easily defined. The final conclusion was that it would have

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to be analysed on an item-by-item basis. However, non-return of the questionnaire by women in the main longitudinal study meant that the ratio of participants to questionnaire items was very low. In addition, the necessity of analysing mood in relation to fifty-three questions would have increased the probability of significant associations being found due to chance. In retrospect, even if there had been sufficient numbers of respondents to allow examination of the questionnaire on an item-by-item basis, it is debatable how meaningful these results would have been, for example, when considering the implication of a significant association between one item on the WCQ and increased mood disturbance.

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These difficulties meant that the WCQ could only be employed in the current study in the examination of patterns of coping responses. The similarity between these patterns and those elicited by the Faith Courtauld Schedule provided further justification for the decision to drop the WCQ from the cross-sectional and longitudinal analyses. Consequently, the WCQ was not of use in examining the association between coping responses and psychological adjustment.

The Faith Courtauld Schedule for Coping with Cancer

The initial manual for coding the Faith Courtauld coping interview also included too large a number of coping categories to facilitate analysis. In addition, the experience of coding highlighted several redundant categories as well as others which were overlapping. The subsequent adaptation of the manual had face validity and retained descriptions of the variety of coping categories which might be employed when dealing with the diagnosis and treatment of cancer. However, this adaptation also meant that the current study could not be directly compared with other studies which employed the original method of assessment.

Standardised versus situation-specific measures of coping

Such difficulties of analysis and generalisability are inherent in the measurement of coping (Sommerfield & Curbow, 1992). Standardised measures of coping such as the WCQ have the potential benefits of strong psychometric properties and increased generalisability (Bloom & Ross, 1982), but these benefits are not always realised. The empirical evidence such as factor analytic support for some questionnaires is limited (Endler & Parker, 1990). Several different types and numbers of factors have been found on the same measure including the WCQ (Costa & McCrae, 1989). Subsequent differences in scoring result in difficulties in interpretation and cross-study comparisons of results. Furthermore, such measures give a general idea of the coping strategies being used (e.g. "I decide what to do next - the next step") but do not provide details of these methods of coping (e.g. what is decided as the next thing to do?) (Leventhal & Nerenz, 1985).

- On the other hand, situation-specific measures such as the Faith Courtauld Coping Schedule can provide a more detailed list of the particular coping strategies used in response to cancer. An interview approach allows for the exploration of responses to determine their nature and may give a better idea of those concrete strategies which are effective for dealing with the specific stressor being studied. Drawbacks of this method of assessment include a lack of information about their psychometric properties, and can result in greater complexity in analysis and limited generalisability.

In addition, standardised questionnaires have often been considered to be more economical in terms of time and money to administer than situation-specific interviews. However, the non-return of the WCQ in the current study might suggest that an interview can sometimes be more acceptable to participants. This may be because it allows them to express in their own words the methods they use to cope and the difficulties they are experiencing. Some women also commented that it was helpful to talk about their feelings about their diagnosis and treatment with someone who was prepared to listen to them for an extended period of time.

The need for the employment of both standardised and situation-specific assessments in the measurement of coping has sometimes been supported by examples of research which obtained different results using these two forms of measurement (Bargagliotti & Trysgtad, 1987; Mechanic, 1989). However, results from both the methodological development and main longitudinal study in this thesis suggest that similar patterns of coping are produced from both the WCQ and Faith Courtauld Coping Schedule. Furthermore, the adaptation of the WCQ for use with women with breast cancer meant that it was equivalent to using a new measure. It has been suggested that this renders the distinction between the standardised measure and the situation-specific interview to be one of degree rather than kind (Newman & al, in press). Therefore, further research might consider the employment of a standardised assessment which does not require modification, or the use of a situation-specific measure only.

Specific stresses of cancer and its treatment

Criticisms of standardised approaches in their lack of applicability to specific stressors have also been levelled at some situation-specific measures of coping. Illnesses such as cancer are considered as comprising a collection of several stressful situations rather than one single stressor (Meyerowitz, Heinrich & Schag, 1983). Instructions to respondents to answer questions in relation to how they cope with their disease are considered too general. Instead, the identification of specific stressors such as the operation or adjuvant treatment are suggested.

In the current study, the use of the semi-structured interview from the Faith Courtauld Schedule enabled specific aspects of the disease, such as the initial response to the diagnosis, to be explored. However, these were not separated out in the analyses. In addition, the use of a homogeneous cohort of women in terms of diagnosis and disease stage aimed to control for variation in stresses according to disease stage. It was assumed that the women would consequently be coping with similar stressors at the various assessment points. This assumption may have been erroneous, such that some women were having to deal with the prospect of adjuvant treatment, whilst at the final assessment there were a number of women who had to cope with the recurrence of the disease.

Several methods have been suggested in order to deal with the assessment of coping in relation to specific stressors which accompany the diagnosis and treatment of cancer (Sommerfield & Curbow, 1992). These might be considered for use in future research .

Firstly, a life events or problem checklist could be employed. Respondents are asked to indicate the specific problem with which they are currently coping. Alternatively, respondents might be asked to indicate their most recent stressful event, and answer the coping questions accordingly.

Another method, which has been used with patients with rheumatoid arthritis, requires participants to describe how they have coped with major substressors of the disease such as pain, threats to self-esteem and problems with mobility and self-care (Cohen, Reese, Kaplan & Riggio, 1986). Whilst this overcomes the problem of determining which aspect

of the disease the respondent is coping with, it has the drawback of failing to gain a picture of the patterns of coping used to deal with the disease overall (Newman, et al., in press).

Finally, a method employed in the study of women with breast cancer rated the participants at each of their assessments according to pre-determined stages of illness (Heim, et al., 1993). These stages included diagnosis, surgery, post-discharge with no adjuvant treatment, post-discharge with adjuvant treatment, adaptation and latency of disease, metastatic disease, terminal illness and death. Women who were rated as being in the same illness stage could then be grouped for the analysis of their coping strategies. Methods of coping at different disease stages could also be compared.

Quantitative versus qualitative measures of coping

Comparison of standardised and situation-specific approaches, and of questionnaire versus interview methods of measurement, are also relevant to issues concerning qualitative and quantitative methods of measurement and analysis.

Quantitative data analyses can provide richer information regarding the individual's coping strategies. Observations can be interpreted in terms of their contextual background and accommodate not-linear causal processes (Stiles, 1993). However, conclusions and interpretations must necessarily be tentative. They are openly subjective and do not aim to conform to traditional criteria of standardisation and validation. On the other hand, qualitative data analysis can be scientifically evaluated for its validity and standardised across different populations, but risks the loss of important information in the reduction of verbal responses to numerical responses (Salmon, 1992).

The interview used in the current study provided the potential for a qualitative description of responses, although these responses were subsequently coded to enable a quantitative analysis. The richness of the descriptions of the individual methods of coping may have been sacrificed in order to facilitate the statistical examination of the association between ways of coping and mood disturbance. A qualitative analysis of the transcripts from the interview might be a way forward for further research.

Insert # 2

At the start of the current study, the predominant emphasis in the research literature on coping was on the effect of specific coping strategies on mood. This was perceived as important as it provided an opportunity for interventions to improve psychological outcome. Thus, the study of coping in the current study was restricted to only one aspect, namely the strategies which are used in response to the specific stresses of the diagnosis and treatment of breast cancer. This necessarily limits the conclusions which can be drawn as it does not provide detailed information on the reasons why someone chooses to cope in a particular way, nor does it produce data on the stability of the coping responses employed or how this relates to mood.

Since this research began, the study of coping has progressed with increasing consideration given to wider aspects of the coping process. These include the detailed examination of the individual's appraisal of the threat of the situation and its effect on their coping responses and subsequent mood. In addition, these might be examined in relation to the individual's reappraisal of the situation, including the consideration of the efficacy of their chosen coping strategies. This may also be associated with the stability in the pattern of strategies over time and its relationship with psychological outcome. None of these were examined in the current study. Knowledge of these areas might increase the effectiveness of an intervention by providing important information on *how* an individual's pattern of responses might be altered.

Influence of other factors on coping

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The use of more detailed methods of assessing coping enables the collection of data on other factors which might influence the choice of coping strategies or their effectiveness in preventing distress. A number of these factors are outlined by Somerfield and Curbow (1992). These include dispositional style of coping, flexibility of response and personality variables. The coping measures used in the current study might be criticised for failing to assess these variables. Each of these factors will therefore be considered in relation to possibilities of alternative measures for use in future research.

The pattern of various cognitive and behavioural coping responses elicited in the current study provide further evidence for the need to assess broader coping responses than those confined to 'coping styles' or 'coping traits'. A similar conclusion was reached by Heim and colleagues (1993) who argue that "focusing of a restricted range of coping modes runs the risk of failing to adequately characterise the coping process by missing important differences" (p.524). However, even Folkman and Lazarus (1984) do not completely reject the notion of dispositional styles, suggesting that individuals may have characteristic ways in which they cope. These may then influence the choice of coping strategies in response to a particular stress. Somerfield and Curbow (1992) suggest that this poses an important research question. How well does the individual's dispositional style of coping fit with the demands of the current stressor? For example, a person who has a dispositional tendency to employ problem-focused strategies might experience greater mood disturbance when faced with an immutable situation than someone who had a tendency to cope with emotion focused strategies.

One of the aims in the development of the COPE scale (Carver, Scheier & Weintraub, 1989) was to address this question. The COPE scale was developed from a theoretical rather than an empirical base using Lazarus' model of stress and coping with a model of behavioural self-regulation (Scheier & Carver, 1988). It is similar in design to the WCQ but provides a choice between a dispositional and a situational frame of reference. Thus, participants are asked to respond in terms of what they *usually* do when under stress, or what they did (or are doing) in *a specific coping episode* or during *a specific period of time*. An effort was made to include only those items in the inventory which could be

answered according to both instructions. The use of this scale might provide a contextual background of a preferred way of coping which could be compared with the coping demands of a specific stress such as the diagnosis of cancer. This might form the basis of future research.

A related issue is the ability to be flexible in the use of coping strategies depending on the demands of the situation. This might be an important determinant of the effect of coping on psychological outcome. This was not specifically assessed in the current study, although the number of strategies employed could be used as a rough guide to flexibility of response. Future research might employ a specialised coping measure to assess this variable such as the Flex (Schwartz & Daltroy, 1991). This comprises a card sorting task where descriptions of coping strategies are placed into categories from "most like me" to "least like me". This procedure is repeated in relation to a number of different stressful situations. Flexibility is determined by calculating the range of movement of each card across situations, such that greater flexibility is suggested by the choice of a coping strategy as being "most like me" in one situation and "least like me" in another (described by Lester, Smart and Baum, 1994).

Finally, in their description of the development of the COPE, Carver and colleagues (1989) discuss the need for research to investigate the association between personality and the use of coping with a specific situation. Variables such as neuroticism and extraversion, have been demonstrated as having an influence on the relationship between coping and psychological outcome (McCrae & Costa, 1986). Other variables such as self-esteem, existential beliefs and personal goals have also been shown to affect an individual's appraisal of a situation, which subsequently affects their use of coping strategies (Gruen, Folkman & Lazarus, 1988; Lazarus & Folkman, 1984). Somerfield and Curbow (1992) argue for the importance of this research with regard to cancer patients, such that "consideration of personal commitments may be useful for explaining individual differences in psychological adjustment to cancer and its treatment" (p.1207). It is suggested that future research on stress and coping should include greater information about the meaning of the stress and how it relates to the individual's personal agenda (Lazarus, 1990; Weber & Laux, 1990).

Some of these issues could be addressed by the application of a broader model of the individual and their response to illness, as opposed to a narrow focus on their cognitive and behavioural coping strategies. One such model which might be employed in future research is outlined below.

A broader approach to the study of coping - The Self-Regulatory Model of Illness

The self-regulatory model of illness integrates individual cognition and emotions with social and cultural factors (Leventhal, Diefenbach & Leventhal, 1992). An illness is perceived as a problem and the patient's subsequent behaviour is viewed as an attempt to solve the problem. As with the cognitive-phenomenological model of stress and coping, this model includes the key components of initial appraisal of the threat of the disease (termed 'cognitive representation'), the development and implementation of coping strategies and subsequent reappraisal of the situation. The self-regulatory model differs from the cognitive-phenomenological model in its emphasis on the cognitive representation of the threat posed by the illness. This is viewed as being based on physical symptoms as well as beliefs about the cause, consequences, duration and possibility of cure. One of the key features of the model is the perception of the cognitive representation, coping and reappraisal as occurring in parallel at a cognitive and emotional level (Horne & Weinman, 1995).

The components of the cognitive representation of the illness are believed to be influenced by the cultural context (Landrine & Klonoff, 1992) as well as the views of significant others and past experience (Leventhal, et al., 1992). This latter aspect was reflected in the current study where previous experience of malignant disease or benign breast disease was found to have an association with mood disturbance. A direction for future research might be the investigation of the effect of these variables on the choice of coping strategies.

9.1.2.3 Measurement of social support

Discussion of the results from the current study in relation to social support (chapter 8) highlighted several problems with the measure and analyses employed: Different aspects of support, such as practical and emotional support, were combined into a single

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The hypothesis linking social support with psychological outcome was based mainly on research with male participants and associations have been found to be more complex in women. For example, Shumaker and Hill (1991) cite evidence that high levels of social support are associated with poorer physical outcome in women from specific age groups. Thus, it might be expected that a study of a population of women, such as the current study, would not find a clear association between social support and outcome. Analyses were not conducted on the interaction between social support, age and psychological adjustment and future research might seek to examine these relationships in more detail. The current study also made no distinction between different types of support such as emotional or practical support, as discussed in chapter eight, instead a composite measure of 'positive social support' was derived by combining various aspects of support. Detailed analyses of the separate components of support might provide greater information about the complex relationship between social support and psychological adjustment. In addition, the perceived helpfulness of the support was not included in the analyses, although it was assessed on the Self-Evaluation and Social Support Schedule. The population studied may have comprised a mixed group, some of whom found the support they received helpful, whilst others experienced it as unhelpful. An interesting area for future research might combine the examination of the perceived helpfulness of social support with the interactive effects of age and other variables on psychological outcome.

Insert # 4

A further limitation of the examination of social support in the current study was its failure to contribute to the debate regarding the direct or buffering effects of support. It was assumed that the women were experiencing similar levels of stress since they all received the diagnosis of operable breast cancer and no attempt was made to differentiate the women according to the levels of stress engendered by their diagnosis and treatment. Consequently it was not possible to determine whether social support had an effect regardless of the amount of stress experienced (direct effects model), or whether it was most beneficial under conditions of high stress (the buffer model). The use of a measure to assess the impact of life events, such as the scale of perceived stress (Cohen, Kamarck & Mermelstein, 1983), might provide a method of categorising the women in terms of the stress they were experiencing in relation to their disease, in order to examine the two different models of support.

definition of positive support; perceptions regarding support were assessed but not analysed separately; support from alternative sources other than the main confidantes was not measured; finally, the effect of support was not analysed in relation to disease stage. Research has demonstrated that the kind of support required varies with the stage of disease (Winnubst, Couzijn & Ros, 1990). This is similar to the debate concerning the importance of assessing coping in relation to specific stresses which occur in different phases of the disease and its treatment.

See insert # 3

These issues have implications for future research which aims to investigate the role of social support and cancer in greater detail. The current research placed a greater emphasis on the examination of cognitive and behavioural coping responses. Thus, a brief measure of social support was required. This necessarily limited the findings and conclusions which could be drawn. Research which aimed to study social support in greater depth might employ an interview measure which would provide more detailed information. An example might be the Interview Schedule for Social Interaction (ISSI), developed by Henderson and colleagues (Henderson, Byrne & Duncan-Jones, 1981). This is a 52 item, semi-structured interview which assesses the availability and perceived adequacy of the support provided by close confiding relationships, as well as less intimate friends and relatives. This might include the support provided by fellow patients.

