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PSYCHOLOGICAL ADJUSTMENT TO CANCER: THE RELEVANCE OF SOCIAL SUPPORT AND FAMILY STRUCTURE

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**PSYCHOLOGICAL ADJUSTMENT TO CANCER: THE RELEVANCE OF SOCIAL
SUPPORT AND FAMILY STRUCTURE**

by

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A thesis submitted to the University of Plymouth
in partial fulfilment for the degree of

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Abstract

Psychological Adjustment to Cancer: The Relevance of Social Support and Family Structure.

This study was designed to investigate psychological adjustment to breast cancer in relation to social support, and family cohesion and adaptability.

A sample of forty one women, admitted to hospital with breast cancer for surgery, were given an assessment package six to eight weeks after hospital discharge. The package consisted of the Mental Adjustment to Cancer Scale (MAC), the Family Adaptability and Cohesion Evaluation Scales (FACES) and the Michigan Social Support Scale for breast cancer patients. An identical package was posted to the patients after six months. Three models were tested corresponding to different levels of consistency with a causal interpretation of a relationship between social support and psychological adjustment. The results indicated that psychological morbidity was high at both time points. Social support from a doctor, nurse specialist, friend, and spouse were each found to be correlated with at least one psychological adjustment sub-scale at time one. The strongest relationship emerged for social support from the nurse specialist and the "fighting spirit" sub-scale of the MAC. None of the family scales were found to be related to psychological adjustment or social support.

Discriminant function analysis was performed to investigate variables which discriminated caseness at time one and time two. Social support from a doctor emerged as the most significant variable discriminating cases from non-cases at time one. At time two negative support was the most significant variable. The results were discussed in relation to previous research and a service development emerging from the study was described.

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AUTHOR'S DECLARATION

At no time during the registration for the degree of Doctor of Clinical Psychology has the author been registered for any other University award.

The contents of this bound volume are identical to the volume submitted for examination in the temporary binding except for the ammendments requested at examination.

This study was conducted while the author was a Trainee Clinical Psychologist in the South West Region based in the Cornwall and Isles of Scilly Learning Disabilities Trust.

Signed: *Martin Dunn*

Date: 30-11-93

Chapter One: Literature Review

1

1.1 Psychological Adjustment to Cancer

1.1.1 Prevalence of Psychological Morbidity

An association between cancer and melancholia was first noted by the Roman physician Galen in the 2nd Century. A number of 18th and 19th Century physicians also documented their impressions of a relationship between depressive affect and cancer. In the 1950's numerous investigators focused on the association between personality and cancer. During this period two seminal papers Renneker and cutler (1952) and Bard and Sutherland (1955) published descriptive accounts of the psychological sequelae following mastectomy. Their anecdotes depicted a high level of anxiety, depression, and sexual dysfunction following mastectomy.

In view of the long history of interest in psychological aspects of cancer, it is surprising that systematic prevalence studies to determine the rates of psychological disorder in cancer patients, were not undertaken until the 1980's.

A number of earlier studies provided relevant data although they all had methodological shortcomings. Achaute and Vauhkonen (1970) reported that 58% of a diagnostically heterogeneous sample of 100 cancer patients were depressed.

Peck (1972) examined 50 randomly selected patients commencing a course of radiotherapy and judged 74% of them to have depressed affect. Craig and Abeloff (1974) assessed 30 patients admitted to an inpatient oncology unit and reported 53% of there patients to have moderate to high levels of depression. Levine et al. (1978) evaluated case notes from 100 cancer patients referred for psychiatric consultation and diagnosed 56% of the sample to be depressed. In a further study Plumb and Holland (1977) considered self-reported symptoms of depression and reported a prevalence rate of 23% in a sample of cancer patients.

Few of the above studies utilised research diagnostic criteria for establishing diagnosis and most avoided formal psychological assessment. Many studies used biased samples of patients referred for psychiatric treatment and focused exclusively on depression. Diagnostic status of patients was typically based on retrospective review of records, unstructured interview, or simple unidimensional mood scales. In view of these methodological shortcomings reliable data on prevalence was not available until a number of methodologically stronger studies were undertaken in the 1980's.

Derogatis et al. (1983) were the first investigators to seriously address these issues. The researchers used an algorithmic procedure to select 215 general oncology patients from three different centres who were then evaluated by a formal diagnostic interview leading to

DSM-III diagnosis. A multidimensional symptom self-report scale, the SCL-90-R (Derogatis 1976) was also used to rate patient status. The main finding of the study was that 47% of the study were assigned a DSM-III diagnosis. The majority of these (32%) were adjustment disorders. Six percent of the sample had major affective disorder.

A number of subsequent studies using psychiatric diagnostic criteria (Bukberg et al., 1984; Massie and Holland, 1988; Razavi et al., 1990) yielded similar case rates close to 50%. Dean (1987) using data derived from Present State Examination interviews reported a lower case rate of 29%.

Research which has utilised psychometric scales to determine psychological status have consistently reported lower case rates than the above studies. Malec et al. (1988) administered the Millon Clinical Multiaxial Inventory to a sample of 68 breast cancer patients four months after diagnosis. 30% of the sample were considered to have a level of symptomology warranting a mental health referral. As part of a larger study Watson et. al (1991) gave 380 recently diagnosed breast cancer patients the Hospital Depression and Anxiety Scale. 22% of the sample obtained scores above a threshold considered to indicate the presence of psychological disorder. Other studies using similar methodologies have reported case rates between 10% and 30% (Weisman et al., 1980; Wellisch et al., 1983; Stam et al. 1986).

1.1.2 Methodological Issues in the Assessment of Psychological Outcome in Cancer Patients

As noted above there is considerable variation in reported case rates between different studies. Of particular significance is the consistent finding of higher case rates in studies employing psychiatric criteria. The explanation for this discrepancy lies in the emphasis placed on somatic symptoms in psychiatric diagnostic systems. Cancer patients suffering symptoms such as fatigue, weight loss or anorexia due to the effects of the illness or chemotherapy are liable to be diagnosed as depressed thus inflating the reported case rates. A number of commonly used psychometric scales also contain somatic items although psychological phenomena are given greater weight.

A further feature of psychiatric assessment procedures likely to inflate case rates is the use, in most studies, of interviewers not blind to the patients diagnosis. This practice does not allow exclusion of the possibility that results were biased by interviewer expectancy effects. Psychometric scales using a self report protocol are immune to this particular source of bias.

The timing of the assessment is also a significant factor in determining psychological status and accounts for some of the variation between studies. Studies administering tests shortly after diagnosis usually reveal greater psychological distress than evaluations undertaken after a period of adjustment. Cancer patients typically

express a multitude of concerns about prognosis and treatment at the point of diagnosis. Applying DSM-III criteria at this stage is likely to lead a significant level of false positive classifications as DSM-III categories are sensitive to minor changes in mood and behaviour.

Differences in the medical status of cohorts across studies is a further source of variation in case rates as deteriorating medical status is related to lower scores on psychological measures (Cassileth et al. 1984). In the Derogatis study (Derogatis et al. 1983) which accrued subjects from three centres wide variation in case rates of psychological disorder between centres was observed. Closer investigation revealed that one of the centres had a preponderance of more severely ill patients.

Treatment is a factor which can have a significant effect on psychological responses to cancer. Maguire et al. (1980) established that Mastectomy patients who were given adjuvant chemotherapy had a higher incidence of depression, anxiety, and sexual dysfunction. Surgery is also associated with psychological morbidity. Maguire et al. (1978) found 25 per cent of mastectomy patients were depressed one year after treatment. However, Fallowfield et al. (1986) found corresponding rates of psychological symptoms between a group of women treated with mastectomy and another group treated with lumpectomy and radiotherapy.

Type of cancer is a factor which is likely to have a significant effect on psychological reaction. For example

testicular cancer for which the cure rate exceeds 90 per cent is likely to prove less distressing than lung cancer for which the cure rate is lower than 5 per cent. Although some studies have included only patients with cancer at the same site (Hughes 1982, Fallowfield et al. 1986) most use diagnostically heterogenous samples (Derogatis et al. 1983, Farber et al. 1984).

In summary the outcome of studies investigating psychological morbidity in cancer patients is a function of choice of assessment instruments, cancer site, medical status, timing of evaluation, treatment, and other factors. The lack of unanimity between studies with regard to these factors precludes definitive conclusions concerning psychological outcomes of cancer.