Alternatively, a detailed questionnaire such as the Social Support Questionnaire can be administered verbally as described by Schaefer and colleagues (Schaefer, Coyne & Lazarus, 1981) in relation to patients with cancer. This was designed to measure separately the emotional, practical and informational aspects of social support. Participants are asked to rate each of these aspects in relation to identified providers of support such as spouse, friends, relatives, neighbours or work colleagues. This list could also include members of the health care team.

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9.1.2.4 Statistical analyses

This final section critically evaluates the choice of statistical analyses as well as offering suggestions for further analyses of this data which were not within the aims of this thesis.

Although the data did not always conform to the requirements for parametric testing, these were used in the univariate analyses in order to ensure compatibility with the final multivariate regression analyses. This may have increased the chance of getting spurious significant results. However, the large sample size and the use of Bonferroni's correction reduced the likelihood of this occurring. The number of analyses performed may similarly have increased the probability of significant associations occurring due to chance. Again, the application of Bonferroni's correction was intended to deal with this problem.

Further analyses of the information collected in the current study might include an examination of the coping patterns used by women through the application of a technique of cluster analysis. Patterns of coping among groups of women could be examined. For example, the coping responses of women with perceived control over disease outcome could be explored to see if they used problem or emotion focused coping strategies. Groups of women who had similar patterns of coping could then be compared with other women in terms of their levels of mood disturbance. This is an extension of the examination of the use of single coping strategies employed in the current study.

The social support data could be analysed further to determine the separate contributions of practical and emotional support to psychological outcome. The perceived helpfulness of the support, which was also assessed, could be examined in relation to mood disturbance. This might be used to address the question whether some women who were in receipt of positive support did not perceive it as helpful. This was suggested as one reason for the lack of an association between positive social support and psychological outcome.

One of the main questions which was not addressed in the analyses of the data from the current study was why women choose to employ certain coping strategies in preference to other responses. This was not an original aim of the study but would provide an interesting focus for future work. This might include correlating coping responses with the other psychosocial variables in order to examine their covariance. These are seen as having an important association by the self-regulatory model previously discussed.

Coping might also be used as an outcome variable to investigate whether it is predicted by previous mood or psychosocial factors. These have been found to be significant predictors of the use of the coping strategies of avoidance and acceptance resignation in cancer patients (Behen & Rodrigue, 1994).

Finally, the data from the current study might be used in a long term follow-up of the participants in order to examine the association between cognitive and behavioural coping strategies and physical outcome from breast cancer.

9.2 IMPLICATIONS FOR THE DELIVERY OF CARE TO WOMEN WITH EARLY BREAST CANCER

In this final section, consideration will be given to the applied relevance of the findings from this thesis. It must be remembered that this was not an intervention study, therefore the following comprises suggestions as to how the results of this study might influence the care of women with early breast cancer. The potential benefit of these would require further research.

Implications for the delivery of care can be subdivided into: The identification of those women who might experience significant distress after diagnosis and treatment, management of pre-operative distress, when might be the optimum time to intervene after operation, as well as what form an intervention might take. Each of these aspects will be examined in turn.

9.2.1 Identification of women who might experience significant distress

Several psychosocial factors were demonstrated as being associated with increased levels of mood disturbance in women with early breast cancer. These included several factors associated with a younger age such as the presence of young children at home, pre-menopausal status and the receipt of a treatment protocol which includes local excision of the tumour and subsequent adjuvant treatment. It was not possible to determine which of these factors had the strongest effect as they were inter-correlated,

although the presence of young children was the only variable to be selected in the regression analyses. These factors might all serve as indicators of a potentially increased risk of distress in the first post-operative year.

Those women who were separated or divorced, as well as women with a family history of malignant disease or personal history of benign breast disease, also demonstrated significantly raised levels of mood disturbance. Such risk factors could be noted on admission for primary operation and these women could be selectively interviewed regarding their levels of distress. This might enable early identification of difficulties and increase the potential for a successful intervention.

High levels of initial distress were also found to be associated with significantly increased mood disturbance after operation. This might indicate the need for a screening questionnaire to identify these women in order to target interventions appropriately. Whilst the HAD scale has been criticised as an outcome measure in relation to the influence of coping strategies, it has been found to be a useful screening instrument for psychological morbidity in physically ill populations (Aylard, et al., 1987; Barczak, et al., 1988; Wilkinson, et al., 1988). The results from the current study suggest that it might be employed as a continuous measure of mood rather than solely to indicate 'case' or 'non-case'. This complicates the decision process regarding who might benefit from an intervention by not providing a clear cut-off. However, the addition of supplementary questions concerning the impact of their mood might mean that those women who would not conform to a criteria of "caseness", but perceive themselves to be experiencing difficulties, would not be overlooked.

9.2.2 Pre-operative distress

Levels of mood disturbance were at their highest prior to operation and fell significantly afterwards. Much of this distress therefore appears to be transient but still represents a significant difficulty for these women at the time. The transience of this mood disturbance might suggest that it is connected with the initial shock of the diagnosis and fears about the treatment. This is supported by the results from the current study where fear of the diagnosis and concerns about treatment, as assessed by the Faith Courtauld

Coping Schedule, were expressed by the majority of women prior to operation. This frequency declined significantly after surgery. Pre-operative counselling and the provision of information about the disease and its treatment might help alleviate some of this distress. This would provide an opportunity for women to express their fears and false beliefs about cancer could then be challenged. In addition, pre-operative counselling might help women prepare for surgery. This might include explaining the procedures involved and enabling women to ask questions. This would aim to reduce the fear which is associated with the unknown. Simple behavioural techniques, such as controlled breathing and relaxation, might also be taught to enable women to manage feelings of anxiety.

9.2.3 When to intervene after operation?

The timing of a structured intervention is important. Women may not be receptive to an intervention which is offered too early, before they have had time to assimilate the implications of the diagnosis and whilst they are still trying to deal with the practical implications of the treatment. An intervention which is offered too late may mean women experiencing increased distress for a long period, by which time their coping strategies may have become more entrenched.

Findings from the current study might suggest that three months after operation would be the optimum time for offering a structured intervention. The initial distress generated by the shock of the diagnosis and treatment had subsided by this point, leaving a smaller number of women who continued to experience raised levels of mood disturbance. The coping strategies employed at this time also showed the strongest association with levels of mood at one year after operation. Thus, an intervention aimed at altering the pattern of coping at three months after operation might have the effect of subsequently lowering levels of distress.

9.2.4 What type of intervention could be offered?

A variety of interventions have been proposed for working with women with breast cancer, including support groups, individual psychotherapy and medication (Ramirez in Fentiman, 1990). It is beyond the scope of the current thesis to review all such

possibilities. The focus of this research was on the cognitive and behavioural coping strategies used to cope with breast cancer. Consequently, the findings have the most relevance for a cognitive or behavioural approach to managing distress. The implications of the results in informing such an approach will be considered. In addition, the influence of negative or critical relationships will be examined in relation to the implications for work with families.

Cognitive therapy is based on the assumption that the way in which an individual thinks about or interprets their experience will determine their mood and subsequent behaviour (Beck, 1976). It aims to alter underlying maladaptive beliefs through identifying and challenging negative thoughts and developing effective coping skills. It often incorporates aspects of behavioural therapy, such as teaching methods of relaxation.

Maladaptive beliefs, such as fearing that the cancer would definitely return or feelings of helplessness, which were associated with increased mood disturbance in the current study, might be identified and challenged using a cognitive approach. The beliefs of those women with a family history of malignant disease or a personal history of benign breast disease could be similarly explored. Cognitive techniques developed for obsessional disorders could be adapted in order to help those women who were pre-occupied with thoughts about the disease. These techniques include distraction, thought-stopping and the substitution of an alternative thought (Salkovskis & Kirk, 1989).

The avoidance of information relevant to the disease, as well as avoiding consideration of the prognosis, were both associated with increased mood disturbance. Such avoidance can paradoxically lead to the intrusion of the frightening thoughts they are trying to suppress. Cognitive therapy aims to manage such maladaptive avoidance by gently helping the patient to consider and explore their negative thoughts. Once these are verbalised, they are open to rationalisation and it is possible to consider alternative thoughts and beliefs (Salkovskis, 1989).

In addition, coping skills can be facilitated by helping women to talk about and acceptance their disease. Methods of managing distressing thoughts about the threat of

the diagnosis and considering alternatives such as focusing instead on positive aspects of life can be explored. These were all found to be associated with decreased mood disturbance in the current study. Behavioural attempts to achieve some control over the disease after the operation as well as trying to return to normal routines of life were also related to an improved psychological outcome and could be included in the behavioural aspect on an intervention.

Finally, the finding that women who were in critical or negative social interactions with their confidantes were significantly more distressed might have implications for considering interventions aimed at couples or families. There are many different models for couple and family therapy, but essentially they work with the whole system rather than singling out one individual. This might aim to explore the underlying reasons for the breakdown in relationships and facilitate communication.

9.2.5 Conclusion

In conclusion, the findings from this study have a number of important implications for women with early breast cancer and the management of distress associated with their diagnosis and treatment. It is hoped that they will be useful in the consideration of the delivery of care to women with breast cancer, though further research would be required to assess the effects of implementing the interventions discussed.

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LIST OF APPENDICES

- Appendix 1: 'Measuring coping in breast cancer'
- Appendix 2: Frequency of scores for each item on the adapted Ways of Coping Questionnaire. Data gathered from the methodological development of the questionnaire.
- Appendix 3: Factors and factor loadings from the factor analysis of the adapted Ways of Coping Questionnaire. Data gathered from the methodological development of the questionnaire.
- Appendix 4: Original categories from the Faith Courtauld Schedule for Coping with Cancer.
- Appendix 5: Sociodemographic data rating form.
- Appendix 6: Pre-operative coping interview from the Faith Courtauld Schedule for Coping with Cancer.
- Appendix 7: Post-operative coping interviews from the Faith Courtauld Schedule for Coping with Cancer.
- Appendix 8: Adapted manual from the Faith Courtauld Schedule for Coping with Cancer.
- Appendix 9: Adapted Ways of Coping Questionnaire.
- Appendix 10: Hospital Anxiety and Depression Scale.
- Appendix 11: Profile of Mood States questionnaire.

Appendix 12: Social Evaluation and Social Support scale.

Appendix 13: Inter-rater reliability data for the adapted Faith Courtauld Schedule for Coping with Cancer.

Appendix 14: Frequency data for the coping categories from the adapted Faith Courtauld Schedule for Coping with Cancer.

Appendix 15: Graphs of the distribution of scores on each sub-scale from the Profile of Mood States.

Appendix 16: Independent variables included in the regression analyses.

a) Prediction of mood at three months after operation

b) Prediction of mood at one year after operation

Appendix 1: Copy of paper 'Measuring Coping in Breast Cancer'

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MEASURING COPING IN BREAST CANCER

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Abstract—The emotional distress associated with breast cancer varies between individual women. These variations may be accounted for by differences in cognitive and behavioural coping responses to diagnosis. This study has attempted to develop a reliable, situation-specific approach to the measurement of coping responses in women with breast cancer. It has adapted a general coping questionnaire and modified an interview-based schedule for coping with cancer. The strengths and weaknesses of the interview and self-report methods of assessment are highlighted. Consistent results from these complementary approaches have been obtained. Both indicate the extensive use of cognitive avoidance and positive reappraisal. It has been shown that the majority of patients use a wide repertoire of coping responses which challenges the notion of mutually exclusive coping styles. These measures may be employed to examine the relationship between women's thoughts and behaviours in response to the diagnosis and treatment of breast cancer and subsequent psychological outcome.

INTRODUCTION

CANCER threatens not only patients physical health but also their emotional well-being. Women with breast cancer commonly experience transient emotional distress in relation to their diagnosis and treatment whilst around one quarter develop clinically significant and persistent anxiety and depression in the first 2 yr after diagnosis [1]. Patients' cognitive and behavioural coping responses to the diagnosis may account for individual differences in psychological adaptation [2-4].

Previous studies of coping with cancer have produced inconsistent and often contradictory findings. For example, Weisman and Worden [5] found that denial, as well as passivity and acceptance were associated with greater vulnerability in cancer patients, while Watson and co-workers [6] showed denial to be related to less distress in women with breast cancer. Conclusions from such studies have been limited by difficulties in defining the concept of coping, the use of unreliable measures and the assumption that patients with different types of cancer respond similarly.

Much of the early research equated coping with psychological adaptation and a successful outcome. Penman [7] and Ray and her colleagues [8] described 'successful' and 'unsuccessful' coping strategies according to apparently arbitrary inferences about the function of the response. Other researchers such as Margarey and co-workers [9] employed a psychoanalytic definition of coping in the study of cancer patients which distinguished between 'coping' and 'defences'. Coping responses were regarded as realistic, flexible and adaptive responses to stress. 'Defences' were viewed as rigid distortions of reality and therefore maladaptive. Such distinctions confound the nature of the coping response with the outcome of psychological adaptation.

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Coping has been commonly regarded as an enduring trait or style. One of the best known studies which examined coping in women with breast cancer grouped patients' responses to a structured interview into four mutually exclusive coping categories [10]. These comprised denial, fighting spirit, stoic acceptance, and helplessness/hopelessness. An attempt to replicate this finding using a more systematic semi-structured interview, the Faith Courtauld Schedule for Coping with Cancer, was largely unsuccessful [11]. Instead it was found that individual patients with cancer used a variety of cognitive and behavioural responses which often reflected all four coping styles in one interview. The large number of possible coping responses within the schedule limited further analysis and interpretation of the data.

Implicit in the theory of exclusive styles of coping with cancer is the assumption of consistency in response over time. However, evidence for such consistency is weak and this assumption has been challenged [12]. The flexible responses of patients with cancer as their situation changes over the course of their disease have been cogently described by Mages and Mendelsohn [13].

Recently, research on coping with cancer has moved away from the search for enduring coping styles and towards the study of situation-specific responses as outlined by Lazarus and Folkman [4]. They define coping (p. 141) as 'the person's constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person.' Accordingly they have devised a questionnaire measure of coping, the Ways of Coping Questionnaire [14]. This describes a wide range of cognitive and behavioural strategies which may be used in response to a specified stressful situation. The identification of coherent groups of items by factor analysis has produced varying factor structures in different populations [15-18]. However, its use with patients who have cancer suggests some relationship between specific ways of coping and emotional well-being [19, 20].

To date, therefore, the measurement of coping with cancer has been beset with problems of low validity and low reliability. The aims of this study are as follows.

(1) To develop a situation-specific approach to the measurement of coping in breast cancer, based on the theoretical approach of Folkman and Lazarus. This involves the adaptation of the Ways of Coping Questionnaire (WCQ) [14] and the Faith Courtauld Schedule for Coping with Cancer [21].

(2) To compare these interview and questionnaire methods of measuring coping with breast cancer.

(3) To describe the cognitive and behavioural coping strategies used by women following primary treatment for early breast cancer.

PATIENTS AND METHODS

Adaptation and use of the WCQ

The WCQ is a widely used and standardized questionnaire. It was originally designed for use with a general population and contained 66 items. On examination of the original scale, some of the items were considered to be inappropriate for patients with breast cancer (e.g. 'I tried to get the person responsible to change their mind'). The questionnaire was therefore modified by asking 10 professionals, involved in the care of breast cancer patients, to rate each of the items on the WCQ for its acceptability or appropriateness to patients with cancer. An agreement of 50% or more on the unacceptability or inappropriateness of an item led to its removal. Thirteen items which mainly described efforts to remove or change the source of the stress, namely the cancer, were consequently eliminated.

The modified 53-item WCQ was completed by 153 women who had been treated for early breast cancer and who were attending their routine follow-up out-patient appointments. All patients were in remission at the time of the study, with remission times ranging from around 9 months to 10 yr. The modified WCQ asks the women to reply in terms of the coping responses they are currently employing. Questionnaires were completed anonymously.

Adaptation and use of the Faith Courtauld Schedule for coping with cancer

The interview of the Faith Courtauld Coping Schedule elicits a patient's cognitive and behavioural responses to a diagnosis of cancer. Specific areas of enquiry include the patient's discovery of symptoms, understanding of the diagnosis and its implications, beliefs about outcome and sense of control. Coping responses are operationally defined in a detailed manual which avoids psychoanalytic language and value judgements concerning the function of the response.

The interview was given to 49 women who were in remission following treatment for early breast cancer. These women were separate from the questionnaire group. Their remission times ranged from 6 months to 12 yr. Initial use of the Faith Courtauld manual highlighted a number of methodological problems. Some of the response categories were not mutually exclusive which made reliable rating difficult. Also, a number of the categories were rarely reported by patients. Finally, the large number of response categories made statistical analysis difficult as has already been described by Burgess and her colleagues [11].

A revised manual was compiled by removing redundant items and combining those which were similar. Response categories were subsequently reduced from 72 to 23 (Table III). The revised categories of coping responses were used to re-rate the 49 coping interviews.

As in the original manual, ratings were intended to be situation-specific and were only made for those statements which refer to the patient's reaction to the diagnosis or treatment of breast cancer. The interviews were audiotaped and subsequently transcribed. The transcriptions were then rated using the revised manual. Ratings were made according to the patient's verbatim statements regarding their thoughts and behaviours in response to their cancer. The ratings were performed by one of the authors (SRJ) and consensus was reached on difficult ratings with a second author (AJR). The frequency of responses during the interview was recorded.

Statistical methods

Frequency analyses were performed for all items from the questionnaire and interview and for each woman according to her pattern of coping responses.

Multivariate analyses consisted of a principal components analysis with mean substitution for missing data using the Statistical Package for Social Scientists [22]. The BioMedical Data Package was used to perform a cluster analysis with median substitution for missing data and minimum distance (single linkage) rules for amalgamation of clusters [23]. The BMDP was employed for a factor analysis with median substitution for missing data and orthogonal rotation. Kaiser's criterion was used for factor selection whereby factors were retained if they had an eigenvalue greater than or equal to 1 [24].

RESULTS

Analysis of the adapted WCQ

Frequency analysis showed that the distribution of the questionnaire scores was skewed. Over 70% of women identified 9 of the 53 ways of coping as responses they used 'sometimes' or 'a lot'. These items reflected cognitive avoidance, positive reappraisal of their illness and life, control of emotional expression and concentration on aspects of the disease over which they have some control (Table I). In addition there were a number of ways of coping which the majority of women did not use. Over 70% identified 10 of the 53 items which they used 'never' or only 'occasionally'. These included strategies of wishful thinking, social avoidance and blaming of self or others.

A group of women was identified who used very few ways of coping. Thus 9 women responded to more than 35 of the 53 items as 'not used'. This cut-off was equal to 2 SD or more above the mean number of questions answered as 'not used'. The items which they reported using consisted mainly of strategies of cognitive

avoidance e.g. 'I try to forget the whole thing' and positive reappraisal e.g. 'I came out of the experience better than I went in'. A cluster analysis identified a similar group of women. The remaining clusters, however, contained only one or two women and were therefore inconclusive.

TABLE I.—FREQUENCY OF COPING RESPONSES USED BY WOMEN WITH EARLY BREAST CANCER ACCORDING TO THE MODIFIED WCQ

WCQ item	Frequency %
WCQ items to which over 70% of women responded used 'sometimes' or 'a lot'	
'I remind myself how much worse things could be'	88.0
'I try to improve my general health'	87.3
'I look for the silver lining, try to look on the bright side of things'	85.6
'I try to keep my feelings from interfering with other things too much'	77.3
'I maintain my pride and keep a stiff upper lip'	77.3
'I know what has to be done so I double my efforts to make things work'	76.2
'I try to keep my feelings to myself'	76.0
'I try to rediscover what is important in life'	75.3
'I go on as if nothing has happened'	74.2
WCQ items to which over 70% of women responded 'not used' or 'used occasionally'	
'I take it out on other people'	91.5
'I think I brought the problem on myself'	87.2
'I generally avoid being with people'	85.4
'I refuse to believe it's happened'	84.2
'I have fantasies or wishes about how things may turn out'	77.0
'I daydream or imagine a better time or place than the one I am in'	75.5
'I have found new faith'	74.5
'I do something which I don't think will work but at least I am doing something'	72.0
'I think about how a person I admire would handle the situation and use it as a model'	71.2
'I try to make myself feel better by eating, drinking or smoking etc'	70.2

Examination of the data also identified a group of 8 women who responded to more than 39 of the 53 items as used 'sometimes' or used 'a lot'. The fact that some of the women responded positively to most of the ways of coping was supported by a principal components analysis in which the first component comprised 40 of the 53 items from the questionnaire.

Further examination of the data based on individual items was limited by the large number of questions. A factor analysis was therefore performed in order to determine whether the items on the WCQ could be sorted into coherent groups on the basis of a correlation matrix. The factor analysis was only partially successful. The first two factors identified after orthogonal rotation contained distinct groups of items which described 'seeking social support' and 'wishful thinking' respectively. A factor loading of ≥ 0.4 was used for retaining items (Table II). These two factors explained 7% of the variation in the distribution of scores on the WCQ. The remaining 15 factors extracted contained a variety of items which could not be summarized under single headings. The variance explained by all of the 17 factors was 35.6%. (Full details of factor loadings are available from SRJ.)

The factors identified in this study were dissimilar to those defined by Folkman and Lazarus using similar multivariate analyses on data from a general population

[14]. Application of Folkman and Lazarus' factors to the current data set from breast cancer patients was therefore limited. This was not surprising as most of the items from the original factor of 'confrontive coping' had been removed during the adaptation of the questionnaire. In addition, correlation matrices of the questionnaire items from the breast cancer data showed that the items within the other factors described by Folkman and Lazarus were poorly correlated.

TABLE II.—FACTOR ANALYSIS OF THE MODIFIED WCQ—FIRST TWO FACTORS

	Factor loading*
Factor 1—'Seeking social support/information'	
'I talk to someone who can do something concrete about the problem'	0.809
'I ask advice from a relative or friend I respect'	0.704
'I get professional help'	0.698
'I talk to someone about how I am feeling'	0.549
'I accept sympathy and understanding from someone'	0.545
'I talk to someone to find out more'	0.497
'I let my feelings out somehow'	0.436
'I try to analyse the problem in order to understand it better'	0.419
Factor 2—'Wishful thinking'	
'I wish that I could change what has happened or how I feel'	0.734
'I wish that the situation would go away or somehow be over with'	0.726
'I turn to work or substitute activity'	0.529
'I hope for a miracle'	0.482
'I have fantasies or wishes about how things may turn out'	0.384

*Factor loadings greater than 0.4 extracted in a factor analysis with median substitution for missing data and orthogonal rotation.

Analysis of the Faith Courtauld coping schedule

A frequency analysis of the data was performed (Table III). Approximately 65% of the women described fear in relation to their diagnosis and treatment. Three quarters expressed uncertainty regarding the prognosis of their cancer. Almost 90% used some form of cognitive avoidance in relation to their cancer and 65% described a positive reappraisal of their illness or life in general.

Coping strategies described by only a minority of women included use of humour, behavioural attempts to facilitate recovery (for example, adopting a special diet), religion and prayer, social avoidance and seeking information. Less than 5% said that they had not considered their prognosis at all and very few believed that they would definitely suffer relapse. Only 20% of women made statements regarding their perceived control over the disease, although the majority of these felt that they had some control.

The responses which were described by the majority of women also tended to be those which were reported several times during their interviews. Those responses which were reported by only a minority of women tended to be mentioned only once during their interviews.

The frequency analysis also highlighted the concurrent use of apparently conflicting responses. This is particularly evident for a number of women who reported differing outcome beliefs within their interviews. This usually involved expressing both the belief that they were cured and uncertainty about their prognosis.

A group of 10 women were identified who used four or less different coping

TABLE III.—FREQUENCY OF COPING CATEGORIES USED BY WOMEN WITH EARLY BREAST CANCER ACCORDING TO THE REVISED FAITH COURTAULD COPING SCHEDULE

Coping category	Frequency %
Cognitive avoidance	89.8
Uncertain whether will suffer adverse consequences	75.5
Fear of diagnosis	69.4
Positive reappraisal of illness and life	65.3
Fear of treatment	61.2
Neutral preoccupation	36.7
Seeking social support	24.5
Believes will suffer no adverse consequences	22.5
No change in thoughts/behaviours	20.4
Avoidance of relevant information	20.4
Fatalistic and passive acceptance	18.4
Realistic acceptance	18.4
Believes can have some control over outcome	14.3
Anger	10.2
Active attempts to return to normal	8.2
Humour	8.2
Social avoidance	8.2
Seeking information	8.2
Religion and prayer	6.1
Behaviour to aid recovery	6.1
Believes probably/certainly will suffer adverse conseq.	6.1
Believes has little/no control over outcome	6.1
Claims not to have considered outcome	4.1

responses during their interview. These responses included avoidance, positive reappraisal and expressions of fear regarding the implications of the diagnosis. A cluster analysis of the data identified a similar but larger group of 21 women whose predominant responses were also avoidance, positive reappraisal and fear regarding the implications of both the diagnosis and treatment, as well as uncertainty regarding the prognosis. A second cluster comprised four women who did not express fear regarding their diagnosis and stated the belief that they would suffer no adverse consequences as a result of their disease. The remaining two clusters each contained only two women and were therefore inconclusive.

The effect of time since diagnosis on the amount of coping the women described was examined. The women were divided into three groups according to their remission times (≤ 2 yr; 3–5 yr; ≥ 6 yr). These divisions were based on the changes in their frequency of follow-up. They were seen 3 monthly for the first 2 yr post diagnosis, then 6 monthly until 5 yr and thereafter yearly. There was no difference in the median number of responses made by the women in the three groups ($p > 0.05$, Kruskal–Wallis test (Table IV)).

TABLE IV.—COMPARISON OF THE NUMBER OF COPING RESPONSES EMPLOYED BY WOMEN ACCORDING TO THE LENGTH OF TIME SINCE DIAGNOSIS

Time since diagnosis	Median number of coping responses	Z value
≤ 2 yr ($N = 21$)	6.0	-0.64
3–5 yr ($N = 17$)	7.0	1.09
≥ 6 yr ($N = 11$)	6.0	-0.49

Kruskal–Wallis test for significance between groups.

$H = 1.198$.

H (adjusted for ties) = 1.254; $p > 0.05$.

DISCUSSION

This study has shown that it is feasible to adapt the Ways of Coping Questionnaire and the Faith Courtauld Coping Schedule in the development of situation-specific measures of coping with breast cancer. In addition, it has highlighted the strengths and weaknesses of these questionnaire and interview approaches to measurement.

The modified WCQ only took about 5–10 min for the patients to complete and eliminated observer bias. A possible drawback of a questionnaire approach is the difficulty patients may have in recognizing and categorizing their thoughts and behaviours in response to their cancer through self-report. This is likely to be a particular problem in the assessment of strategies which involve avoidance. This problem was similarly encountered by Watson and her colleagues [25] in their development of a self-report questionnaire to identify the four styles of coping previously described. Only one of the questions which was designed to measure denial/avoidance obtained statistical significance in a multivariate analysis of their data from 236 cancer patients.

Analysis of these data from women with breast cancer using the modified WCQ demonstrated that it is not appropriate to impose a factor structure on the data as previous researchers have done [19]. The 17 factors extracted explained only a small proportion of the variance. In addition, the majority of the factors contained dissimilar items which could not be summarized by single headings. However, it is interesting that 'seeking social support' and 'wishful thinking' did emerge as two distinct factors. This may be because the relevant items are particularly clear and unambiguous. Furthermore, the seeking of social support and wishful thinking are perhaps easier to comprehend compared with the more complex cognitive manipulations such as emotional control.

The limited success in applying Folkman and Lazarus' factors [14] to this dataset suggests that factors derived from other populations are not applicable in assessing coping in women with early breast cancer.

The Faith Courtauld Coping Schedule provides a more flexible, individually orientated approach to the assessment of coping with cancer. It avoids the forced choice of responses required by a questionnaire and provides the opportunity for patients to describe coping strategies on more than one occasion which may reflect the degree to which they are employing these strategies. Furthermore, the interview approach allows patients to express ambivalence in their responses as evidenced by the conflicting outcome beliefs expressed by some women. Apparently conflicting responses may reflect the uncertainty associated with the diagnosis and treatment of breast cancer.

The limitations of an interview include the time consuming nature of the collection and collation of data and difficulty with data analyses. A further problem relates to the responses which are not described by a patient during an interview. This may indicate that the particular response is not used but it may also reflect a lack of specific probing by the interviewer or a difficulty in describing the coping response on the part of the patient. The appropriateness of detailed probing when exploring sensitive areas such as the thoughts and beliefs regarding a potentially life threatening situation such as cancer can be difficult to judge. Insufficient probing may mean that some strategies are missed whilst excessive questioning may cause distress and challenge coping responses such as avoidance.

The interview as it was used in this particular study enquired about the coping responses over considerable lengths of time. This potential limitation would not apply in a prospective design.

This study suggests that the modified WCQ and Faith Courtauld Coping Schedule can complement one another and indeed produce similar results. Both methods identified the extensive use of cognitive avoidance and positive reappraisal. These may correspond to an overall strategy of 'selective ignoring' which was defined by Pearlin and Schooler [2] as ignoring the unpleasant aspects of a situation and concentrating instead on positive attributes. They found that the strategy of selective ignoring was adaptive in situations which are not amenable to personal control. Similarly, Folkman and Lazarus [14] have found that health problems which are appraised as not amenable to personal control are more effectively dealt with through emotion-focused strategies. These are responses directed at the regulation of painful emotions engendered by the health problem rather than attempting to change the cause of the problem. Results using the original Faith Courtauld Schedule to assess coping in patients with cancer have suggested that an overall strategy of selective ignoring is related to reduced levels of anxiety and depression 1 yr after diagnosis [26]. In this context, selective ignoring involved not attempting to change aspects of the disease which are outside the patient's control and concentrating instead on ways to make life more enjoyable.

Conversely, strategies of wishful thinking and blaming oneself or others were used infrequently by most women. This contrasts with the results from a study which found that attributions of blame were prevalent amongst American women with breast cancer [27]. Attributions of blame as well as wishful thinking have been related to a poor psychological outcome in patients with cancer and other chronic illnesses [19, 20, 27, 28].

A further strength of this interview is that it allows patients to express beliefs and emotions regarding the diagnosis. The interview data identified the prevalence of fear related to the diagnosis and treatment of cancer and uncertainty regarding disease prognosis. All patients in this study were informed of their diagnosis of cancer and their fear and uncertainty probably demonstrates a generally high level of realistic understanding of the disease and its implications.

Two interesting subgroups of patients were identified. The first subgroup was identified by both the interview and the questionnaire. It contained women who used very few ways of coping except for avoidance and some responses of positive reappraisal. The second subgroup was identified by the WCQ and consisted of women who reported using most of the ways of coping in response to their cancer. This latter finding in particular challenges the concept of exclusive styles of coping. There is disagreement in the literature about the adaptiveness of a wide repertoire of coping responses. In studies of the general population it has been associated with both increased and decreased emotional distress [2, 29].