1.1.3 Main Problems Encountered by Cancer Patients

An important issue arising from the above studies concerns the range of phenomena researchers should investigate to optimise clinically relevant knowledge in this area. House (1988) has argued that a preoccupation with screening for and diagnosing depression in cancer patients has led to a neglect of other important aspects of adjustment. This argument gains support from the finding that depressed affect rarely occurs in isolation (Stam et al. 1986, Petersen et al. 1988, Wellisch et al. 1989, Vinokur et al. 1990). Stam et al. (1986) studied the range of problems presented by a sample of cancer patients referred to a psychology service. The most frequent problem

category encountered was family/significant other concerns.

This category included:

- A. Impairment with family/significant others
- B. Familial role difficulties
- C. Sexual dysfunction
- D. Bereavement issues
- E. Anticipatory grief

The second most frequent category was personal concerns.

This category included:

- A. Depression
- B. Anxiety
- C. Denial
- D. Significant concerns about body image

Patients typically displayed a constellation of problems involving more than one category. Wellisch (1983) in a study of the problems of the homebound cancer patient reported similar problem categories. The most frequent of these were; family/relationship problems, mood disturbance, somatic symptoms, cognitive impairment, and equipment problems. These findings confirm the multiple interrelated nature of the problems often encountered by this population and suggest that the patients psychological status is intimately connected to other psychosocial circumstances initiated by the disease.

1.2 Social Support and Cancer

1.2.1 An Overview of the Social Support Construct

In the 1970's a number of influential studies were published demonstrating a relationship between social support and a variety of health outcomes (Cobb, 1976, Cassel, 1976). Cassel's study was prompted by observations from his work in clinical medicine which led him to believe that human relationships could alter the host's vulnerability to infectious disease agents. These epidemiological studies utilised strong methodologies including prospective, longitudinal designs, and tightly operationalised, atheoretical measures of social support based on objective indices of social connectedness such as marriage and organizational affiliation. Following these initial studies a proliferation of papers appeared in the literature confirming that individuals with more social ties had decreased rates of mortality and had better psychological health (Lynch, 1977; Berkman & Syme, 1979; Henderson et al. 1980; Mueller 1980; House et al. 1982).

In the 1980's a second research tradition emerged from North American community psychology which was more theoretically driven, utilised functional as opposed to structural measures of social support and focused on social support in the context of stressful life events or particular medical conditions (Bloom, 1982; Cohen & Wills 1985, Seeman & Syme 1987; Blumenthal et al. 1987). The functional approach conceptualised social support as a

subjective appraisal of interactions within social relationships or the provision of specific supportive behaviours. Early research within this paradigm was beset by methodological difficulties involving cross-sectional designs, confounding of stress and social support, poor operationalisation of the social support construct, and a disregard for the negative effects of social support.

Child development work provides a third research tradition in social support. This approach derives from Bowlby's work (Bowlby 1969) on attachment and views social support as a personality variable which originates from early relationships.

1.2.2 Definitions and Conceptual Issues

Any review of this area must acknowledge the diversity of definitions and measurements of social support found in the literature. Earlier studies eschewed the issue of definition altogether and simply operationalised the concept in terms of number of social ties. Although such studies provided robust findings concerning the importance of social ties to health, the lack of any definition prevented investigators from determining, what aspect of social relationships had a beneficial effect on health, and how findings might be applied in the health care setting. Many of the definitions given by researchers have been circular or too vague to be theoretically useful. The issue of how social support should be defined is also important because the definition has implications for measurement.

For example Wortman (1983) notes that Lin (1979) defines social support as " support accessible to an individual through social ties to other individuals, groups, and the larger community" as Wortman wryly comments this amounts to defining social support as support that is social. Other investigators have employed operational definitions which are an amalgamation of anything which might benefit individuals experiencing stress or disease including elements such as self esteem or job satisfaction which are likely to be confounded with outcome measures.

An influential approach to measurement conceptualises social support in terms of a taxonomy of specific support provisions. Weiss (1974) proposed six provisions of social relationships: attachment, social integration, opportunity for nurturance, reassurance of worth, a sense of reliable alliance, and guidance. Kahn and Antinucci distinguish three types of social support: affect, affirmation, and aid. House (1981) identifies emotional support, appraisal support, informational support, and instrumental support as distinct types of social support. Examining the taxonomies it is possible to identify at least 10 distinct types of support. Although there is considerable overlap among the taxonomies none include all types of support. The diasaggregated approach to social support is appealing because it suggests the possibility of specifying which types of support are beneficial for particular stressors. Researchers who have investigated the relationship between functional components of social support and behaviour have

not obtained significant differences in outcome that are attributable to disaggregated support elements (Bolton & Oatley, 1987; Mallinckrodt & Fertz, 1988). A number of factor analytic studies have found a significant general social support factor instead of a set of factors related to specific types of support (Brookings & Bolton, 1988; Cutrona & Russell, 1987; Sarason et al. 1987).

Early research on social support made no distinction between support objectively provided to an individual and the individuals perception or appraisal of that support. Subsequent work has given this distinction more attention. This work has demonstrated that perceived support is more reliably related to outcome measures than structural indices or receipt of supportive behaviours (Blazer, 1982; Cohen & Wills, 1985; Kessler & McCloud, 1984; Seeman & Syme, 1987; Wethington & Kessler, 1986).

The finding that perceived support is a better predictor of health and adjustment, than more objective measures of support actually received, suggests that social support may be closely related to internal cognitive representations of, self and significant interpersonal relationships.

1.2.3 Selective Review of the Relationship Between Social Support and Health

Social Support and Mortality

As mentioned earlier most of the studies examining the relationship between social support and mortality have been

conducted within the field of epidemiology and have used structural indices of social relationships as a proxy measure of social support. The most influential of these was the Alameda County Study (Berkman & Syme, 1979) which followed up a cohort of subjects for nine years having established prospective measures of social relationships using an operational index which included organizational affiliation, marital status, and contact with friends and relatives. The main finding of the study was a strong negative relationship between quantity of social ties and mortality. Replications of this study have since been conducted in three other centres in North America (House et al., 1982; Blazer, 1982; and Schoenbach, 1986). A consistent finding in all three studies was an inverse relationship between quantity of social ties and mortality. These studies did not establish whether social ties modify disease incidence, case fatality, or recovery from disease. More significantly they do not address the issue of how social relationships could influence mortality. Further research has demonstrated that a deficiency of social relationships is a risk factor following life threatening illness. Chandra et al. (1983) followed up 1400 myocardial infarction (MI) patients in a 10 year prospective study and found that marital status at the time of MI predicted mortality over the ten year period. In a study evaluating the efficacy of beta-blocker medication in 2300 post MI patients social isolation was predictive of mortality.

1.2.4 Social Support and Disease Outcomes

Social support has been most extensively investigated in relation to Cardiovascular disease and cancer. Blumenthal et al. (1987) controlling for standard risk factors found that Type A patients with lower levels of social support had more severe angiographically documented occlusion of the coronary arteries. Seeman and Syme (1987) compared the ability of structural and functional indices of social support to predict Coronary Artery Disease in a multivariate design controlling for standard risk factors. They found that men who reported "feeling loved" had lower levels of angiographically documented atherosclerosis.

1.2.5 Social Support and Psychological Outcomes

Depression has been studied by social support researchers more than any other psychological disorder. Brown and Harris (1978) studied a population of depressed women and established that the presence of an intimate confiding relationship was a strong protective factor.

1.2.6 Explanations of the Relationship

Two main theories have been advanced to explain the relationship between social support and health outcomes. The stress buffering hypothesis posits that support modifies the damaging effects of stress. The main effects hypothesis argues for an independent health promoting effect of social support.

Social Support and the Buffering Hypothesis

The buffering hypothesis was first suggested by Cassel (1976) who argued that stress can induce adverse physiological changes which may increase the host's vulnerability to disease agents. This notion is supported by laboratory based animal experiments which demonstrate that social stress can modify immunological and neurotransmitter systems and accelerate tumour progression (Anisman and Sklar 1980). Cassel postulated that the presence of supportive relationships could modulate the effects of stress such that its pathogenic effects are reduced. A number of studies have supported the stress buffering hypothesis. Bloom (1986) studied a cohort of women treated by mastectomy for breast cancer in a longitudinal design examining the effect of emotional support and coping on anxiety. Emotional support was found to have an indirect effect on anxiety via a relationship with enhanced coping. Coping had a direct effect on anxiety.

Social Support and the Main Effects Hypothesis

The main effects model postulates that social support can enhance health irrespective of the presence of stress. Evidence supporting this model is obtained from statistical analysis which demonstrates a main effect of support on outcome measures in the absence of an interaction effect between stress and support.

A number of mechanisms by which social support may exert a beneficial main effect on health have been

advanced. Firstly, social support may affect health behaviours such as smoking, exercise, and diet. Secondly, health care behaviour such as uptake of screening services could be affected by social support. A further pathway which has been suggested involves the possible beneficial influence of social support on neurohormonal and immunological systems.