The interview data suggests there is little change in the number of coping responses the women use in relation to the time since their diagnosis. This is perhaps not surprising in view of the chronic nature of the threat of breast cancer. It is a threat of which they are constantly reminded by regular hospital check-ups to examine for evidence of disease progression and increasingly frequent reports of breast cancer and related survival statistics. It is likely, however that specific examination of

coping responses in the weeks and early months following initial diagnosis would reveal a peak in the frequency of coping responses.

The use of situation-specific interview and questionnaire methods of assessing coping in women with early breast cancer has highlighted the complex nature of these responses. Both approaches identified a number of ways of coping with the stress of diagnosis and treatment. Overall it appears that the majority of women are employing psychologically adaptive coping responses whilst avoiding dysfunctional thoughts and behaviours. This accords with the distribution of emotional distress among patients with breast cancer. Prevalence studies show that the majority of patients are not clinically anxious or depressed whilst about 25% experience clinically significant mood disorder. The measures developed in this study will enable detailed examination of the relationship between coping responses and psychological outcome in prospective studies. It is hoped that understanding the nature of this relationship may provide the basis for a cognitive psychological treatment aimed at reducing emotional distress in women with early breast cancer.

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Appendix 2: Frequency of scores for each item on the adapted WCQ. Data gathered from the methodological development of the questionnaire. N=153

WCQ item	Does not apply or not used Freq (%)	Used occasionally Freq (%)	Used quite a bit Freq (%)	Used a lot Freq (%)	Missing Freq (%)
1. I just concentrate on what I have to do next - the next step	43 (28.1)	23 (15.0)	29 (19.0)	56 (36.6)	2 (1.3)
2. I try to analyse the problem in order to understand it better	34 (22.2)	34 (22.2)	42 (27.5)	41 (26.8)	2 (1.3)
3. I turn to work or substitute activity to take my mind off things	36 (23.5)	13 (8.5)	28 (18.3)	75 (49.0)	1 (0.7)
4. I feel that time will make a difference - the only thing to do is wait	49 (32.0)	16 (10.5)	37 (24.2)	45 (29.4)	6 (3.9)
5. I do something which I don't think will work, but at least I am doing something	78 (51.0)	30 (19.6)	25 (16.3)	17 (11.1)	3 (2.0)
6. I talk to someone to find out more about the situation	40 (26.1)	37 (24.2)	44 (28.8)	29 (19.0)	3 (2.0)
7. I criticise or lecture myself	56 (36.6)	25 (16.3)	42 (27.5)	27 (17.6)	3 (2.0)
8. I hope for a miracle	64 (41.8)	21 (13.7)	30 (19.6)	33 (21.6)	5 (3.3)
9. I go along with fate; sometime I just have bad luck	47 (30.7)	31 (20.3)	35 (22.9)	36 (23.5)	4 (2.6)
10. I go on as if nothing has happened	22 (14.4)	17 (11.1)	32 (20.9)	80 (52.3)	2 (1.3)

WCQ item	Does not apply or not used Freq (%)	Used occasionally Freq (%)	Used quite a bit Freq (%)	Used a lot Freq (%)	Missing Freq (%)
11. I try to keep my feelings to myself	15 (9.8)	21 (13.7)	43 (28.1)	71 (46.4)	3 (2.0)
12. I look for the silver lining, so to speak; I try to look on the bright side of things	11 (7.2)	11 (7.2)	30 (19.6)	101 (66.0)	0 (0)
13. I sleep more than usual	78 (51.0)	28 (18.3)	35 (22.9)	12 (7.8)	0 (0)
14. I accept sympathy and understanding from someone	25 (16.3)	68 (44.4)	43 (28.1)	14 (9.2)	3 (2.0)
15. I tell myself things that help me to feel better	23 (15.0)	40 (26.1)	47 (30.7)	39 (25.5)	4 (2.6)
16. I am inspired to do something creative	51 (33.3)	36 (23.5)	33 (21.6)	31 (20.3)	2 (1.3)
17. I try to forget the whole thing	34 (22.2)	20 (13.1)	39 (25.5)	29 (38.6)	1 (0.7)
18. I get professional help	63 (41.2)	35 (22.9)	27 (17.6)	23 (15.0)	5 (3.3)
19. I change or grow as a person	28 (18.3)	33 (21.6)	50 (32.7)	34 (22.2)	8 (5.2)
20. I wait to see what will happen before doing anything	52 (34.0)	36 (23.5)	41 (26.8)	19 (12.4)	5 (3.3)
21. I make a plan of action and follow it	33 (21.6)	26 (17.0)	46 (30.1)	44 (28.8)	4 (2.6)
22. I let my feelings out somehow	21 (13.7)	57 (37.3)	49 (32.0)	23 (15.0)	3 (2.0)

WCQ item	Does not apply or not used Freq (%)	Used occasionally Freq (%)	Used quite a bit Freq (%)	Used a lot Freq (%)	Missing Freq (%)
23. I think I brought the problem on myself	113 (73.9)	17 (11.1)	13 (8.5)	6 (3.9)	4 (2.6)
24. I come out of the experience better than when I went in	35 (22.9)	17 (11.1)	33 (21.6)	65 (42.5)	3 (2.0)
25. I talk to someone who can do something concrete about the problem	43 (28.1)	38 (24.8)	41 (26.8)	24 (15.7)	7 (4.6)
26. I try to get away from everything for a while by resting or taking a holiday	40 (26.1)	55 (35.9)	46 (30.1)	10 (6.5)	2 (1.3)
27. I try to make myself feel better by eating, drinking, smoking etc.	77 (50.3)	29 (19.0)	27 (17.6)	18 (11.8)	2 (1.3)
28. I try not to act too hastily or follow my first hunch	35 (22.9)	39 (25.5)	42 (27.5)	31 (20.3)	6 (3.9)
29. I've found new faith	86 (56.2)	22 (14.4)	18 (11.8)	19 (12.4)	8 (5.2)
30. I maintain my pride and keep a stiff upper lip	13 (8.5)	21 (13.7)	34 (22.2)	82 (53.6)	3 (2.0)
31. I try to rediscover what is important in life	17 (11.1)	20 (13.1)	29 (19.0)	84 (54.9)	3 (2.0)
32. I generally avoid being with people	104 (68.0)	25 (16.3)	19 (12.4)	3 (2.0)	2 (1.3)
33. I don't let it get to me; I refuse to think too much about it	24 (15.7)	30 (19.6)	31 (20.3)	67 (43.8)	1 (0.7)

WCQ item	Does not apply or not used Freq (%)	Used occasionally Freq (%)	Used quite a bit Freq (%)	Used a lot Freq (%)	Missing Freq (%)
34. I ask advice from a relative or friend I respect	54 (35.3)	35 (22.9)	44 (28.8)	18 (11.8)	2 (1.3)
35. I keep others from knowing how bad things are	36 (23.5)	33 (21.6)	32 (20.9)	51 (33.3)	1 (0.7)
36. I make light of the situation; I refuse to get too serious about it	23 (15.0)	25 (16.3)	40 (26.1)	64 (41.8)	1 (0.7)
37. I talk to someone about how I am feeling	32 (20.9)	58 (37.9)	43 (28.1)	18 (11.8)	2 (1.3)
38. I take it out on other people	108 (70.6)	32 (20.9)	11 (7.2)	2 (1.3)	0 (0)
39. I know what has to be done, so I double my efforts to make things work	12 (7.8)	24 (15.7)	34 (22.2)	81 (52.9)	2 (1.3)
40. I refuse to believe that it has happened	112 (73.2)	16 (10.5)	17 (11.1)	7 (4.6)	1 (0.7)
41. I accept the situation and focus on other aspects of my life	40 (26.1)	20 (13.1)	16 (10.5)	72 (47.1)	5 (3.3)
42. I try to keep my feelings from interfering too much	11 (7.2)	23 (15.0)	30 (19.6)	86 (56.2)	3 (2.0)
43. I wish that I could change what has happened or how I feel	40 (26.1)	29 (19.0)	29 (19.0)	51 (33.3)	4 (2.6)

WCQ item	Does not apply or not used Freq (%)	Used occasionally Freq (%)	Used quite a bit Freq (%)	Used a lot Freq (%)	Missing Freq (%)
44. I change something about myself	61 (39.9)	30 (19.6)	36 (23.5)	17 (11.1)	9 (5.9)
45. I daydream or imagine a better time or place than the one I am in	81 (52.9)	33 (21.6)	23 (15.0)	14 (9.2)	2 (1.3)
46. I wish that the situation would go away or somehow be over with	33 (21.6)	42 (27.5)	36 (23.5)	39 (25.5)	3 (2.0)
47. I have fantasies or wishes about how things may turn out	78 (51.0)	39 (25.5)	17 (11.1)	18 (11.8)	1 (0.7)
48. I pray	28 (18.3)	38 (24.8)	37 (24.2)	49 (32.0)	1 (0.7)
49. I prepare myself for the worst	67 (43.8)	30 (19.6)	32 (20.9)	20 (13.1)	4 (2.6)
50. I go over in my mind what I will say or do	44 (28.8)	37 (24.2)	45 (29.4)	23 (15.0)	4 (2.6)
51. I think about how a person I admire would handle the situation and use that as a model	86 (56.2)	18 (11.8)	26 (17.0)	16 (10.5)	7 (4.6)
52. I remind myself how much worse things could be	13 (8.5)	20 (13.1)	28 (18.3)	89 (58.2)	3 (2.0)
53. I try to improve my general health	6 (3.9)	13 (8.5)	40 (26.1)	91 (59.5)	3 (2.0)

Appendix 3: Factors and factor loadings from the factor analysis of the adapted Ways of Coping Questionnaire. Data gathered from the methodological development of the questionnaire (N=153).

* WCQ question number refers to the questions from the adapted WCQ (appendix 9)

* WCQ	Question No.	FACTOR 1	FACTOR 2	FACTOR 3	FACTOR 4	FACTOR 5	FACTOR 6	FACTOR 7	FACTOR 8	FACTOR 9	FACTOR 10
C25	25	0.809	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000
C34	34	0.704	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.288	0.000
C18	18	0.698	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000
C37	37	0.549	0.251	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000
C14	14	0.545	0.000	0.000	0.000	0.000	0.000	0.262	0.000	0.000	0.000
C43	43	0.000	0.734	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000
C46	46	0.000	0.726	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000
C3	3	0.000	0.524	0.000	0.000	0.000	0.279	-0.306	0.000	0.000	0.000
C29	29	0.000	0.000	0.747	0.000	0.000	0.000	0.000	0.000	0.000	0.000
C48	48	0.000	0.000	0.661	0.000	0.000	0.000	0.000	0.000	0.000	0.000
C8	8	0.000	0.482	0.546	0.000	0.000	0.000	0.000	0.000	0.000	0.000
C11	11	0.000	0.000	0.000	0.706	0.000	0.000	0.000	0.000	0.000	0.000
C35	35	0.000	0.000	0.000	0.684	0.000	0.000	0.000	0.000	0.000	0.000
C30	30	0.000	0.000	0.000	0.585	0.401	0.000	0.000	0.000	0.000	0.000
C12	12	0.000	0.000	0.000	0.000	0.646	0.000	0.000	0.000	0.000	0.000
C10	10	0.000	0.000	0.000	0.000	0.586	0.000	0.000	0.000	0.000	0.447
C9	9	0.000	0.254	0.000	0.000	0.000	0.708	0.000	0.000	0.000	0.000
C4	4	0.000	0.000	0.000	0.000	0.000	0.632	0.000	0.000	0.000	0.000
C32	32	0.000	0.000	0.000	0.000	-0.321	0.569	0.000	0.000	0.000	0.000
C20	20	0.250	0.000	0.000	0.000	0.000	0.520	-0.289	0.000	0.000	0.000
C16	16	0.000	0.000	0.000	0.000	0.000	0.000	0.754	0.000	0.000	0.000
C21	21	0.369	0.000	0.000	0.000	0.000	0.000	0.514	0.000	0.000	0.000
C49	49	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.803	0.000	0.000
C50	50	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.722	0.000	0.000
C45	45	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.791	0.000
C47	47	0.000	0.384	0.000	0.000	0.000	0.000	0.000	0.000	0.572	0.000
C17	17	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.737
C33	33	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.630
C28	28	0.000	0.000	0.000	0.289	0.000	0.000	0.000	0.000	0.000	0.000
C53	53	0.000	0.000	0.336	0.000	0.000	0.000	0.000	0.000	0.000	0.000
C23	23	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000
C27	27	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000
C13	13	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000
C5	5	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000
C36	36	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.254
C40	40	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000
C41	41	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000
C38	38	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.405	0.278	0.000
C39	39	0.000	0.000	0.294	0.404	0.335	0.000	0.348	0.000	0.000	0.000
C19	19	0.000	0.000	0.487	0.000	0.256	0.000	0.000	0.000	0.000	0.000
C15	15	0.357	0.000	0.394	0.000	0.000	0.000	0.000	0.000	0.000	0.337
C42	42	0.000	0.312	0.000	0.437	0.000	0.000	0.380	0.000	0.000	0.000
C6	6	0.497	0.333	0.000	-0.272	0.000	0.000	0.000	0.000	0.000	0.000
C44	44	0.000	0.000	0.000	0.000	0.000	0.000	0.320	0.000	0.493	0.000
C1	1	0.348	0.000	0.000	0.301	0.000	0.399	0.000	0.000	0.000	0.000
C7	7	0.000	0.377	0.000	0.000	0.260	0.000	0.000	0.000	0.000	0.000
C26	26	0.382	0.257	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.342
C22	22	0.436	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000
C31	31	0.328	0.000	0.390	0.000	0.413	0.000	0.000	0.000	0.000	0.000
C24	24	0.000	0.000	0.324	0.000	0.480	0.000	0.000	0.342	0.000	0.000
C51	51	0.329	0.000	0.320	0.000	0.000	0.000	0.000	0.000	0.000	0.000
C52	52	0.000	0.000	0.000	0.000	0.264	0.000	0.277	0.000	0.000	0.000
C2	2	0.419	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000	0.000

* WCQ question number refers to the questions from the adapted WCQ
(appendix 9)

* WLO QUESTION NO	FACTOR 11	FACTOR 12	FACTOR 13	FACTOR 14	FACTOR 15	FACTOR 16	FACTOR 17
C25	25	0.000	0.000	0.000	0.000	0.000	0.000
C34	34	0.000	0.000	0.000	0.000	0.000	0.000
C18	18	0.000	0.000	0.000	0.000	0.000	0.000
C37	37	0.000	0.000	-0.324	0.000	0.000	0.000
C14	14	0.000	0.000	0.000	0.000	0.000	0.000
C43	43	0.000	0.000	0.000	0.000	0.000	0.000
C46	46	0.000	0.000	0.000	0.000	0.000	0.000
C3	3	0.000	0.000	0.000	0.257	0.000	0.000
C29	29	0.000	0.000	0.000	0.000	0.000	0.000
C48	48	0.000	0.000	0.000	0.000	0.000	0.000
C8	8	0.000	0.000	0.000	0.000	0.000	0.000
C11	11	0.000	0.000	0.000	0.000	0.000	0.000
C35	35	0.000	0.000	0.000	0.000	0.000	0.000
C30	30	0.000	0.000	0.000	0.000	0.000	0.000
C12	12	0.000	0.000	0.000	0.000	0.000	0.000
C10	10	0.000	0.000	0.000	0.000	0.000	0.000
C9	9	0.000	0.000	0.000	0.000	0.000	0.000
C4	4	0.000	0.000	0.000	0.000	0.000	0.000
C32	32	0.000	0.000	0.000	0.000	-0.304	0.000
C20	20	0.000	-0.370	0.000	0.000	0.000	0.000
C16	16	0.000	0.000	0.000	0.000	0.000	0.000
C21	21	0.342	0.000	0.000	0.000	0.000	0.000
C49	49	0.000	0.000	0.000	0.000	0.000	0.000
C50	50	0.000	0.000	0.000	0.000	0.000	0.000
C45	45	0.000	0.000	0.000	0.000	0.000	0.000
C47	47	0.000	0.000	0.000	0.000	0.000	0.000
C17	17	0.000	0.000	0.000	0.000	0.000	0.000
C33	33	0.266	0.000	0.000	0.000	0.000	0.000
C28	28	0.652	0.000	0.000	0.000	0.000	0.000
C53	53	0.579	0.000	0.000	0.255	0.000	0.000
C23	23	0.000	0.745	0.000	0.000	0.000	0.000
C27	27	0.000	0.000	0.731	0.000	0.000	0.000
C13	13	0.000	0.000	0.712	0.000	0.275	0.000
C5	5	0.000	0.000	0.000	0.670	0.000	0.000
C36	36	0.000	0.000	0.000	0.000	0.782	0.000
C40	40	0.000	0.000	0.000	0.000	0.000	0.780
C41	41	0.000	0.000	0.000	0.000	0.000	0.772
C38	38	0.000	0.394	0.000	0.000	-0.405	0.000
C39	39	0.000	0.000	0.000	0.000	0.000	0.000
C19	19	0.000	0.000	0.000	0.000	0.000	0.000
C15	15	0.000	0.000	0.000	0.270	0.000	0.000
C42	42	0.000	0.000	0.000	0.000	0.000	0.000
C6	6	0.000	0.387	0.000	0.000	0.000	0.000
C44	44	0.000	0.346	0.000	0.000	0.000	0.000
C1	1	0.000	0.000	0.000	0.417	0.000	0.000
C7	7	0.000	0.000	0.000	0.453	0.000	0.000
C26	26	0.000	0.000	0.000	0.000	0.000	0.000
C22	22	0.298	0.364	0.000	0.000	0.000	0.000
C31	31	0.000	0.000	0.000	0.000	0.000	0.000
C24	24	0.000	0.000	0.000	0.000	0.000	0.000
C51	51	0.000	0.000	0.000	0.000	0.000	0.467
C52	52	0.000	0.000	0.000	0.000	0.000	0.493
C2	2	0.296	0.000	0.312	0.308	0.000	0.000

The above factor loading matrix has been rearranged so that the columns appear in decreasing order of variance explained by factors. The rows have been rearranged so that for each successive factor, loadings greater than 0.5000 appear first. Loadings less than 0.2500 have been replaced by zero

Variance explained by each factor:

Factor 1:	4.17%
Factor 2:	2.80%
Factor 3:	2.68%
Factor 4:	2.49%
Factor 5:	2.28%
Factor 6:	2.21%
Factor 7:	2.05%
Factor 8:	2.00%
Factor 9:	1.95%
Factor 10:	1.83%
Factor 11:	1.78%
Factor 12:	1.77%
Factor 13:	1.69%
Factor 14:	1.64%
Factor 15:	1.56%
Factor 16:	1.35%
Factor 17:	1.35%

Appendix 4: Original categories from the Faith Courtauld Schedule for Coping with Cancer.

APPRAISAL STATEMENTS

- A₀ No statements made
- A₁ Finds the seriousness of the event/change unreal
- A₂ Believes that the event/change will not have adverse consequences
- A₃ Lacks concern about the event
- A₄ Claims more pressing concern(s) than that of the event
- A₅ Passively accepts the event
- A₆ States reduced response to event results from already diminished expectations of life
- A₇ Attributes the event to a specific factor
- A₈ Expresses fear in relation to the event and its possible developments
- A₉ Sees the event as a severe threat to valued aspects of his life
- A₁₀ Sees the event as a challenge

PALLIATING STATEMENTS

- P₁ Blocking
- P₂ Dissociating
- P₃ Partializing
- P₄ Assigning control
- P₅ Assigning concern
- P₆ Directing anger
- P₇ Using humour
- P₈ Using prayer
- P₉ Compensating

FACILITATING STATEMENTS

- C₁ Using Religion
- C₂ Encouraging positive mental set
- C₃ Changing his perceptions of life himself

- C₄ Rehearsing emotion
- C₅ Planning positive events and activities
- C₆ Exerting imaginative control over the outcome

BEHAVIOUR -

- B₁ Has intense emotional outburst(s) or experience which may make normal behavioural patterns difficult to maintain
- B₂ Expresses anger or behaves consciously in an angry way
- B₃ Behaves in a self-indulgent way
- B₄ Gives himself/herself a good experience
- B₅ Musters the support of others
- B₆ Seeks opportunities for talking about the event without necessarily mustering support
- B₇ Puts on a good show or face
- B₈ Refrains from talking about the event and/or expressing feelings about it
- B₉ Conceals knowledge of the gravity of the situation or his feelings about it from one or more close others, and/or isolates himself from them
- B₁₀ Avoids or dispenses with reminders of the event, including others' sympathetic responses
- B₁₁ Avoids seeking information about his situation
- B₁₂ Seeks information to clarify his own situation
- B₁₃ Seeks out possibilities for alternative or additional therapy
- B₁₄ Cuts down demanding obligations or reduces his options
- B₁₅ Sticks to routine
- B₁₆ Allows external commitments to distract him from thinking about the event
- B₁₇ Distracts himself or keeps busy
- B₁₈ Returns to physically demanding routines earlier than would be expected
- B₁₉ Takes general health measures
- B₂₀ Tries alternative therapy or markedly changes life style in bid to improve health or conquer illness
- B₂₁ Acts or makes changes to allow for adverse consequences of event which might affect others

OUTCOME BELIEFS - 0

- O₁ Believes he/she will suffer no adverse consequences
- O₂ Believes he/she will probably not suffer adverse consequences
- O₃ Is uncertain whether he/she will suffer adverse consequences
- O₄ Believes he/she will probably suffer adverse consequences
- O₅ Believes he/she will certainly suffer adverse consequences
- O₆ Believes that adverse long-term consequences have already occurred which are irreversible
- O₇ Finds it difficult to contemplate adverse long-term consequences because the seriousness of the event is unreal to him/her
- O₈ Claims that the long-term consequences will depend on the outcome of an intermediate event
- O₉ Claims not to have considered long-term consequences

CONTROL OF OUTCOME -

- F₁ Believes that he/she can have control over long-term adverse consequences
- F₂ Believes that he/she can have some control over any long-term adverse consequences
- F₃ Believes that he/she can have little, if any, influence on any long-term consequences
- F₄ Is uncertain whether or not he/she can influence any adverse long-term consequences
- F₅ Believes that he/she can definitely have no control over any long-term adverse consequences
- F₆ Believes that any adverse consequences of the event are now in the past and that personal control over such consequences in the future is therefore not at issue
- F₇ Finds it difficult to contemplate control over adverse long-term consequences of the event because the event itself is unreal to him/her

INTERVIEW RATINGS -

- I₁ General dissatisfaction
- I₂ Currently experienced anger
- I₃ Information & reassurance

- I₄ Emotive outpourings
- I₅ Inappropriate content
- I₆ Use of humour or laughter
- I₇ Qualifying adjectives which inappropriately minimize the seriousness of the content
- I₈ Aggregation(s) of words or phrases which unnecessarily expand
- I₉ The use of impersonal language in order to avoid the use of personal pronouns

Appendix 5: Sociodemographic data rating form.

Sociodemographic Data (SD)

ID	Subject identity	ID
SD0	Date of interview	SD0
SD1	Date of birth	SD1
SD2	Marital status 0 = Single 1 = Married or living together for >6 months 2 = Separated or divorced 3 = Widowed	SD2
SD3	Occupation 1 = Professional 2 = Intermediate 3 = Skilled non-manual or manual 4 = Partly skilled 5 = Unskilled 6 = Unemployed 7 = Housewife	SD3
SD4	Social class (husbands occupation if married, fathers occupation if single and living at home, own occupation if single and living alone). 1 = Professional 2 = Intermediate 3 = Skilled 4 = Partly skilled 5 = Non skilled	SD4
SD5	Country of birth 0 = UK 1 = Asia 2 = West Indies 3 = Orient 4 = Other	SD5
SD6	Number of children	SD6
SD7	Life stage 0 = Under 35, no children 1 = Youngest child under 6, at home 2 = Child aged 6 - 14, at home 3 = Child aged 15+, at home 4 = Over 35, no children	SD7
SD8	Previous psychiatric history 0 = None 1 = Received treatment from GP 2 = Received treatment from Psychiatrist	SD8

<p>SD9 Religion</p> <ul style="list-style-type: none"> 0 = None 1 = Church of England 2 = Other Protestant 3 = Roman Catholic 4 = Greek Orthodox 5 = Other Christian 6 = Jew 7 = Moslem 8 = Hindu 	<p>SD9</p>
<p>SD10 Formal practice of religion</p> <ul style="list-style-type: none"> 0 = No 1 = Yes 	<p>SD10</p>
<p><u>Confiding</u></p> <p>If you had a problem of some sort, who would be the first person with whom you would want to discuss it. If no confidant - what about your husband/partner?</p>	
<p>SD11 '1st confidant'</p> <ul style="list-style-type: none"> 0 = No confidant 1 = Husband/lover 2 = Mother 3 = Father 4 = Sister 5 = Brother 6 = Daughter 7 = Son 8 = Other relative 9 = In-law 10 = Friend 11 = Professional i.e. doctor 	<p>SD11</p>
<p>SD12 Location</p> <ul style="list-style-type: none"> 0 = Same household 1 = Same town/city 2 = UK 3 = Abroad 	<p>SD12</p>
<p>SD13 Frequency of contact</p> <ul style="list-style-type: none"> 0 = Daily 1 = Several times weekly 2 = Weekly 3 = Fortnightly 4 = Monthly 5 = 6 monthly 6 = Less than 6 monthly 	<p>SD13</p>
<p>SD14 Quality of confiding</p> <ul style="list-style-type: none"> 0 = Close, intimate and confiding 1 = Close and intimate but impossible to discuss certain topics 2 = Not very close, but with definite elements of confiding 	<p>SD14</p>

<p>SD15 '2nd confidant'</p> <ul style="list-style-type: none"> 0 = No confidant 1 = Husband/lover 2 = Mother 3 = Father 4 = Sister 5 = Brother 6 = Daughter 7 = Son 8 = Other relative 9 = In-law 10 = Friend 11 = Professional i.e. doctor 	<p>SD15</p>
<p>SD16 Location</p> <ul style="list-style-type: none"> 0 = Same household 1 = Same town/city 2 = UK 3 = Abroad 	<p>SD16</p>
<p>SD17 Frequency of contact</p> <ul style="list-style-type: none"> 0 = Daily 1 = Several times weekly 2 = Weekly 3 = Fortnightly 4 = Monthly 5 = 6 monthly 6 = Less than 6 monthly 	<p>SD17</p>
<p>SD18 Quality of confiding</p> <ul style="list-style-type: none"> 0 = Close, intimate and confiding 1 = Close and intimate but impossible to discuss certain topics 2 = Not very close, but with definite elements of confiding 	<p>SD18</p>

- 0 = A(1) Truly intimate relationship with husband/boyfriend
Can talk on all subjects
Strong evidence of warmth and satisfaction
Contact at least 4 times per week if boyfriend
- 1 = A(1) Confidence between women, included even without evidence of any physical relationship but they should be living together
- 2 = A(1) Truly intimate relationship with husband/boyfriend (as above) modified or interrupted by illness etc.
- 3 = A(2) Humdrum relationship with husband/boyfriend but has another intimate confidant contact as above
- 4 = A(3) Humdrum relationship but with no other confidant contact as above
- 5 = A(4) Conflictful marriage or relationship, but with evidence of periods of warmth and intimacy. Contact as above
- 6 = B(1) Intimate relationship with another person
Contact at least 4 times per week
- 7 = B(2) Has a confidant seen at least once a week and other social contact
- 8 = C Must have a confidant
- 9 = D No confidant

Appendix 6: Pre-operative coping interview from the Faith Courtauld Schedule for Coping with Cancer.

AN INTERVIEW OF COGNITIVE RESPONSES TO A DIAGNOSIS OF CANCER
FOR USE AT POST-DIAGNOSIS BUT PRE-OPERATIVE STAGE

1. Discovery of symptoms

Can you tell me what was the first thing you found to be wrong with you?

(When were you first ill with this present illness? What did you think was wrong with you then?)

When did you think that something more serious might be wrong?

What did you think was wrong then?

How did you feel then; can you remember?

(Can you tell me about anything else that was happening then which reminds you vividly of how you felt?)

How long was it before you went to a doctor?

(Did you speak to anyone else about it?)

Do you think in your own mind that you hesitated to go to a doctor because you were fearful of what he might say or find?

2. Understanding of diagnosis

(When did you finally learn what was wrong?)

(What did they tell you was wrong?)

Can you tell me what you understood by that?

Apart from what they told you, what else did you want to know (about the breast trouble)?

What sort of things are going through your mind now you know what is wrong?

(Can you tell me a little more about how you feel?)

How much does it come into your mind now?

(Do you find it constantly popping into your mind, that things constantly remind you about it?)

(How much does this happen?)

Do you make a conscious effort to avoid thinking about it or find you have developed ways to avoid thinking about it?

(What are these?)

Would you like to know more about the breast trouble?

(Have you asked any of the doctors about it? Anyone else?)

(Have you tried to find out more in any other way? Why?)

Do you have any ideas of your own as to why you developed the breast trouble?

Usually, how important is your physical appearance to you?

How important is your physical appearance to you now?
(Is it something you think about much?)

Can we just go over the picture at the moment?
(You told me at the beginning that you had x symptoms,
difficulties.....)
What do you worry about mostly?

Appendix 7: Post-operative coping interview from the Faith Courtauld Schedule for Coping with Cancer.

AN INTERVIEW OF COGNITIVE RESPONSES TO A DIAGNOSIS OF CANCER
FOR USE AT 3 MONTHS AND 1 YEAR POST-DIAGNOSIS

A. Understanding of diagnosis

How much does the thought of the breast trouble come into your mind now?

(Do you find it constantly popping into your mind, that things constantly remind you about it?)

(How much does this happen?)

Do you make a conscious effort to avoid thinking about it or find you have developed ways to avoid thinking about it?

(What are these?)

Have you known anyone with a similar illness i.e. cancer?

(Was this anyone close to you?)

Would you like to know more about the breast trouble?

(Have you asked any of the doctors about it? Anyone else?)

(Have you tried to find out more in any other way? Why?)

Do you have any (more) ideas of your own as to why you developed the breast trouble?

To what extent has the breast trouble interfered with your future plans?

As a result of the breast trouble, has your view of what life has in store for you changed?

(In what way? Have you changed your plans or your life in any way to reflect this change?)

Can we just go over the picture at the moment?

(You told me at the beginning that you had x symptoms, difficulties.....)

What do you worry about mostly?

B. Sexual adjustment

How important is your physical appearance to you usually?

How important is your physical appearance to you now?

(Is it something you think about much?)

Have you had any difficulties as regards the loss of the breast itself/the change in shape of your breast, in terms of the prosthesis, wearing the clothes you used to, activities like swimming etc?

How has your partner reacted to the loss of the breast/change in shape of the breast?

Often an illness can make you lose interest in sexual activities, have you found this happening?

Has there been a reduction in the number of times that you make love?

When you actually make love, do you still get as much physical pleasure/satisfaction as you used to?

Have you had any difficulty with radiotherapy/ chemotherapy/ ovarian irradiation?

C. Work/finance

(For housewives only)

Prior to the onset of the breast trouble did you feel that you were a good manager at home? Has that changed since the onset of the breast trouble?