1.2.7 Social Support and the Cancer Patient

Beneficial Effects of Social Support

In view of the threat and uncertainty associated with cancer social support may be particularly important to cancer patients. Before the 1970's the term social support was used casually by researchers and clinicians in the cancer field. Anecdotal accounts of the importance of social support to cancer patients abounded (Quint, 1963) but empirical studies were not undertaken at this time. One of the first studies using the social support construct in the context of cancer reported an inverse relationship between perceived emotional support and self-reported fear and pain among 16 cancer patients with terminal illness (Weidman-Gibbs & Achterberg-Lawlis, 1978). Jamison et al. (1978) reported a positive relationship between perceived support and psychological adjustment in a cohort of cancer patients.

A number of studies (Spiegel et al., 1981, 1989; Spiegel & Bloom 1983) have examined the effect of support groups on a variety of outcome indices and reported cancer patients attending groups to have improved mood, increased

self-esteem, greater knowledge about cancer and it's treatment, and longer survival in comparison to controls not enroled in a group. Although these studies did not measure social support directly they suggest that the beneficial effects of attending a group may have been due to improved social support.

1.2.8 Negative Aspects of Social Interaction

Whereas the beneficial effects of social support for the cancer patient are well substantiated, evidence suggests that support is not always forthcoming or appropriate. The stigma associated with cancer is well documented (Peters-Golden, 1982; Severo, 1977) and probably originates from a number of popular misconceptions. Firstly cancer tends to be regarded as almost universally fatal (Fiore, 1979) despite the availability of statistics demonstrating a 47% cure rate. Cancer is often represented as a physically repulsive disease which contaminates and erodes the person from within. A further factor contributing to the stigma of cancer is the prevalent belief that cancer is contagious. Bloom et al., 1987 reported that 62% of an American sample believed cancer to be contagious. Stigma often results in avoidance behaviour and withdrawal of support. A survey of attitudes among a disease free population reported that 56% stated they would avoid someone with cancer (Peters-Golden, 1982). A number of other factors may mitigate against the cancer patient obtaining appropriate support. Wortman and Dunkel-Schetter

(1979) reviewed the literature on interpersonal relationships and cancer which suggests that others often feel threatened and uneasy in the presence of a cancer sufferer. Although they have negative feelings about the patients illness, others may believe they should put on a cheerful act for the patient and avoid discussing difficult aspects of the situation. This conflict in communication may be detrimental to the patient and lead to behaviours such as avoidance of the patient, uncomfortable interactions, and subtle non-verbal cues which signal rejection to the patient (Wortman, 1984).

1.2.9 Social Support and Breast Cancer

Twelve studies are reviewed which have examined social support in the context of breast cancer. Northouse (1981) studied the relationship between fear of recurrence and social support. They found that patients who reported the highest number of significant others with whom they could discuss cancer related concerns had the least fear of recurrence.

Spiegel et al. 1981 compared the psychological adjustment of patients in a cancer support group with a control group of patients who did not receive group therapy. After several months the support group patients demonstrated improvement in mood whereas the mood of control patients declined.

In a further study of support groups Spiegel et al. 1991 investigated the effect of support groups on the survival of patients with metastatic breast cancer. Both

the treatment group and the control group received orthodox oncologic therapy. The main finding of the study was a mean survival time of 36.6 months for the support group compared with 18.9 months for the control group.

Bloom (1982) interviewed 130 women between one week and two-and-a-half years after surgery and obtained measures of adjustment and social support. The results demonstrated that women who reported higher levels of social support used fewer modes of stress reduction such as drinking and smoking, had higher self esteem, manifest fewer symptoms of psychological distress, and perceived greater control over the illness.

Funch and Marshall (1983) followed up 208 women with stage I or II breast cancer for 20 years. They operationalised social support in terms of number of social ties and also measured stressful experiences including events such as death of a family member, divorce, and unemployment. The authors examined the relationship between these variables and length of survival. Their findings indicated that both social support and life stress had significant independent effects on length of survival.

Vachon (1986) studied 162 recently widowed women and 187 recently diagnosed breast cancer patients who were assessed at intake to the study and two years later. They measured social support by enquiring about the number of family members, friends, and health professionals who could be expected to provide support and assistance. Psychological distress was measured by the General Health

Questionnaire. The results indicated that for both groups amount of social support at intake predicted severity of psychological distress after two years.

Lichtman et al. (1982) interviewed 78 woman who had been diagnosed as having breast cancer between one and sixteen years previously and found that perceived support from family members and friends was significantly associated with a measure of psychological adjustment derived from patient and doctor ratings.

As part of a wider research programme investigating biological and psychological influences on survival in cancer patients Levy et al.(1990) studied the relationship between perceived social support from a number of sources and Natural Killer (NK) cell activity in a sample of breast cancer patients receiving primary treatment. The main finding of their study was that perceived support from the patients spouse and doctor were the strongest predictors of NK cell activity in a multiple regression model which included biological variables, such as oestrogen receptor status, which are thought to be related to NK activity.

Methodological Appraisal

A number of factors make comparison across studies problematic. Firstly, the studies utilise diverse instruments for assessing social support and no unifying theoretical framework is apparent. A number of authors, Funch and Marshall (1983), Northouse (1981), and Vachon (1986) operationalised support in terms of structural indices whereas Bloom, (1982) and Levy et al. (1990)

focused on functional characteristics of relationships. None of the studies examined the relationship between structural and functional attributes of social networks. Some researchers used interviews (Funch & Marshall, 1983; Northouse, 1981) while other authors used self report questionnaires (Levy, 1990).

Few studies give detailed information on patient's age adding to the difficulties in comparability. Lichtam et al. (1987) and Vachon (1986) omit any details of their patient's ages.

Stage of disease is an important factor which might have a significant bearing on social relationships. For example, patients at stage III of the illness may have reduced mobility and therefore a smaller network of relationships. Some studies neglect to provide details of patients disease stage while others include patients in more than one stage without controlling for this variable.

Few studies provide information on treatment received by patients included in the study. Type of treatment might have a systematic effect on support variables. For example, women who have received a mastectomy might initially be reluctant to socialise thus reducing their opportunities for obtaining support.

1.3. Family Relations and the Cancer Experience

As noted above family relationships are frequently cited as being problematic in studies investigating the adjustment of cancer patients (Wellisch 1983). Families are also a major, often the main source of support for cancer

patients. It is important therefore to ascertain the structural and functional characteristics of families associated with providing optimal support to cancer patients.

1.3.1 Descriptive Studies

Until the mid-1980's the literature on family relations and cancer was mainly descriptive and emphasized developmental stages of the illness which posed different demands on family adjustment. These accounts documented the problems which can arise in a family adapting to a life threatening and potentially chronic disease. This typically involves major role transition for the patient and family. The patient may be unable to perform previous instrumental or emotional functions requiring other family members to compensate. Families often have uncertainties about the patient's health and fears of the patient dying. These apprehensions are equally apparent in the early and advanced stages of the disease and focus on uncertainties concerning the prognosis, outcome of treatment, and possibility of recurrence . A study by Gotay (1984) identified fear of recurrence as the most frequently cited problem for both the patient and spouse. Chekryn (1984) described pervasive uncertainty as characterising the life's of patients and spouses in her study. A related pre-occupation facing family members concerns the potential death of the patient. Krant and Johnston (1978) found this to be a significant concern for 38% of family members in their study. Welch (1981) reported that 34% of their sample

of family members were afraid of leaving the patient alone.

Communication problems between family members and cancer patients are frequently reported in the literature. This may involve avoidance of discussing the illness by family members due to their own fear of cancer or from a mistaken belief that open discussion will upset the patient. Peters-Golden (1982) found that over 50% of a sample of breast cancer patients considered interactions with significant others to be unsatisfactory due to inappropriate optimism and cheerfulness.

Morris et al. (1978) reported a 32% rate of sexual dysfunction among breast cancer patients. Wellisch et al. (1978) studied male partners of mastectomy patients and found 35% of them reported the mastectomy had a detrimental effect on their sexual relationship.

1.3.2 Studies Employing Systematic Assessments of Family Structure

A search of the literature identified three studies which have used systematic procedures to quantify characteristics of family structure in investigations of psychological adjustment to cancer. That such few studies appear in the published literature is a surprising finding given the growing awareness of the importance of the family in chronic illness.