(If in employment before diagnosis)

You mentioned that you worked before the onset of your breast trouble. Is/was this something important to you?
(Generally speaking did you feel on top of your work?)

Are you working now?

How much time have you had/did you have off work? Days_____

(If not returned to work: why is this?

PROBE: Is that the real reason, or do you think it might be a way of finding a reason for something you didn't want to do anyway?)

Do you have any worries about managing financially?

D. Interests

What are your interests?

Has the breast trouble made any difference to them?

Are you able to do _____ as you did before?

(Or are you less inclined to? Why do you think this is?)

E. Beliefs about outcome

What do you think the outlook is as far as your breast trouble is concerned?

(Do you think that you will recover completely?)

What have the doctors said?

Have you asked them ?

Have you asked anyone else, or tried to find out in any other way?

What do you yourself believe, in your heart of hearts?

When you think about the future, how do you feel?

(Do you feel hopeful or very fearful, or what?)

Appendix 8: Adapted manual from the Faith Courtauld Schedule for Coping with Cancer.

MANUAL OF COGNITIVE AND BEHAVIOURAL RESPONSES
TO A DIAGNOSIS OF CANCER

1. ACCEPTANCE

- a) Fatalistic and passive acceptance of the diagnosis.
(A5, P3_{IV})
- b) Realistic acceptance of the event.
("There is nothing you can do so you just have to get on with life."
"I've gradually come to terms with it as time's gone by")

2. FEAR

- a) Perceives the diagnosis as a threat &/or experiences fear (worry) in relation to the diagnosis.
(A8)
- b) Perceives the treatment as a threat &/or experiences fear (worry) in relation to the treatment.
(A9)

3. NEUTRAL PREOCCUPATION WITH THE DIAGNOSIS, no associated affect.

4. AVOIDANCE

- a) (i) Cognitive strategies to avoid thinking about the threat of the diagnosis or treatment.
e.g. Blocking "I put up a mental barrier"
Focussing on other things "I worry about my children"
Keeping busy "I just get on and keep myself busy"
Focussing on a limited period of time "I take each day as it comes"
(A4, P1-P3, P5, B16, B17)
- (ii) Cognitive actions to change the meaning of the event thereby reducing it's threat.
e.g. "All the Doctors have been very reassuring and lots of people get cured so I don't worry too much"
"It was a disturbance of my routine or regular life, not really life threatening"
- (iii) Difficulties in accepting or assimilating the threat of the diagnosis.
e.g. "I just couldn't accept it"
"It wasn't registering, I was in a shocked state"
(A1, 07, F7) P2_{II}

- (iv) Patient states that they are not worried by the diagnosis or treatment but it is unclear what cognitive processes are being used to achieve this
e.g. "I don't really worry much"
"I don't think about it"
(A3)
 - b) Social avoidance.
e.g. "I haven't wanted to talk to my husband"
"I kept it all quiet from my parents because I didn't want them to worry"
(B8-B10)
 - c) Avoidance of information relevant to the diagnosis.
e.g. "You don't go into it, I'd rather not know"
"I avoid reading articles and TV programmes, I think sometimes one can know too much"
(B11)
5. USING HUMOUR.
(P7, I6)
 6. EXPRESSIONS OF ANGER.
(P6)
 7. POSITIVE APPRAISAL.
 - a) Emphasising the positive aspects of the patient's experience of their illness.
(P9)
 - b) Positive changes in perception of life and self.
(C2, C3, C5)
 8. USING RELIGION AND PRAYER.
(P8, C1)
 9. SEEKING HELP.
 - a) Seeking social support.
(B5, B6)
 - b) Seeking information.
(B12)
 10. BEHAVIOURAL ACTIVITIES TO AID PHYSICAL RECOVERY.
E.g. seeking alternative therapy.
(B13, B19, B20)

11. RETURNING TO NORMAL.

- a) Active attempts to return to normal life.
(B15. "I've made an effort to work the same and going and doing things.")
- b) Apparently no change in thoughts or behaviour as a consequence of cancer.
(Q. To what extent has the breast trouble interfered with your future plans?
- A. Not at all.
- Q. Has your view of what life has in store for you changed?
- A. No, things are the same as before.)

OUTCOME BELIEFS

12. BELIEVES WILL SUFFER NO ADVERSE CONSEQUENCES.
(A2, 01)
13. IS UNCERTAIN WHETHER SHE WILL SUFFER ADVERSE CONSEQUENCES.
(02, 03, ?08)
14. BELIEVES SHE PROBABLY/CERTAINLY WILL SUFFER ADVERSE CONSEQUENCES.
(04, 05)
15. CLAIMS NOT TO HAVE CONSIDERED LONG TERM CONSEQUENCES.
(09)

OUTCOME CONTROL

16. BELIEVES SHE CAN HAVE SOME CONTROL OVER LONG-TERM ADVERSE CONSEQUENCES.
(F1, F2, C6)
17. BELIEVES SHE CAN HAVE LITTLE OR NO CONTROL OVER LONG-TERM ADVERSE CONSEQUENCES.
(F3-F6)

Appendix 9: Adapted Ways of Coping Questionnaire.

BELOW ARE LISTED A NUMBER OF WAYS IN WHICH PEOPLE COPE WITH ILLNESS. PLEASE READ EACH OF THE STATEMENTS AND INDICATE, BY TICKING THE APPROPRIATE BOX, HOW MUCH YOU PRESENTLY USE THE METHODS LISTED TO HELP YOU COPE WITH YOUR BREAST TROUBLE.

	Doesn't apply or not used	Used occasio- ally	Used quite a bit	Used alot
1. I just concentrate on what I have to do next - the next step.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I try to analyse the problem in order to understand it better.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I turn to work or substitute activity to take my mind off things.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I feel that time will make a difference- the only thing to do is to wait.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I do something which I don't think will work, but at least I am doing something.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I talk to someone to find out more about the situation.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I criticise or lecture myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I hope for a miracle	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I go along with fate; sometimes I just have bad luck.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I go on as if nothing has happened.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. I try to keep my feelings to myself.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Doesn't apply or not used	Used occasio- ally	Used quite a bit	Used alot

BELOW ARE LISTED A NUMBER OF WAYS IN WHICH PEOPLE COPE WITH ILLNESS. PLEASE READ EACH OF THE STATEMENTS AND INDICATE, BY TICKING THE APPROPRIATE BOX, HOW MUCH YOU PRESENTLY USE THE METHODS LISTED TO HELP YOU COPE WITH YOUR BREAST TROUBLE.

	Doesn't apply or not used	Used occasio- ally	Used quite a bit	Used alot
12. I look for the silver lining, so to speak; I try to look on the bright side of things....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. I sleep more than usual.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. I accept sympathy and understanding from someone.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. I tell myself things that help me to feel better.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. I am inspired to do something creative.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. I try to forget the whole thing.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. I get professional help.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. I change or grow as a person.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. I wait to see what will happen before doing anything.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. I make a plan of action and follow it.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. I let my feelings out somehow	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. I think I brought the problem on myself.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. I come out of the experience better than when I went in...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Doesn't apply or not used	Used occasio- ally	Used quite a bit	Used alot

BELOW ARE LISTED A NUMBER OF WAYS IN WHICH PEOPLE COPE WITH ILLNESS. PLEASE READ EACH OF THE STATEMENTS AND INDICATE, BY TICKING THE APPROPRIATE BOX, HOW MUCH YOU PRESENTLY USE THE METHODS LISTED TO HELP YOU COPE WITH YOUR BREAST TROUBLE.

	Doesn't apply or not used	Used occasio- ally	Used quite a bit	Used alot
25. I talk to someone who can do something concrete about the problem.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. I try to get away from everything for a while by resting or taking a holiday.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. I try to make myself feel better by eating, drinking, smoking etc.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. I try not to act too hastily or follow my first hunch.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. I've found new faith.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. I maintain my pride and keep a stiff upper lip.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. I try to rediscover what is important in life.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. I generally avoid being with people.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. I don't let it get to me; I refuse to think too much about it.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. I ask advice from a relative or friend I respect	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. I keep others from knowing how bad things are.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Doesn't apply or not used	Used occasio- ally	Used quite a bit	Used alot

BELOW ARE LISTED A NUMBER OF WAYS IN WHICH PEOPLE COPE WITH ILLNESS. PLEASE READ EACH OF THE STATEMENTS AND INDICATE, BY TICKING THE APPROPRIATE BOX, HOW MUCH YOU PRESENTLY USE THE METHODS LISTED TO HELP YOU COPE WITH YOUR BREAST TROUBLE.

	Doesn't apply or not used	Used occasio- ally	Used quite a bit	Used alot
36. I make light of the situation; I refuse to get too serious about it.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. I talk to someone about how I am feeling.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. I take it out on other people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. I know what has to be done, so I double my efforts to make things work.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. I refuse to believe that it has happened.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. I accept the situation and focus on other aspects of my life.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42. I try to keep my feelings from interfering with other things too much.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43. I wish that I could change what has happened or how I feel.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
44. I change something about myself.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
45. I daydream or imagine a better time or place than the one I am in.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
46. I wish that the situation would go away or somehow be over with.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Doesn't apply or not used	Used occasio- ally	Used quite a bit	Used alot

BELOW ARE LISTED A NUMBER OF WAYS IN WHICH PEOPLE COPE WITH ILLNESS. PLEASE READ EACH OF THE STATEMENTS AND INDICATE, BY TICKING THE APPROPRIATE BOX, HOW MUCH YOU PRESENTLY USE THE METHODS LISTED TO HELP YOU COPE WITH YOUR BREAST TROUBLE.

	Doesn't apply or not used	Used occasio- ally	Used quite a bit	Used alot
47. I have fantasies or wishes about how things may turn out.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
48. I pray.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
49. I prepare myself for the worst.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
50. I go over in my mind what I will say or do.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
51. I think about how a person I admire would handle this situation and use that as a model.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
52. I remind myself how much worse things could be.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
53. I try to improve my general health.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Doesn't apply or not used	Used occasio- ally	Used quite a bit	Used alot
54. I try something entirely different from the above. (Please describe any methods which you think you use to help you cope but which are not described here)...				

HAD Scale

Name:

Date:

Doctors are aware that emotions play an important part in most illnesses. If your doctor knows about these feelings he will be able to help you more.

This questionnaire is designed to help your doctor to know how you feel. Read each item and place a firm tick in the box opposite the reply which comes closest to how you have been feeling in the past week.

Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response.

Tick only one box in each section

I feel tense or 'wound up':

- Most of the time
- A lot of the time
- Time to time, Occasionally
- Not at all

<input type="checkbox"/>	<input checked="" type="checkbox"/>
<input type="checkbox"/>	<input checked="" type="checkbox"/>
<input type="checkbox"/>	<input checked="" type="checkbox"/>
<input type="checkbox"/>	<input checked="" type="checkbox"/>

I feel as if I am slowed down:

- Nearly all the time
- Very often
- Sometimes
- Not at all

<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>

I still enjoy the things I used to enjoy:

- Definitely as much
- Not quite so much
- Only a little
- Hardly at all

<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>

I get a sort of frightened feeling like 'butterflies' in the stomach:

- Not at all
- Occasionally
- Quite often
- Very often

<input type="checkbox"/>	<input checked="" type="checkbox"/>
<input type="checkbox"/>	<input checked="" type="checkbox"/>
<input type="checkbox"/>	<input checked="" type="checkbox"/>
<input type="checkbox"/>	<input checked="" type="checkbox"/>

I get a sort of frightened feeling as if something awful is about to happen:

- Very definitely and quite badly
- Yes, but not too badly
- A little, but it doesn't worry me
- Not at all

<input type="checkbox"/>	<input checked="" type="checkbox"/>
<input type="checkbox"/>	<input checked="" type="checkbox"/>
<input type="checkbox"/>	<input checked="" type="checkbox"/>
<input type="checkbox"/>	<input checked="" type="checkbox"/>

I have lost interest in my appearance:

- Definitely
- I don't take so much care as I should.....
- I may not take quite as much care
- I take just as much care as ever

<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>

I can laugh and see the funny side of things:

- As much as I always could
- Not quite so much now
- Definitely not so much now
- Not at all

<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>

I feel restless as if I have to be on the move:

- Very much indeed
- Quite a lot
- Not very much
- Not at all

<input type="checkbox"/>	<input checked="" type="checkbox"/>
<input type="checkbox"/>	<input checked="" type="checkbox"/>
<input type="checkbox"/>	<input checked="" type="checkbox"/>
<input type="checkbox"/>	<input checked="" type="checkbox"/>

Worrying thoughts go through my mind:

- A great deal of the time
- A lot of the time
- From time to time but not too often ...
- Only occasionally

<input type="checkbox"/>	<input checked="" type="checkbox"/>
<input type="checkbox"/>	<input checked="" type="checkbox"/>
<input type="checkbox"/>	<input checked="" type="checkbox"/>
<input type="checkbox"/>	<input checked="" type="checkbox"/>

I look forward with enjoyment to things:

- As much as ever I did
- Rather less than I used to
- Definitely less than I used to
- Hardly at all

<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>

I feel cheerful:

- Not at all
- Not often
- Sometimes
- Most of the time

<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>

I get sudden feelings of panic:

- Very often indeed
- Quite often
- Not very often
- Not at all

<input type="checkbox"/>	<input checked="" type="checkbox"/>
<input type="checkbox"/>	<input checked="" type="checkbox"/>
<input type="checkbox"/>	<input checked="" type="checkbox"/>
<input type="checkbox"/>	<input checked="" type="checkbox"/>

I can sit at ease and feel relaxed:

- Definitely
- Usually
- Not often
- Not at all

<input type="checkbox"/>	<input checked="" type="checkbox"/>
<input type="checkbox"/>	<input checked="" type="checkbox"/>
<input type="checkbox"/>	<input checked="" type="checkbox"/>
<input type="checkbox"/>	<input checked="" type="checkbox"/>

I can enjoy a good book or radio or TV programme:

- Often
- Sometimes
- Not often
- Very seldom

<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>
<input checked="" type="checkbox"/>	<input type="checkbox"/>

Appendix 12: Social Evaluation and Social Support Scale

ID Subject identity

Support from husband/partner

SS1 Practical support
(e.g. "As far as your breast trouble is concerned, what does he actually do to help you?" Probe for objective evidence).

- 1 = Marked
- 2 = Moderate
- 3 = Some
- 4 = Little or none

SS2 Active emotional support
(e.g. "How supportive has he been emotionally, if you were feeling tearful or low would he be able to support you or respond to your feelings?)

- 1 = Marked
- 2 = Moderate
- 3 = Some
- 4 = Little or none

SS3 Negative response
(e.g. "Has he ever been negative or unsympathetic about your breast trouble?)

- 1 = Marked
- 2 = Moderate
- 3 = Some
- 4 = Little or none

SS4 Confiding
(e.g. "How much do you actually confide your worries and concerns about the breast trouble with him?)

- 1 = Marked
- 2 = Moderate
- 3 = Some
- 4 = Little or none

SS5 Perceived helpfulness of support
(e.g. "How helpful do you think he has been for you?)