The first study was an investigation of 50 metastatic breast cancer patients randomized to a weekly support group and followed up over 12 months. The family assessment

consisted of the Family Environment Scale (Moos & Moos, 1981), which was administered to the patients and spouses or other family members at baseline. The FES is a true-false questionnaire with ten subscales yielding measures of : (1) cohesiveness, (2) expressiveness, (3) conflict, (4) independence, (5) achievement orientation, (6) intellectual orientation, (7) recreational orientation, (8) moral/religious orientation, (9) organization, and (10) control. The main measure of psychological adjustment was the Profile of Mood States Scale (McNair, Lorr and Drappelman, 1977). Reduced mood disturbance was predicted by higher scores on the expressiveness subscale, and lower scores on the conflict and moral/religious subscales.

The second study to systematically examine the relationship between family variables and psychological adjustment to cancer was undertaken with 35 postlumpectomy and 27 postmastectomy patients. The FES was administered to patients and spouses at intake and adjustment was measured using the Beck Depression Inventory (BDI) and the Psychosocial Adjustment to Illness Scale (PAIS) (Derogatis & Lopez, 1983). The main finding of the study was a strong positive correlation between scores on the cohesion subscale and patient adjustment. A further significant finding of the study was that the level of psychological morbidity reported by the spouses was as great as that reported by the patients.

Friedman et al. (1988) investigated the influence of family variables on psychological adjustment with a sample

of 98 breast cancer patients. The authors used an assessment of family structure derived from Olson et al.'s circumplex model of family systems. The circumplex model of family systems comprises two dimensions of family structure: cohesion, the extent to which family members are emotionally connected; and adaptability, the extent to which the family system has the flexibility to adapt to changing demands. Both these dimensions are conceived as having four ordinal levels which yield a matrix of 16 family system types. The theory proposes that in the four central types there is optimal family functioning and in the extreme types there is family dysfunction. The researchers were interested in examining if better adjustment to breast cancer occurred at balanced levels of cohesion and adaptability as predicted by family systems theory. The main finding of the study was that patients who reported the best adjustment to breast cancer also reported the highest levels of cohesion which in many cases was so high that they would be considered dysfunctional by systems theorists.

1.3.3. The Present Study

Most studies investigating psychological outcomes in cancer have used scales designed for mental health populations. Relatively little is known about what might constitute a healthy psychological response to cancer and if this is influenced by social support. Almost all studies of the relationship between social support utilise either structural or functional measures of support. Consequently,

little is known concerning the structure of social relationships which provide support functions. Family cohesion has been identified as a determinant of psychological adjustment but it is not known if any effect is mediated by social support. These issues will be addressed in the study.

1.4 Aims

1. To establish rates of psychological disorder in the study sample of breast cancer patients.
2. To determine which if any sources of support are significantly associated with psychological adjustment.
3. To establish the structural characteristics of families associated with good psychological adjustment.
3. To examine differences in psychological adjustment among women undergoing the following surgical procedures; mastectomy, tylectomy, and lumpectomy.
3. To examine differences in psychological adjustment between women receiving radiotherapy, and/or chemotherapy, with women receiving no adjunctive therapy.
4. To develop a screening instrument to enable detection of significant psychological distress, in breast cancer patients, by a nurse specialist.

1.5 Hypotheses

1. Higher levels of perceived social support at time one will be associated with better psychological adjustment at time one.

2. Higher levels of perceived social support at time one will be associated with better psychological adjustment at time two.
3. Higher levels of perceived social support at time one will be associated with better psychological adjustment at time two after controlling for the level of psychological adjustment at time one.
4. Higher levels of negative support experiences will be associated with poorer psychological adjustment.
5. A curvilinear relationship will be identified between perceived family cohesion and psychological adjustment to cancer such that psychological adjustment will be better in the mid-range of cohesion than at the extremes.
6. A curvilinear relationship will be identified between perceived family adaptability and psychological adjustment to cancer such that psychological adjustment will be better in the mid range of adaptability than at the extremes.
7. Patients from families identified as dysfunctional will report poorer psychological adjustment than patients from functional families.
8. Patients from families identified as dysfunctional will report lower levels of social support from spouses than patients from functional families.
9. A linear combination of the study variables will significantly predict caseness.

2.1 Subjects

The sample included all patients attending the Royal Cornwall Hospital (Treliske) for surgical treatment, with a diagnosis of primary breast carcinoma, between June 1992 and July 1993 meeting the inclusion criteria.

Table 1. Selected Demographic and Clinical Characteristics

Characteristics	Number of Patients	Percentage of Patients
Age		
30-40	4	9.7
40-50	9	22
50-60	14	34
60-70	11	27
70-80	3	7.3
Clinical Stage		
I	30	73.2
II	7	17.1
III	4	9.8
Type of Surgery		
Lumpectomy	6	14.6
Tylectomy	13	31.7
Mastectomy	22	53.7
Radiotherapy		
Received	28	68.3
Not-received	13	31.7
Chemotherapy		
Received	8	19.5
Not-received	33	80.5

The mean age of the sample was 54.3

2.1.1 Inclusion Criteria

- (a) Diagnosis of primary breast carcinoma
- (b) Aged between 18 and 70
- (c) Informed of diagnosis
- (d) Married or cohabiting
- (e) No evidence of organic brain dysfunction
- (f) No history of learning disability
- (g) No history of psychosis

2.2 Setting

The Royal Cornwall Hospital (Treliske) is a modern district general hospital serving the 400,000 population of Cornwall.

2.3 Design

A repeated measures design was employed to follow up a group of 41 recently diagnosed breast cancer patients.

2.4 Instruments

2.4.1 The Family Cohesion and Evaluation Scales

Conceptual organization

The Family Cohesion and Evaluation Scales (FACES II) are derived from the circumplex model of family functioning (Olson et al. 1979) and assess both family cohesion and adaptability. Family cohesion is defined as the "emotional bonding that family members have towards one another", and family

adaptability is defined as "the ability of a family system to change it's power structure, role relationships, and relationship rules in response to situational and developmental stress" (Olson 1982). Each of these variables is conceptualized as a continuum divided into four discrete levels. For cohesion the four levels are; disengaged, separated, connected, and enmeshed. For the four levels are; rigid, structured, flexible, and chaotic. When the dimensions are combined they yield 16 family types.

Description

FACES is a thirty item self-report questionnaire which contains 16 cohesion and 14 adaptability items. There are two items for the following eight concepts related to the cohesion dimension: emotional bonding, family boundaries, coalitions, time, space, friends, decision-making, and interest and recreation. There are two or three items for the six concepts related to the dimensions: assertiveness, leadership, discipline, negotiation, roles, and rules. An adapted version of the questionnaire was given to families with all their children living away from home.

Construct Validity

As part of the initial development of FACES II 464 adults were asked to complete the scales (Olson, 1982). Factor analysis was undertaken which demonstrated that the first four factors for each dimension accounted for approximately 75% of the variance.

Reliability

Internal Consistency

To study internal consistency a total sample of 2,412 respondents were divided into two equal groups (Olson, 1982). Cronbach's Alpha figures for each of these groupings are reported below:

Table 2.4.1 Reliability Data for FACES II

	<u>Total Sample</u>	<u>Sample 1</u>	<u>Sample 2</u>
Cohesion	0.87	0.88	0.86
	0.78	0.78	0.79
Total Scale	0.90	0.90	0.90

Test-Retest Reliability

A test-retest study was conducted with a sample of 124 university students (Olson, 1982). The Pearson correlation for FACES II was 0.83 for cohesion and 0.80 for .

2.4.2 Mental Adjustment to Cancer Scale

Conceptual Organization

The Mental Adjustment to Cancer Scale (MAC) was designed to measure specific psychological responses to cancer diagnosis and treatment. The response categories were derived from content analysis of structured clinical interviews with cancer patients (Greer et al., 1979). The four response categories identified are: "fighting spirit", "helpless/hopeless", "anxious preoccupation", and "fatalism". The authors make no a priori assumptions as to whether these categories represent psychological traits or states.

Validity

To investigate criterion validity Greer et al. (1989) compared clinical ratings with MAC Scale scores. The level of agreement between MAC Scale scores and clinical ratings was found to be high ($\text{Kappa} = 0.72$). Agreement was higher for "fighting spirit", "anxious preoccupation", and "helplessness/hopelessness" than for fatalism.

Reliability

Internal consistency

The reliability of the MAC was investigated by Watson et al. (1988) using a sample of patients with 25 different types of cancer. The internal consistency of the sub-scales was measured by examining item remainder and item total correlations. The results indicated that each sub-scale was distinctly homogeneous as there were significant correlations between items and sub-scale totals. Alpha coefficients were reported as: "fighting spirit" 0.84, "anxious preoccupation" 0.65, "fatalistic" 0.65, "helpless" 0.79.

Test-Retest Reliability

The test-retest reliability was evaluated by selecting a random sample of 34 patients who completed the questionnaire on two occasions an average of 24 days apart (Watson et al. 1988). None of the patients were receiving active treatment during this period. Pearson's correlation coefficients for test-retest stability of the MAC Scale responses were reported as follows: "fighting spirit" 0.52, "anxious preoccupation" 0.56, "fatalistic" 0.38, "helpless" 0.65, and "avoidance" 0.34. All correlations were significant apart from "avoidance".

Criteria Used for Establishing Caseness

The ability of the MAC scale to assess psychological distress in cancer patients has been validated against clinical ratings (Greer et al. 1988). The present study used cut-offs detailed in the MAC manual as establishing appropriate cases for psychological intervention. (Watson et al. 1989). Cases were identified by fulfilling any one of three criteria :- 1. A score of less than 47 on the "Fighting Spirit" sub-scale and a score of greater than 11 on the "Helplessness/Hopelessness" sub-scale, or 2. A score of greater than 25 on the "Anxious Preoccupation" sub-scale, or 3. A score of more than 22 on the "Fatalism" sub-scale. The "Avoidance" sub-scale of the MAC was excluded from the present analysis because it's relationship to psychological adjustment is uncertain (Watson et al. 1988).

2.4.3 Michigan Social Support Scale for Breast Cancer Patients (Wortman, personal communication)

Conceptual Organization

The scale differentiates between eight distinct sources of support on the basis of empirical evidence indicating that some providers of support may be more important than others. It may be important to assess support from the cancer patient's doctor. Bloom (1981) in a study of cancer patients found that the doctor was ranked higher than family or friends as a provider of support.

The Michigan Social Support Scale for Breast Cancer Patients (Michigan-SSS) assesses perceived social support. The theoretical justification for focusing on perceived support stems from work on cognitive appraisal of stressful life

events. This work indicates it is the individuals appraisal of events which determines outcome rather than characteristics of the event per se (Folkman et al., 1978; Lazarus & Launier, 1979). Empirical studies have established that perceived support has strongest association with health outcomes (Seeman & Syme, 1987).

The scale also quantifies negative support effects which are considered to be a significant aspect of many cancer sufferers experience (Wortman, 1983).

Description

The Michigan-SSS consists of five separate scales measuring perceived support from spouse, friend, nurse, doctor, and other family member. Identical questions were asked for each source of support, with Likert-type responses ranging from 1 = strongly disagree to 5 = strongly agree. For each source of support, patients were asked to rate their agreement with eight statements regarding the quality of the perceived support. The scale was amended to include a sub-scale to measure social support from the breast nurse specialist. The items used were identical to the other sub-scales with breast nurse specialist substituted.

Reliability

Internal Consistency

Levy et al. (1988) analyzed data from a sample of 120 patients and reported Cronbach alpha coefficients, for items associated with each interpersonal category of support, ranging from 0.79 (perceived social support from a doctor) to 0.95 (perceived support from a spouse).

Test-Retest Reliability

Test-retest reliability with a sample of 120 patients tested over a three month period ranged from 0.5 (perceived support from a family member to 0.62 (perceived support from a spouse) (Levy et al. 1988).

2.5 Procedure

The author worked closely with the breast nurse specialist attached to the hospital who was notified of all women attending the hospital with a diagnosis of breast cancer receiving surgical treatment. Patients entered the hospital system via three sources; the radiotherapy department, surgeons operating on breast cancer patients, and the breast screening service. As soon as possible after notification patients were given a brief assessment interview by the breast nurse specialist during which the study was mentioned and the patient's views on being included in the study were elicited. Six to eight weeks after completion of initial treatment patients who agreed to participate in the study were either posted an assessment package, or handed one if an outpatient appointment fell within the required time frame. The package included the three assessment instruments, a patient consent and information form, and a pre-paid return envelope. All completed self report assessments were posted to the author using the pre-paid envelopes. 51 packages were given out and 41 were returned yielding a response rate of 80%. After six months patients entered in the study were posted a follow-up package consisting of the three instruments completed at time one. One patient declined to take part in the study. Of the women

who initially agreed to take part in the study eight did not return the assessment package. A higher proportion of these women had stage III disease; 25% compared to 10% in the study sample. 78% of the non-returners were receiving radiotherapy compared with 68% in the study sample. Distribution of surgical procedures were similar for the non-returners and study sample. Five of the non-returners were judged by the breast nurse specialist to be experiencing significant psychological distress.

2.6 Data Analysis

All data was analysed using the S.P.S.S.-P.C.+ computerised package (S.P.S.S. 1988).

2.6.1 Social support and psychological adjustment

Most studies investigating social support and cancer employ correlational designs which render causal inferences problematic. Quinn et al. 1986 have suggested useful methods by which social support researchers can strengthen their designs. These include measuring variables at more than one time point and examining change in psychological adjustment rather than adjustment per se. Some of these have been incorporated into the design of the study. In order to overcome some of the limitations imposed by the correlational design three models were tested corresponding to increasing levels of consistency with a causal interpretation of the relationship between social support and psychological adjustment. The analysis was complicated by having five subs-scales of the MAC measuring different dimensions of psychological adjustment. As no satisfactory method of combining the scales to obtain an

overall index of psychological adjustment was possible the analysis examined the relationship between each sub-scale and each support source. The three models were considered separately for each source of support.

The first model exemplifies a standard cross-sectional study in which the dependent and independent variables are measured at one point in time. This involved computing Pearson's R correlations between the support measures and the psychological adjustment scales at time one. The weakness of this model lies in its inability to distinguish whether, the independent variable is causing the dependent variable, or the reverse.

The second model attempts to overcome some of the limitations of the first model by introducing a time period between the dependent and independent variables. In this model social support is measured at time one and its relationship to psychological adjustment at time two is determined. It eliminates some of the difficulties in establishing causal direction associated with the first model as it could not be argued that psychological adjustment at time two causes social support at time one. Sources of support found to be significantly correlated with psychological adjustment scales at time one were then tested in the second model. This involved obtaining Pearson's R coefficients between social support at time one and psychological adjustment at time two. Although this model is stronger than the first it does not exclude the possibility that psychological adjustment at time one is causing both social support at time one and psychological

adjustment at time two.

The third model enables the most confident statements regarding causality to be made. In this model the relationship between social support at time one and psychological adjustment at time two was examined while simultaneously controlling for the level of psychological adjustment at time one. Those sources of support significantly related to adjustment measures in the second model were tested by obtaining a correlation coefficient of social support at time one with psychological adjustment at time two while partialling out the variance in social support at time one and psychological adjustment at time two attributable to psychological adjustment at time one. Partial correlations were constructed from within the regression command in S.P.S.S.-P.C.+.

2.6.2 Family Cohesion, Adaptability and Psychological Adjustment to Cancer.

A number of analyses were undertaken to examine the relationship between levels of family cohesion , and psychological adjustment as measured by the MAC. One way univariate analyses of variance (ANOVAS) were conducted comparing group mean MAC scores across the four levels of cohesion. A similar ANOVA was conducted across the four levels of adaptability. A further set of one-way ANOVAS were performed to examine the relationship between different levels of cohesion and adaptability and social support.

2.6.3 Predicting Casesness

Stepwise Discriminant Function Analyses were performed. At each

stage of the analyses the variable which maximises the separation between the groups using Wilk's Lambda is chosen.

3.1 Rates of Psychological Disorder in the Study Sample

3.1.1 Aim (1)

"To establish rates of psychological disorder in the study sample of breast cancer patients".

Using the criteria obtained from the MAC manual 13 patients were identified as cases at time one yielding a rate of 31.7%. At time two seven cases were identified, 25% of the sample with complete data sets for both time points, and 17% of the total sample. Of the 13 patients who were cases at time one, two (5%) remained cases at time two. Five patients (12.5%) who were not cases at time one became cases at time two.

3.1.2 Aim (2)

" To examine differences in psychological adjustment between women undergoing the following surgical procedures; lumpectomy, tylectomy, and mastectomy".

Mean scores on the MAC sub-scales were computed for each of the surgical procedures across both time points. No significant differences in adjustment for different surgical procedures were identified.

3.1.3 Aim (3)

"To examine differences in psychological adjustment between women receiving radiotherapy, and/or chemotherapy, with women

receiving no adjunctive therapy".

Patients receiving radiotherapy and patients not receiving radiotherapy were compared on mean MAC sub-scale scores at both time points. Patients receiving radiotherapy were found to have higher "fatalism" scores at time two than patients not receiving radiotherapy ($F(1, 26) = 5.08, p < .05$). All other comparisons were non-significant.

Patients receiving chemotherapy and patients not receiving chemotherapy were compared on mean MAC sub-scale scores at both time points. Patients receiving chemotherapy were found to have higher "anxious pre-occupation" scores at time one ($F(1, 26) = 4.12, p < .05$). All other comparisons were non-significant.