- 1 = Marked
- 2 = Moderate
- 3 = Some
- 4 = Little or none

Support from '1st confidante' if not husband/partner

- SS6** Practical support
(e.g. "As far as your breast trouble is concerned, what do they actually do to help you?" Probe for objective evidence).
- 1 = Marked
 - 2 = Moderate
 - 3 = Some
 - 4 = Little or none
- SS7** Active emotional support
(e.g. "How supportive have they been emotionally, if you were feeling tearful or low would they be able to support you or respond to your feelings?")
- 1 = Marked
 - 2 = Moderate
 - 3 = Some
 - 4 = Little or none
- SS8** Negative response
(e.g. "Have they ever been negative or unsympathetic about your breast trouble?")
- 1 = Marked
 - 2 = Moderate
 - 3 = Some
 - 4 = Little or none
- SS9** Confiding
(e.g. "How much do you actually confide your worries and concerns about the breast trouble with them?")
- 1 = Marked
 - 2 = Moderate
 - 3 = Some
 - 4 = Little or none
- SS10** Perceived helpfulness of support
(e.g. "How helpful do you think they have been for you?")
- 1 = Marked
 - 2 = Moderate
 - 3 = Some
 - 4 = Little or none

Support from '2nd confidante' if not husband/partner

- SS11 Practical support**
(e.g. "As far as your breast trouble is concerned, what do they actually do to help you?" Probe for objective evidence).
- 1 = Marked
 - 2 = Moderate
 - 3 = Some
 - 4 = Little or none
- SS12 Active emotional support**
(e.g. "How supportive have they been emotionally, if you were feeling tearful or low would they be able to support you or respond to your feelings?")
- 1 = Marked
 - 2 = Moderate
 - 3 = Some
 - 4 = Little or none
- SS13 Negative response**
(e.g. "Have they ever been negative or unsympathetic about your breast trouble?")
- 1 = Marked
 - 2 = Moderate
 - 3 = Some
 - 4 = Little or none
- SS14 Confiding**
(e.g. "How much do you actually confide your worries and concerns about the breast trouble with them?")
- 1 = Marked
 - 2 = Moderate
 - 3 = Some
 - 4 = Little or none
- SS15 Perceived helpfulness of support**
(e.g. "How helpful do you think they have been for you?")
- 1 = Marked
 - 2 = Moderate
 - 3 = Some
 - 4 = Little or none

Appendix 13: Inter-rater reliability data for the adapted Faith Courtauld Schedule for Coping with Cancer.

COGNITIVE AND BEHAVIOURAL RESPONSES	Levels of Concordance (%)	Cohen's Kappa	Standard Error	95% Confidence Intervals
Cognitive avoidance	93.3	0.630	0.25	0.13 - 1.13
Fear of the diagnosis	80.0	0.585	0.15	0.29 - 0.88
Concerns regarding treatment	93.3	0.866	0.09	0.69 - 1.05
Positive appraisal of the disease	86.7	0.724	0.13	0.47 - 0.98
Acceptance of the disease	83.3	0.590	0.17	0.26 - 0.92
Seeking social support	93.3	0.464	0.37	-0.30 - 1.20
Seeking information	93.3	0.814	0.13	0.56 - 1.06
Attempts to return to normal	83.3	0.664	0.14	0.40 - 0.93
Use of religion	96.7	0.911	0.09	0.74 - 1.08
Positive appraisal of life	93.3	0.831	0.12	0.60 - 1.06
Avoidance of information	100	1.0	0	1.00 - 1.00
Neutral pre-occupation with disease	96.6	0	0.98	-1.90 - 1.90
Anger	100	1.0	0	1.00 - 1.00
Use of humour	90.0	0.348	0.36	-0.40 - 1.00
Behaviours to aid recovery	90.0	0.366	0.35	-0.30 - 1.00
Social avoidance	90.0	-0.047	0.57	-1.20 - 1.10
OUTCOME BELIEFS				
Uncertain about the prognosis	93.3	0.865	0.09	0.68 - 1.05
Believes disease will probably/ definitely not recur	90.0	-0.047	0.57	-1.20 - 1.10
Believes disease will probably/ definitely recur	100	1.0	0	1.00 - 1.00
Not considered prognosis	96.7	0	0.98	-1.90 - 1.90
Feels some control over outcome	86.7	0.661	0.16	0.35 - 0.97
Feels no control over outcome	90.0	0.516	0.27	0 - 1.00

Appendix 14: Frequency data for the coping categories from the adapted Faith Courtauld Schedule for coping with Cancer.

COGNITIVE AND BEHAVIOURAL RESPONSES	Pre-op (N=107) n (%)	3 Months post-op (N=100) n (%)	12 Months post-op (N=96) n (%)	#Sig
Cognitive avoidance	98 (91.6)	93 (93.0)	92 (95.8)	
Fear of the diagnosis	85 (79.4)	42 (42.0)	48 (50.0)	A B
Concerns regarding treatment	55 (51.4)	36 (36.0)	29 (30.2)	A B
Positive appraisal of the disease	49 (45.8)	45 (45.0)	43 (44.8)	
Acceptance of the disease	33 (30.8)	25 (25.0)	38 (39.6)	A
Seeking social support	17 (15.9)	10 (10.0)	15 (15.6)	
Seeking information	17 (15.9)	29 (29.0)	29 (30.2)	A B
Attempts to return to normal	11 (10.3)	57 (57.0)	54 (56.2)	A B
Use of religion	11 (10.3)	8 (8.0)	6 (6.2)	
Positive appraisal of life	10 (9.3)	68 (68.0)	62 (64.6)	A B
Avoidance of information	10 (9.3)	15 (15.0)	15 (15.6)	
Neutral pre-occupation with disease	7 (6.5)	13 (13.0)	9 (9.4)	
Anger	6 (5.6)	4 (4.0)	4 (4.2)	
Use of humour	4 (3.7)	2 (2.0)	2 (2.1)	
Behaviours to aid recovery	1 (0.9)	7 (7.0)	7 (7.3)	
Social avoidance	0	3 (3.0)	3 (3.1)	
OUTCOME BELIEFS				
Uncertain about the prognosis	-	82 (82.0)	81 (84.4)	
Believes disease will probably/ definitely not recur	-	22 (22.0)	19 (19.8)	
Believes disease will probably/ definitely recur	-	4 (4.0)	8 (8.3)	
Not considered prognosis	-	4 (4.0)	3 (3.1)	
Feels some control over outcome	-	54 (54.0)	38 (39.6)	C
Feels no control over outcome	-	32 (32.0)	40 (41.7)	

McNemar's test for significance of change: $P \leq 0.01$

A = significant change from pre-op to 3 months post-op

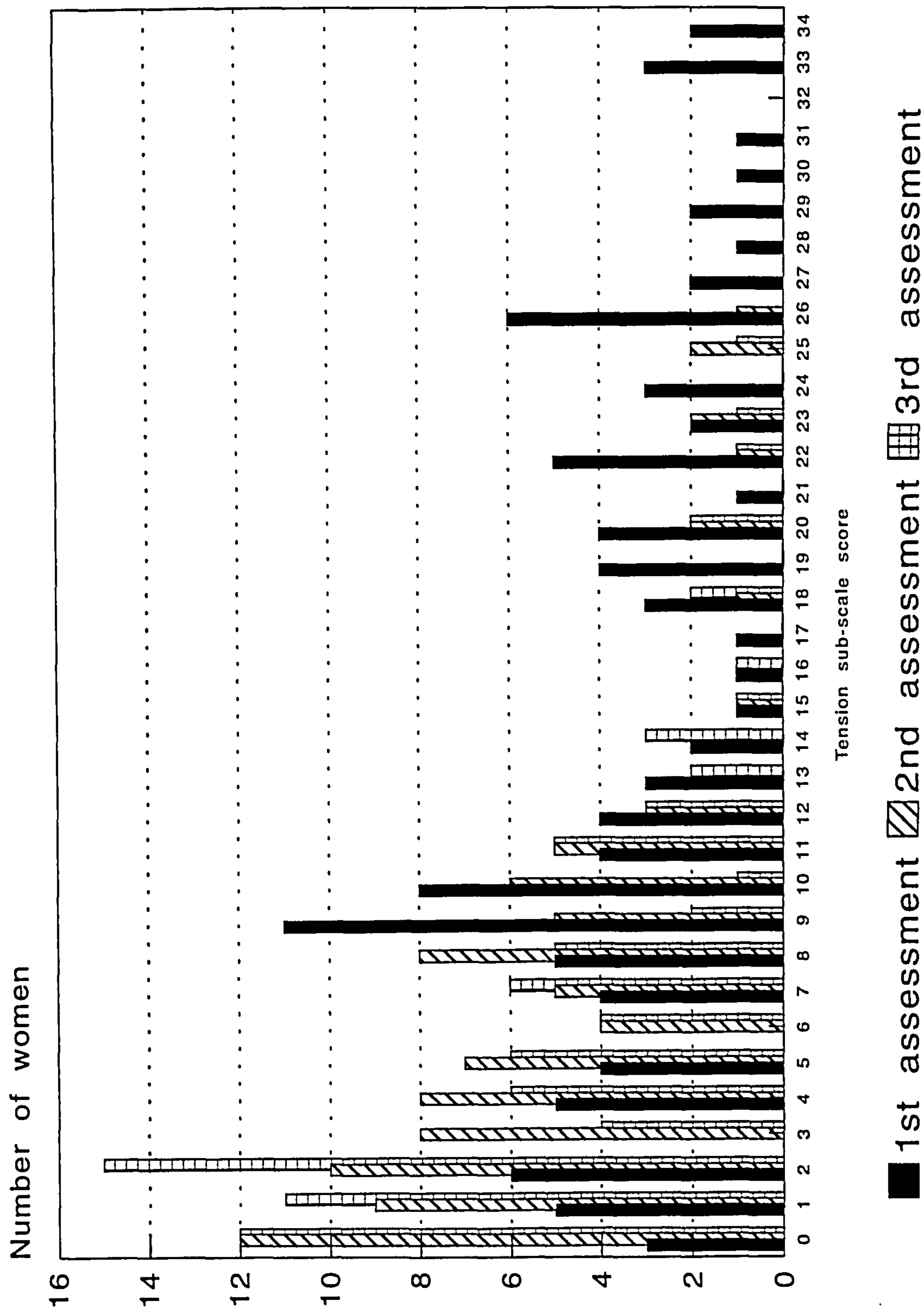
B = significant change from pre-op to 12 months post-op

C = significant change from 3 months post-op to 12 months post-op

Appendix 15: Graphs of the distribution of scores on each sub-scale of the POMS.