3.2 Social Support and Psychological Adjustment

3.2.1 Hypothesis (1)

"Higher levels of perceived social support at time one will be associated with better psychological adjustment at time one."

Statistical Procedures

Pearsons product-moment correlations were computed for each source of social support and each sub-scale of the MAC. High scores on the "Fighting Spirit" sub-scale indicate good psychological adjustment. Low scores on the other sub-scales correspond to good psychological adjustment. One tailed tests of significance were applied.

Statistical Outcome

Table 3.2.1 Correlations between Social Support and Psychological Adjustment Variables at Time One (N=41)

	<u>Source of Social Support</u>					
	Spouse	Family Member	Friend	Nurse	Nurse Specialist	Doctor
Fighting Spirit	NS	NS	NS	NS	.35*	.29*
Helpless/ Hopeless	NS	NS	NS	-.28*	NS	-.55***
Anxious Preoccupation	NS	NS	NS	NS	NS	-.44**
Fatalism	-.40**	NS	-.27*	NS	NS	NS

*=p<0.05, **=p<0.01, ***=p<0.001

These results demonstrate significant correlations between; social support from a spouse and "fatalism", social support from a friend and "fatalism", social support from a nurse and "helplessness/hopelessness", and social support from the nurse specialist and "fighting spirit". Social support from a doctor was significantly correlated with "fighting spirit", "helplessness/hopelessness, and anxious preoccupation. Social support from a family member was unrelated to any of the psychological adjustment scales. These results are consistent with hypothesis one.

3.2.2 Hypothesis (2)

"Higher levels of perceived social support at time one will be associated with better psychological adjustment at time two".

Statistical Procedures

Pearson's product moment correlations were computed between those sources of support found to be significantly related to psychological adjustment in the first model.

Statistical Outcome

Significant correlations were demonstrated; between social support from the nurse specialist at time one and "fighting spirit" at time two, ($r=.61$, $p<.001$), and between social support from a doctor at time one and anxious preoccupation at time two, ($r=-.52$, $p<.01$).

3.2.3 Hypothesis (3)

"Higher levels of social support at time one will be associated with better psychological adjustment at time two after the level of psychological adjustment at time one has been removed from the relationship".

Statistical Procedures

The regression command in S.P.S.S./P.C.+ was used to compute first order partial correlations; between social support from a doctor and "anxious preoccupation" at time two controlling for the level of "anxious preoccupation" at time one, and between social support from the nurse specialist at time one and "fighting spirit" at time two controlling for the level of "fighting spirit" at time one.

Statistical outcome

Table 3.1.2 Correlations and Partial Correlations of Social Support(T1), and Anxious Preoccupation(T1) with Anxious Preoccupation(T2) (N=28).

	Correlation	Semi-partial Correlation	Partial Correlation
Soc. Support (Doctor)	-.52	-.22	-.31
Anxious Preocc.(T1)	.69	.50	.59

The above results indicate that Social support from a doctor at time one was not significantly correlated with "anxious preoccupation" at time two when the variance of both variables attributable to "anxious preoccupation" at time one was removed ($r = -.31$, ns).

Table 3.1.3 Correlations and Partial correlations of Social Support(T1), and Fighting Spirit(T1) with Fighting Spirit(T2) (N=28).

	Correlations	Semi-partial Correlations	Partial Correlations
Soc.Support Nurse Specialist	.61	.54	.58
Fighting Spirit	.38	.26	.33

The above results indicate that social support from a nurse specialist at time one is significantly correlated with "fighting spirit" at time two when the variance in both

variables attributable to "fighting spirit" at time one is removed ($r=.51, p<.05$).

3.2.4 Hypothesis(4)

"Higher levels of perceived negative support will be associated with poorer psychological adjustment".

Statistical Procedures

Pearsons product-moment correlations were computed between negative support at time one and the MAC sub-scales. Sub-scales found to be correlated with negative support at time one were tested at time two for association with negative support at time one. Finally partial correlations were computed to examine the relationship between negative support at time one and psychological adjustment at time two controlling for the initial level of psychological adjustment.

Statistical Outcome

Negative support at time one was found to be significantly correlated with the helplessness/hopelessness sub-scale of the MAC at time one ($r=.38, p<.05$), and at time two ($r=.35, p<.05$).

Table 3.1.4 Correlations and Partial correlations of Negative Social Support(T1), and Helplessness/Hopelessness(T1) with Helplessness/Hopelessness(T2) (N=28).

	Correlations	Semi-partial Correlations	Partial Correlations
Negative Soc.Support	.35	.18	.21
Helpless/ Hopeless	.47	.37	.39

These results indicate that negative support at time one is

significantly associated with "Helplessness/Hopelessness at time one and two. The relationship between negative support at time one and Helplessness/Hopelessness at time two is non-significant when the initial level of Helplessness/Hopelessness is controlled for. These results provide limited support for the hypothesis.

3.3 Family Environment and Psychological Adjustment

3.3.1 Hypothesis(4)

"A curvilinear relationship will be identified between family cohesion and adjustment such that psychological adjustment will be better in the mid-range of cohesion than at the extremes".

Statistical Procedures

A multivariate analysis of variance(MANOVA) was computed comparing the four cohesion groups on the MAC scales.

Statistical Outcome

Table 3.2.1 Means of MAC Scores for Four Levels of Family Cohesion

	Family Cohesion			
	Disengaged (n = 1)	Separated (n = 5)	Connected (n = 17)	Enmeshed (n = 18)
Fighting Spirit	43	53.2	53.06	53.39
Helpless/ Hopeless	7	8	8.06	8.56
Anxious Preoccupation	22	19.4	19.59	20.06
Fatalism	13	19	17.12	16.78

The analysis revealed no significant group effect, approximate ($F(12, 90)=1$, ns), using Wilks' Lambda. Hypothesis(4) is not supported by these results.

3.3.2 Hypothesis(5)

"A curvilinear relationship will be identified between family adaptability and psychological adjustment such that adjustment will be better in the mid-range of adaptability than at the extremes".

Statistical Procedures

A MANOVA was computed comparing the four adaptability sores on the MAC sub-scales.

Statistical Outcome

Table 3.2.1 Means of MAC Scores for four levels of family adaptability

	Family Adaptability			
	Chaotic (n = 2)	Flexible (n = 2)	Structured (n = 18)	Rigid (n = 19)
F i g h t i n g Spirit	59	52	52	53.44
Helpless/ Hopeless	6.5	7.5	8.7	7.9
A n x i o u s Preoccupation	21	16	21.2	18.67
Fatalism	21.5	15.5	16.95	16.94

The analysis revealed no significant group effect, approximate ($F(12,90)=1.25,ns$), using Wilks' Lambda.

3.3.3 Hypothesis (7)

"Patients from families identified as dysfunctional will report poorer psychological adjustment".

Families were classified as functional, mid-range, or dysfunctional on the basis of criteria obtained from the FACES manual (Olson 1982).

COHESION

ADAPTABILITY		Disengaged	Separated	Connected	Enmeshed	TOTAL
	Chaotic	0	2	0	0	2 (5)
	Flexible	0	1	1	0	2 (5)
	Structured	1	2	10	6	19 (46)
	Rigid	0	0	6	12	18 (44)
	TOTAL	1 (2)*	5 (12)	17 (42)	18 (44)	

*MARGINAL PERCENTAGES IN BRACKETS

Fig. 1. Frequency Distribution for the Sixteen Types of Family Systems of the Circumplex Model.

Statistical Procedures

A series of One Way Analyses of Variance were computed comparing group means on the MAC scores across the three levels of family functioning.

Statistical Outcome

Table 3.2.2 Means on MAC Scores by Levels of Family Functioning (N=41)

	Family Functioning			F	SIG
	Functional (n=14)	Mid-Range (n=15)	Dysfunctional (n=12)		
Fighting Spirit	52.43	52.8	53.83	.2	ns
Helpless Hopeless	8.07	8.87	7.67	.9	ns
Anxious Preocc.	19.57	21.13	18.5	1.3	ns
Fatalism	16.86	17.8	16.5	.62	ns

These results indicate no effect of level of family functioning on psychological adjustment. The hypothesis is not supported.

3.3.4 Hypothesis(8)

"Patients from families identified as dysfunctional will report lower levels of social support from spouses than patients from dysfunctional families."

Statistical Procedures

A One-Way Analysis of Variance was computed comparing group means on the spouse sub-scale of the Social Support Scale.

Statistical Outcome

Table 3.2.3 Mean Spousal Social Support by Level of Family Functioning (N=41)

	Family Functioning			F	SIG
	Functional (n=14)	Mid-Range (n=15)	Dysfunctional (n=12)		
Social Support	33.43	32.8	36.58	2.2	ns

These results indicate no effect of level of family functioning on spousal social support. The hypothesis is not supported.

3.4 Predicting Caseness

3.4.1 Hypothesis (8)

" A linear combination of the study variables will significantly predict caseness".

Statistical Procedures

Means of the relevant study variables for cases and non-cases were compared using One-Way Analysis of Variance. Output from this was used to rationalise selection of variables for the Discriminant Function Analysis.

Statistical Outcome

Table 3.4.1 Means of Study Variables by Caseness at Time One (N=41).

	Non-cases (N=28)	Cases (N=13)	F	SIG.
Age	56.2	50.2	3.2	ns
Cohesion	69.18	65.77	1.09	ns
Adaptability	54.86	51.3	2.02	ns
Soc.Support (Spouse)	35.07	32.08	3.36	ns
Soc.Support (Family Member)	33.96	33.23	.28	ns
Soc.Support (Friend)	34.68	33.62	.66	ns
Soc.Support (Nurse)	32.57	30.77	1.26	ns
Soc.Support (Nurse Specialist)	36.61	34.85	3.17	ns
Soc.Support (Doctor)	31.21	26.38	8.05	.007
Negative Support	21.43	25.92	4.44	.04

These results indicate that cases report significantly less perceived social support from their doctor and significantly more negative support than non-cases.

Table 3.4.2 Means of Study Variables by Caseness at Time Two (N=28) .

	Non- cases (N=21)	Cases (N=7)	F	SIG.
Age	57.71	54.76	.50	ns
Cohesion(T1)	67.24	70.29	.38	ns
Adaptability(T1)	55.48	51.57	1.46	ns
Soc.Support(T1) (Spouse)	35.80	35.86	0	ns
Soc.Support(T1) (Family Member)	34.71	33.00	.85	ns
Soc.Support(T1) (Friend)	34.42	35.29	.24	ns
Soc.Support(T1) (Nurse)	33.57	30.43	2.27	ns
Soc.Support(T1) (Nurse Specialist)	36.48	35.14	.96	ns
Soc.Support(T1) (Doctor)	31.71	26.85	4.78	.038
Negative Support(T1)	20.04	24.71	2.91	ns
Cohesion (T2)	69.04	69.14	0	ns
Adaptability (T2)	56.14	54.43	.19	ns
Soc.Support(T2) (Spouse)	35.67	31.58	3.51	ns
Social Support(T2) (Family member)	34.90	34.42	.08	ns
Social Support(T2) (Friend)	33.71	30.00	2.24	ns
Social Support(T2) (Nurse)	34.43	28.14	4.69	.039
Social Support(T2) (Nurse Specialist)	35.09	33.86	.27	ns
Social Support(T2) Doctor	32.48	25.29	7.80	.01
Negative Support(T2)	19.67	29.43	10.93	.003

These results indicate that cases report significantly less perceived social support from their doctor at times one and two, significantly less perceived social support from nurses at time two and greater levels of negative support.

**Table 3.4.3 Discriminant Analysis of Caseness at Time One.
(N=41)**

	Pooled Within-Groups Correlations	Wilks Lambda	Sig.
Social Support (Doctor)	.63	.83	.007
Stage of Disease	-.58	.75	.004
Radiotherapy	.30	.68	.003
Adaptability	.31	.66	.003
Classification results		Predicted Group Membership	
Actual Group	No. of patients	Non- cases	Cases
Non-cases	28	28	0
Cases	13	5	8
Per-cent of grouped cases corectly classified : 87.8%			

The classification results from the analysis demonstrate that 87.8% of patients are correctly classified applying the discriminant function postdictively. To test the contributions of individual variables to the accuracy of classification, variables with the lowest Canonical Discriminant Function Coefficients were progressively eliminated and the change in percentage of patients accurately classified was observed. After elimination of adaptability the percentage of patients correctly classified dropped to 82.9%. Elimination of

radiotherapy resulted in 73.2% of cases being correctly classified. Social support from a doctor entered alone resulted in 70.7% of cases being correctly classified.

**Table 3.4.4 Discriminant Analysis of Caseness at Time Two.
(N=28)**

	Pooled Within-Groups Correlations	Wilks Lambda	Sig.
Negative support (T2)	.81	.70	.003
Stage of Disease	.44	.66	.005
Social Support (Family member) (T2)	.43	.61	.007
Classification results		Predicted Group Membership	
Actual Group	No. of patients	Non- cases	Cases
Non-cases	21	21	0
Cases	7	3	4
Percent of cases correctly classified : 89.29%			

The classification results from the analysis demonstrate that 89.2% of patients are correctly classified applying the discriminant function postdictively. To test the contributions of individual variables to the accuracy of classification, variables with the lowest Canonical Discriminant Function Coefficients were progressively eliminated and the change in percentage of patients accurately classified was observed.

Eliminating Stage III resulted in a reduction to 87% of cases being correctly classified. Removal of the variable Social Support from a Family Member reduced the rate of correct

classification to 82%. Negative Support entered alone resulted in an 85% rate of correct classification.

Chapter Four: Discussion

4

Results are discussed in the order in which they were presented in chapter Three.

4.1 Rates of Psychological Disorder in the Study Sample

4.1.1 Aim (1)

"To establish rates of psychological disorder in the study sample of breast cancer patients".

Thirteen patients, 31.7% of the sample, were found to be cases at time one using criteria obtained from the MAC manual. Seven patients, 25% of the sample with complete data sets for both time periods, were identified as cases at time two. The later figure is probably an underestimate of the true rate at time two due to sampling bias. Of the four patients who did not return assessment packages at time two, three had been cases at time one. Five patients (12.5%) who were non-cases at time one became cases at time two. Eleven patients (27%) who were cases at time one were non-cases at time two. Two patients (5%) remained cases at both time points. Eighteen patients (44%) were cases at some point in the study. The rate of 31.7% identified at time one is comparable with other studies, e.g. Farber et al.(1984) reported 34% of their sample to have clinically significant psychological morbidity. Fallowfield et al(1986) reported rates of 32% among women receiving a mastectomy. Means for the MAC sub-scales were very similar to

those in a normative sample of breast cancer patients attending the Royal Marsden Hospital in London (Watson 1989).

Table 4.1.1 Comparison of Subscale Means for a Normative Sample of Breast Cancer Patients Attending the Royal Marsden Hospital (N = 179) with Present Study (N = 41).

	Royal Marsden sample		Present study sample	
	Mean	S.D.	Mean	S.D
Fighting Spirit	51.5	5.8	53.0	5.7
Anxious Preoccupation	20.9	4.2	19.8	4.3
Helpless/ Hopeless	9.0	2.6	8.2	2.4
Fatalism	17.9	3.7	17.1	3.2

The volatility of caseness across the two time points may indicate different causes. It suggests that a substantial proportion of patients identified as cases at time one may have been experiencing adjustment reactions. Caseness at time two might have been a reflection of enduring concerns emerging in relation to factors such as body image and sexual relationships.

4.1.2 Aim (2)

"To examine differences in psychological adjustment between women undergoing the following surgical procedures; lumpectomy, tylectomy, and mastectomy".

No significant differences in adjustment for different surgical procedures were identified. This area has been thoroughly reviewed by Hall and Fallowfield (1989) who concluded that there is no evidence that breast conserving surgery reduces psychological morbidity. The present findings are consistent with those authors conclusions.

4.1.3 Aim (3)

"To examine differences in psychological adjustment between women receiving radiotherapy and/or chemotherapy, with patients receiving no adjunctive therapy".

Patients receiving radiotherapy were found to have higher "Fatalism" scores at time two than patients not receiving radiotherapy. Lucas et al.(1987) have reported a strong relationship between total dose of radiotherapy and psychological morbidity. Fatigue is the most commonly reported side effect of radiotherapy. An aspect of radiotherapy which may induce fatalistic responses in recently diagnosed cancer patients concerns the fact that it brings patients into contact with other patients who will be clearly very ill. Patients may conclude that they too will deteriorate over time.

Patients receiving chemotherapy were found to have higher "Anxious Pre-occupation" scores than patients not receiving chemotherapy. Chemotherapy is generally given to pre-menopausal women because empirical research has established that it confers a modest protection against recurrence in this group. It is not possible to predict that an individual breast cancer patient will benefit from chemotherapy. Chemotherapy is often highly aversive due to side effects such as severe nausea, alopecia, and decreased resistance to infection. Maguire et al.(1980) compared psychological morbidity between a group of breast cancer patients being treated by mastectomy plus chemotherapy with patients receiving only a mastectomy. Patients in the chemotherapy group were found to be

significantly more anxious and depressed. A women in the position of experiencing such highly aversive side effects for a possible distant gain is likely to feel less in control. She may rationalize the treatment by suspecting that a significant amount of cancer cells remain after the surgery in order to make sense of taking such powerful drugs.