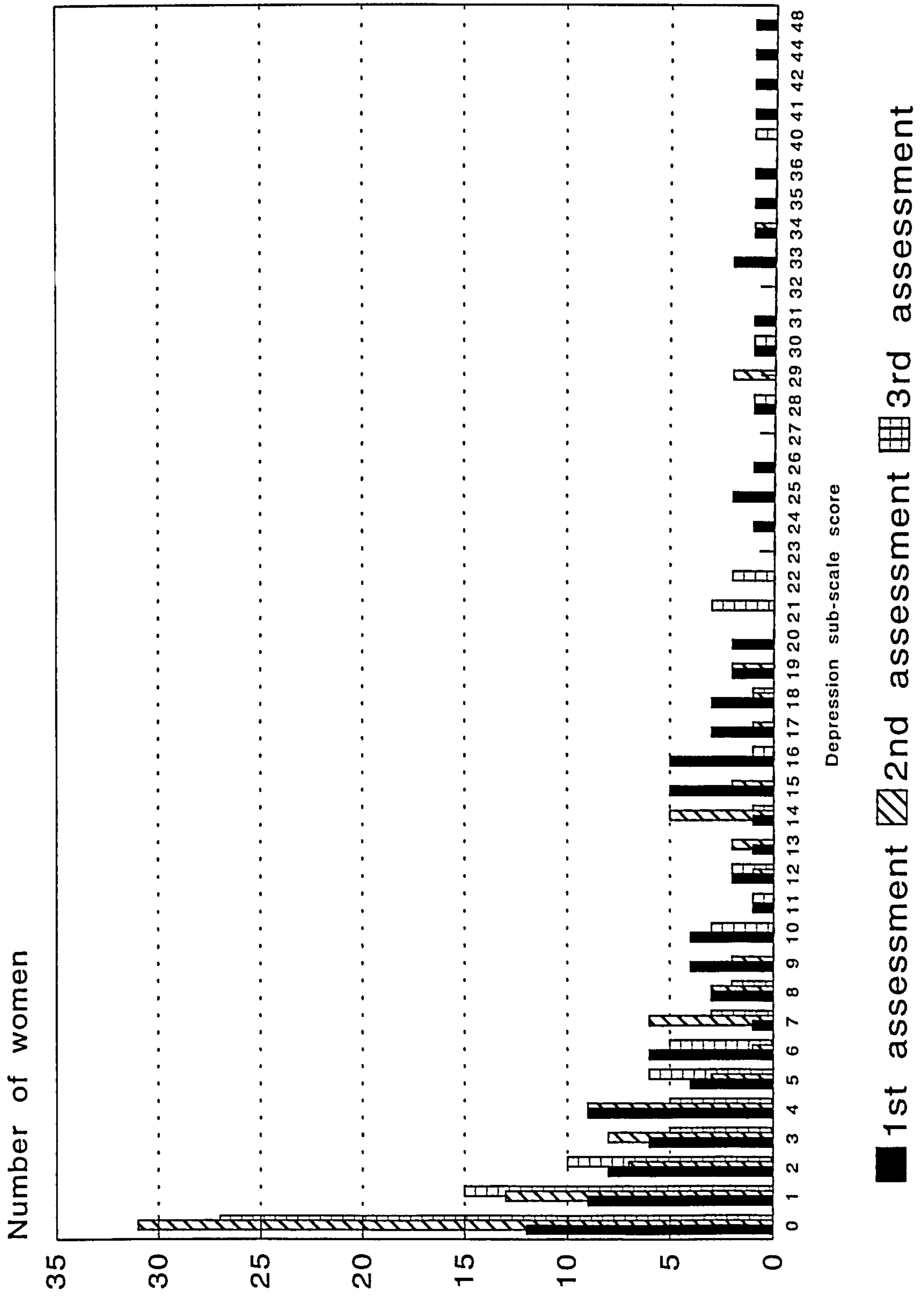
a) Tension sub-scale

POMS - Tension Sub-scale



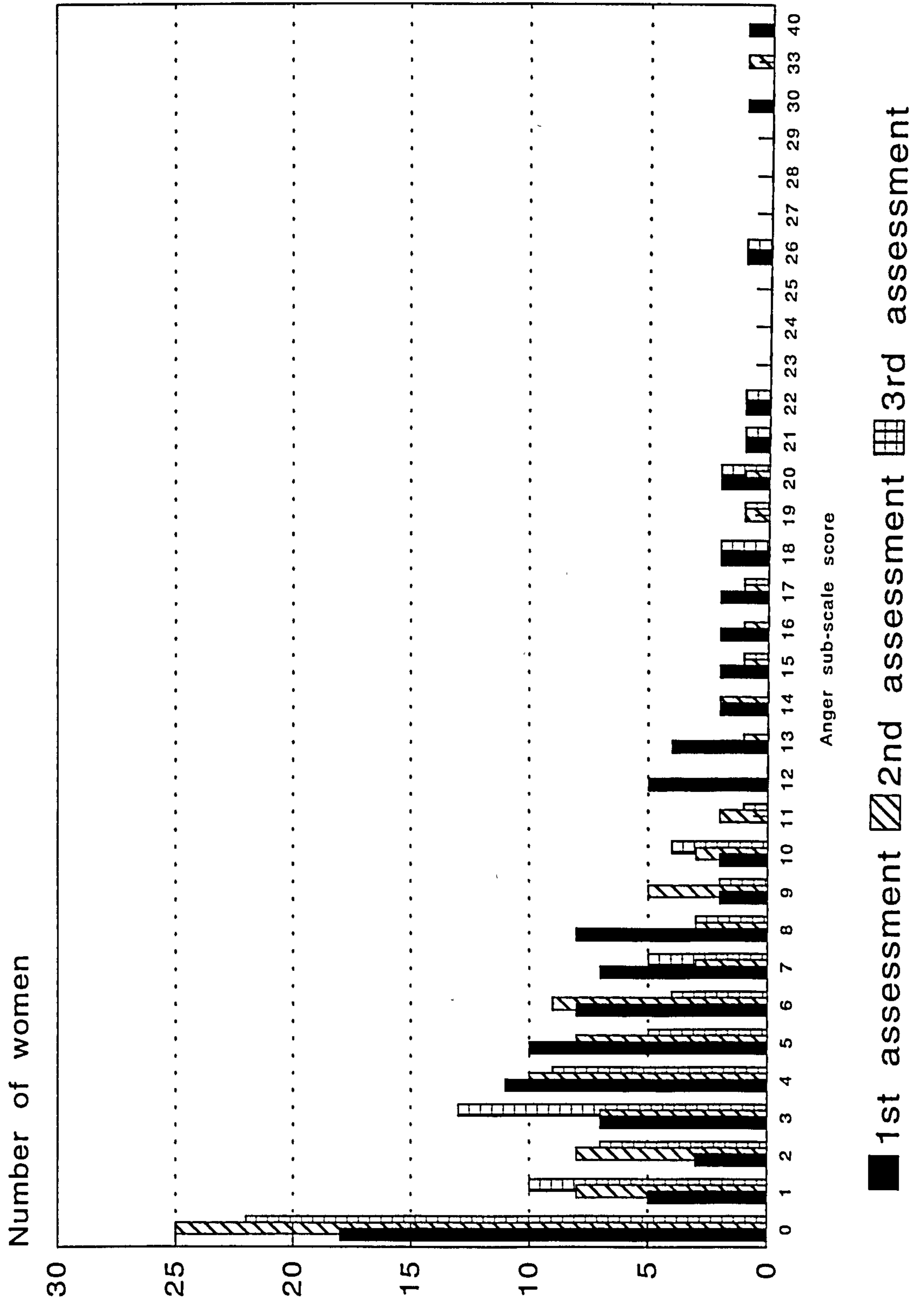
POMS - Depression sub-scale

b) Depression sub-scale



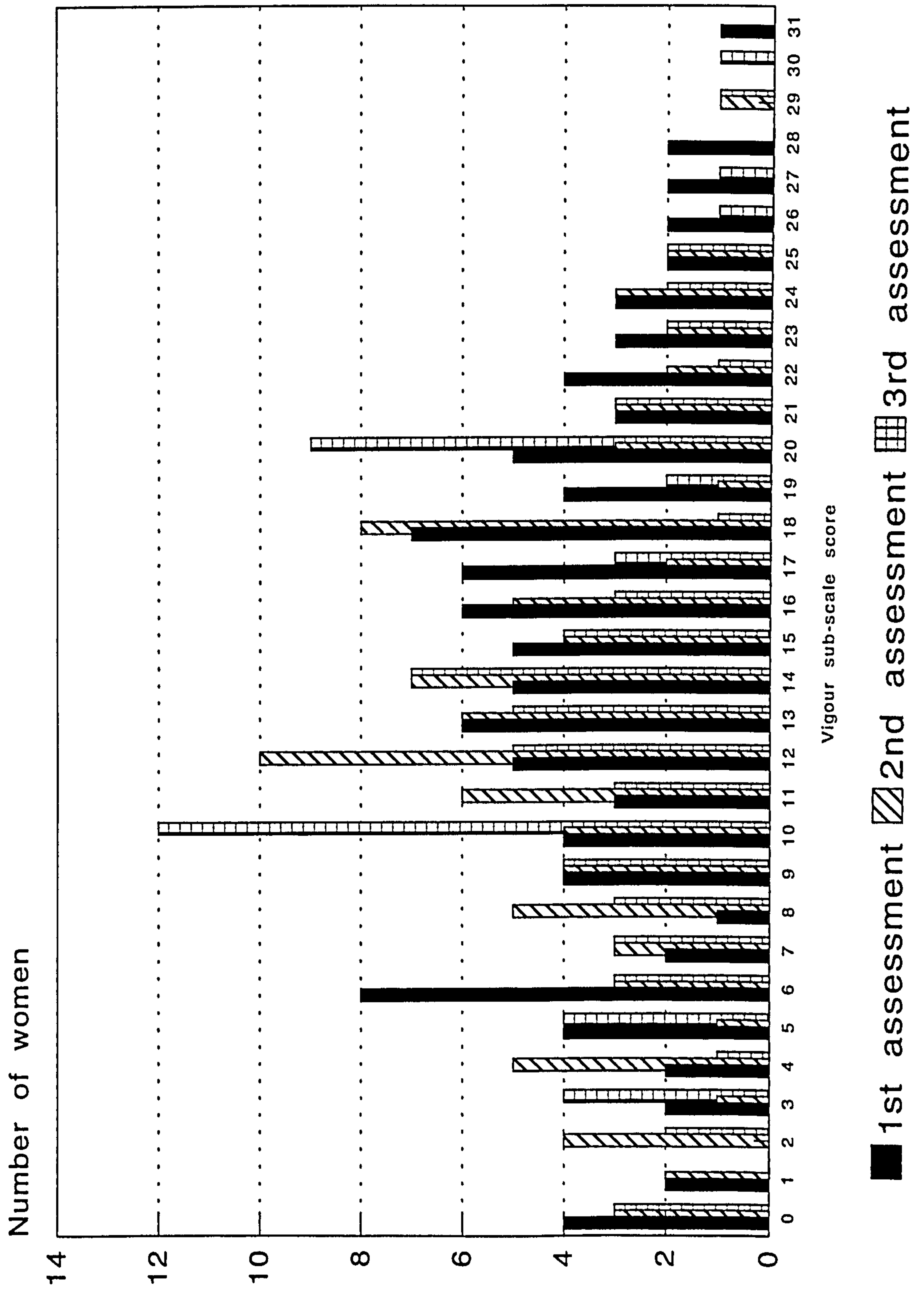
c) Anger sub-scale

POMS - Anger sub-scale



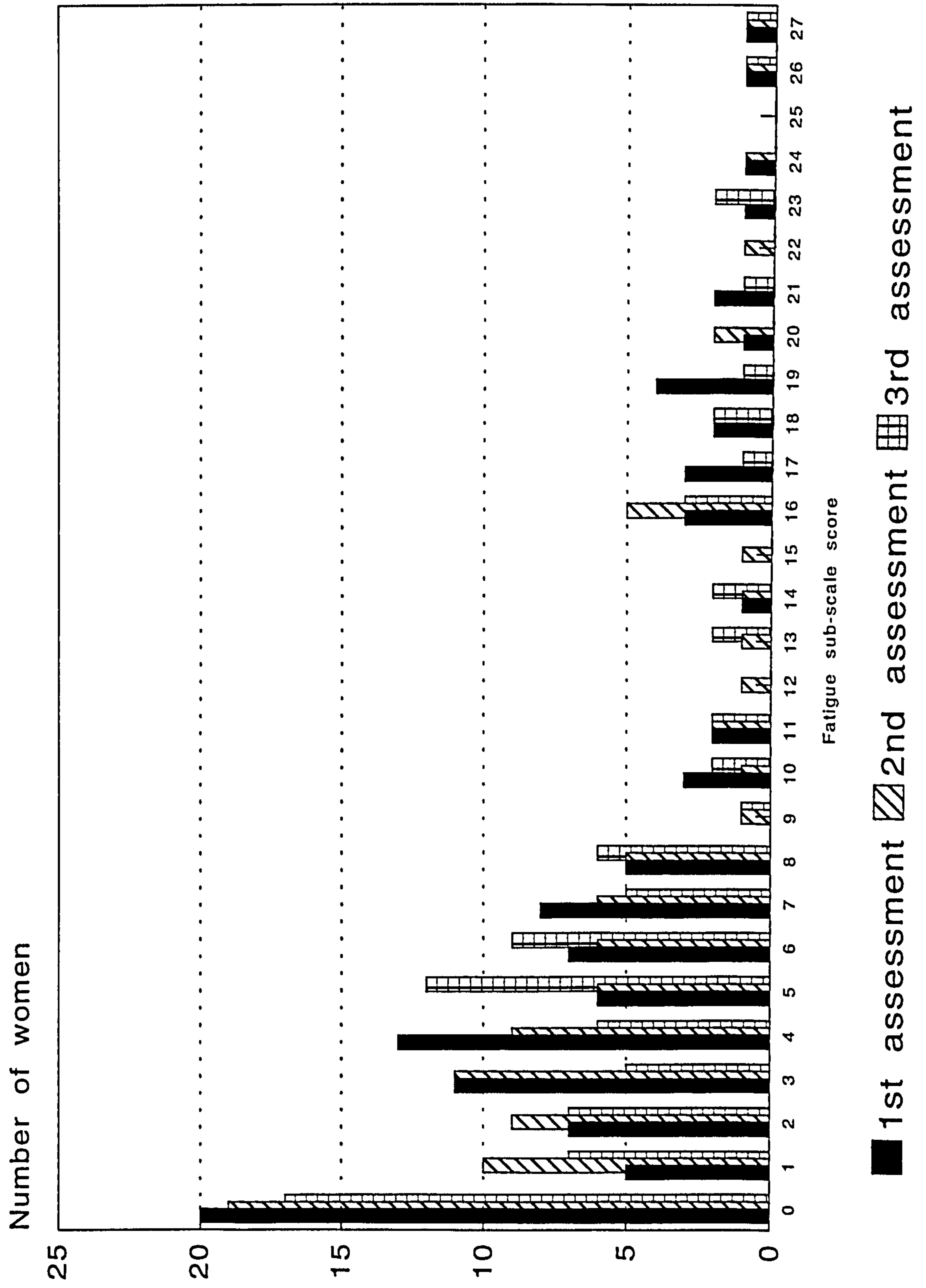
d) Vigour sub-scale

POMS - Vigour sub-scale



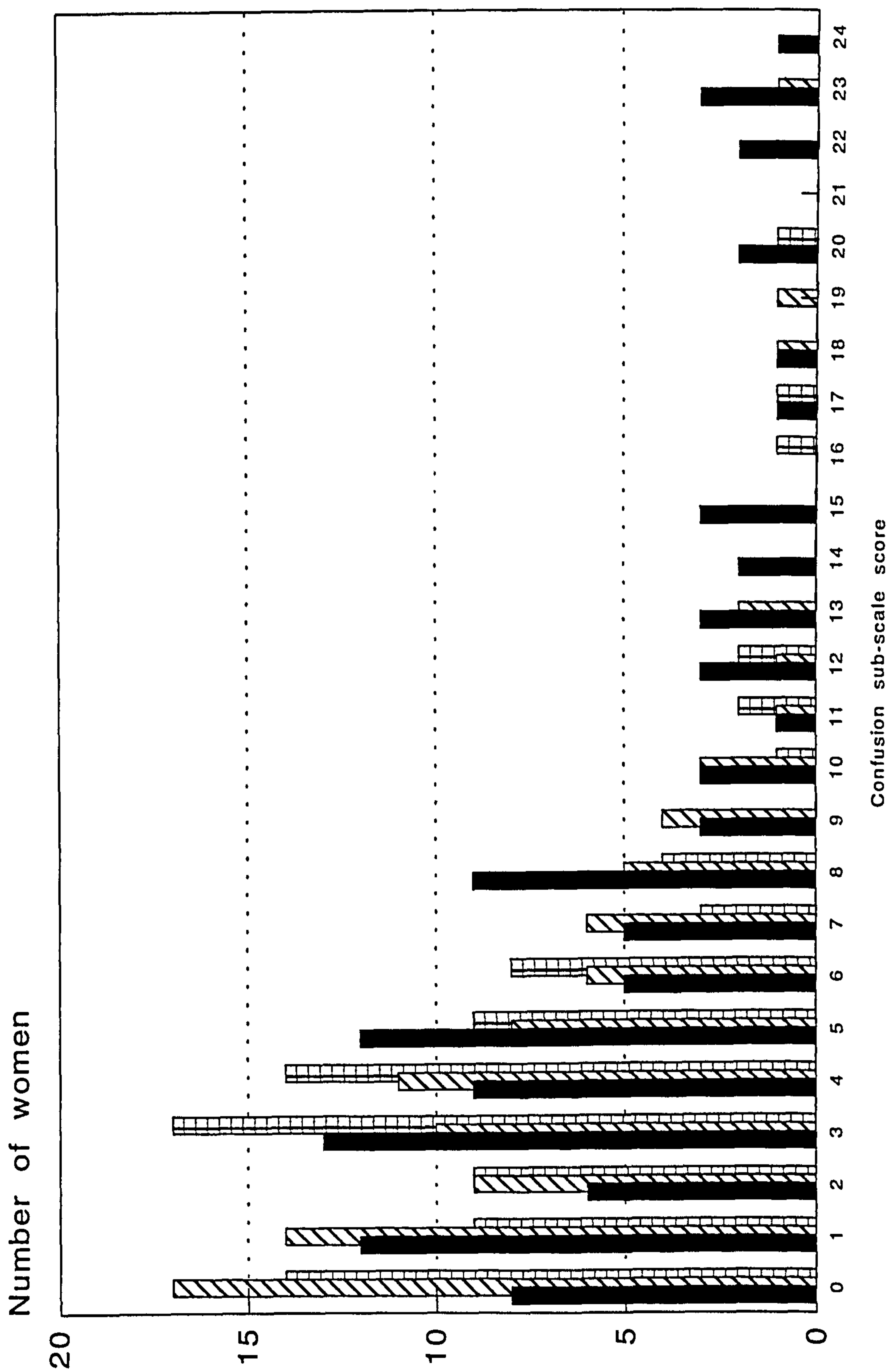
e) Fatigue sub-scale

POMS - Fatigue sub-scale



f) Confusion sub-scale

POMS - Confusion sub-scale



■ 1st assessment ▨ 2nd assessment ▩ 3rd assessment

Appendix 16: Independent variables included in the regression analyses

a) Prediction of mood at three months after operation

Block 1: Pre-operative coping categories from the Faith Courtauld Schedule of Coping with Cancer and negative social support.

Acceptance of the disease

Apprehension regarding the diagnosis

Concern regarding the treatment

Pre-occupation with thoughts of the disease

Cognitive actions to change the meaning of the diagnosis

Not thinking/not worried about the diagnosis

Cognitive avoidance (combined category)

Avoidance of information

Use of humour

Positive appraisal of the disease

Positive appraisal of life in general

Use of religion

Seeking social support

Seeking information

Behaviours to aid recovery

Returning to normal

Number of different coping strategies used (repertoire of coping strategies)

Negative support

Block 2: Sociodemographic, physical and pathological variables

Life stage

Previous psychiatric history

Marital status

Formal religious practice

Age

Type of surgical procedure
Adjuvant treatment
Menopausal status
Family history of malignant disease
Personal history of benign breast disease

Block 3: Pre-operative mood score

b) Prediction of mood at one year after operation

Block 1: Coping categories from the Faith Courtauld Schedule for Coping with Cancer and negative social support assessed 3 months after operation

Acceptance of the disease
Apprehension regarding the diagnosis
Concern regarding the treatment
Pre-occupation with thoughts of the disease
Cognitive actions to change the meaning of the diagnosis
Not thinking/not worried about the diagnosis
Cognitive avoidance (combined category)
Avoidance of information
Use of humour
Positive appraisal of the disease
Positive appraisal of life in general
Use of religion
Seeking social support
Seeking information
Behaviours to aid recovery
Returning to normal
Number of different coping strategies used (repertoire of coping strategies)
Negative support

Block 2: Pre-operative coping categories from the Faith Courtauld Schedule of Coping with Cancer and negative social support

Variables as listed in block 1

Block 3: Sociodemographic, physical and pathological variables

Life stage

Previous psychiatric history

Marital status

Formal religious practice

Age

Type of surgical procedure

Adjuvant treatment

Menopausal status

Family history of malignant disease

Personal history of benign breast disease

Block 4: Mood score assessed at three months after operation

Block 5: Pre-operative mood score