4.2 Social Support and Psychological Adjustment

4.2.1 Hypothesis (1)

"Higher levels of perceived social support at time one will be associated with better psychological adjustment at time one".

Correspondence Between Data and Hypothesis

The results demonstrated significant negative correlations between; social support from a friend and "fatalism", social support from a nurse and "helplessness/hopelessness", and a significant positive correlation between social support from the nurse specialist and "fighting spirit". Social support from a doctor was significantly positively correlated with "fighting spirit", and negatively correlated with "helplessness/hopelessness", and "anxious preoccupation". The hypothesis was not constructed to specify which sources of support would be correlated with particular dimensions of social support. Social support from a spouse and social support from a family member were not significantly correlated with any of the psychological adjustment measures. The data are consistent with the hypothesis but do not provide unequivocal support for it.

Statistical Issues

The pattern of significant correlations do not suggest spurious results as they are all in line with a priori expectations. However the use of multiple statistical tests can increase the probability of a type I error. Hypothesis one was tested by correlating six independent variables with four dependent variables. Although the significance level was set at .05 with 24 correlations it would be expected to find one significant correlation by chance. One way of dealing with the problem is to test each correlation for significance at .001. This would provide an overall significance level of .024. The problem with this solution is that it greatly reduces the power of the test given the small sample in the study. That is the probability of falsely rejecting the hypothesis when it is true sharply increases as significance levels become more stringent. In deciding the appropriate significance level to apply, issues concerning applied aspects of the research were considered. This involved an appraisal of the consequences of rejecting the hypothesis when it is true in comparison with the consequences of rejecting the hypothesis when it is untrue. The consequences of providing information to relevant clinicians that the quality of their supportive interactions with patients, is related to patient adjustment, when this is false, probably has less serious consequences than providing information that the quality of their supportive interactions with patients is unrelated to patient adjustment when this is false. If for example the study had been investigating the efficacy of exposure therapy (a potentially harmful treatment in this context) for patients with severe anxiety prior to attending

for chemotherapy, a stringent level of significance would be appropriate, as the consequences of rejecting the null hypothesis when it is true could be serious.

Relationship of Findings to Previous Research

The findings suggest that support from healthcare workers may be relatively more important in relation to adjustment than has been previously identified. Neuling and Winfield (1988) investigated the effects of support from different sources in a cohort of breast cancer patients assessed in hospital seven days post-operatively, and at one and three months post-operatively. They found that psychological adjustment in hospital was inversely related to amount of support from friends and family and unrelated to support from their doctor. At one month post-operatively patients reporting more satisfaction with support from their doctor were less anxious and depressed. At three months, satisfaction with support from family members and doctor was associated with fewer symptoms of anxiety and depression. Amount of support from family and doctor was related to more physical difficulties at three months. The study used an instrument which measured amount of supportive behaviours, and satisfaction with support, from various sources. Instruments which measure social support in terms of supportive behaviours tend to reveal an inverse relationship between social support and adjustment. This is because supportive behaviours are more likely to be elicited when an individual is physically or psychologically unwell. The present study used an instrument which measured perceived social support from various sources. The different approaches

to measurement probably account for the discrepancies between the Neuling and Winfield (1988) study and the present study. Levy et al. (1988) using the same social support instrument as the present study reported that both perceived social support from a doctor and perceived social support from a spouse were significant predictors of natural killer cell activity as part of a long term study investigating possible biological and psychological predictors of recurrence. The authors did not report on psychological adjustment in this article. Mean levels of perceived social support from a doctor were 33.5 compared to 29.7 in the present study.

4.2.2 Hypothesis (2)

"Higher levels of perceived social support at time one will be associated with better psychological adjustment at time two."

Correspondence Between Data and Hypothesis

Strong support for the hypothesis was found in relation to social support from a doctor and social support from the nurse specialist. Data from correlations of the spouse, family member, friend and nurse did not support the hypothesis. Overall the support for the hypothesis is weak.

Statistical Issues

The size of the correlations was moderate $r=.61$ for the nurse specialist and $r=-.52$ for a doctor. The significance levels were high $p<.001$ for the nurse specialist, and $p<.01$ for a doctor. The correlations are therefore very unlikely to be spurious .

Relationship of Findings to Previous Research

The great majority of social support studies have been cross-sectional. Few researchers have examined the relationship between social support at one time point and health outcomes at a second time point. Williams, Ware and Donald (1981) measured social support, negative life events, and well being. They reported a significant relationship between baseline social support and mental health after one year. In the context of lung cancer Quinn et al. (1986) found a significant relationship between social support at intake to the study and psychological distress four months later. The importance of these findings is their ability to clarify causal ambiguities

4.2.3 Hypothesis (3)

"Higher levels of social support at time one will be associated with better psychological adjustment at time two after the level of psychological adjustment at time one has been removed from the relationship.

Correspondence Between Data and Hypothesis

For the two sources of support tested there was some support for the hypothesis. The strongest support came from the moderate positive partial correlation between support from the nurse specialist and "fighting spirit" ($r=.58$, $p<.05$). The partial correlation between support from a doctor and anxious pre-occupation just failed to reach significance. An increase in the size of the correlation by .01 would have made it significant.

Statistical Issues

With only 28 patients in the sample at both time periods the statistical power was only .52. That is the chance of a

significant correlation not attaining .05 significance is .48. The chance therefore of overlooking a significant finding is quite high. Stevens (1992) has argued that researchers using small samples need to pay more attention to power in order to avoid type II errors which he believes to be much more of a problem than is commonly recognised. For small samples ($N < 21$) he advocates testing at a more liberal level i.e. .1 or .15. in order to increase power.

Relationship of Findings to Previous Research

The relationship between social support from clinicians and adjustment to cancer is a neglected area of research. Studies of the relationship between social support and cancer has tended to focus on the patients primary network. The Neuling and Winefield study was the only study which could be obtained which investigated the relationship between social support from doctors and adjustment to cancer across two time points. There is an assumption in the literature that cancer patients require what has been termed informational support from medical staff and emotional support from relatives. Although optimum communication from clinicians is clearly of great importance in cancer treatment the importance of emotional support from medical staff may have been underestimated. Cancer patients in a study by Bloom(1981) ranked their doctors higher than family and friends as an important source of support. In one study (Dunkel-Schetter 1984) cancer patients rated medical care as most effective when it combines direct assistance, advice or guidance, and emotional support. Thirty per-cent of patients in the Neuling and Winefield study expressed dissatisfaction in

the empathic support they received from their doctor. Although support from doctors emerged in the present study as a relatively important correlate of psychological adjustment the mean level of perceived support was less than for any other support category.

4.2.4 Hypothesis (4)

"Higher levels of perceived negative support will be associated with poorer psychological adjustment".

Correspondence Between Data and Hypothesis

The hypothesis was supported by moderate correlations ($r=.38$, $p<.05$), ($r=.35$ $P<.05$) in the first two tests. The results of the strongest test of the hypothesis did not provide support. Overall the hypothesis was supported.

Relationship of Findings to Previous Research

The concept of negative support derives from the work of Camille Wortman on victimization (Wortman and Lehman 1985). According to her theory individuals experiencing a life crisis often fail to obtain the support they need due to the feelings they engender in others and misconceptions about what they require. In relation to cancer a commonly held view is that it is better for patients to be cheerful and optimistic rather than discuss difficult feelings. Evidence suggests that victims who do express negative feelings about their situation are more likely to encounter rejection from support providers (Coates et al. 1979). The author is not aware of any empirical studies which have directly examined the impact of negative support on adjustment to cancer. Peters-Golden (1982) compared the beliefs of 100 healthy individuals concerning the support they would

expect to receive if they were diagnosed with cancer, with 100 breast cancer patients. The healthy subjects reported that they would expect a dense social network to provide plentiful social support. Additionally they did not expect others to avoid them. The breast cancer patients reported dissatisfaction with the amount and appropriateness of the support they received. Patients in the study attributed much of the inappropriate support to the assumption of the primacy of breast loss and the devaluation of breast cancer as a life threatening disease. Evidence from the present study confirms the views of Wortman and Dunkel-Schetter that negative aspects of support attempts are an important area for investigation.

4.3 Family Environment and Psychological Adjustment

4.3.1 Hypothesis (5)

"A curvilinear relationship will be identified between family cohesion and adjustment such that psychological adjustment will be better in the mid-range of cohesion than at the extremes".

Correspondence Between Data and Hypothesis

There was no discernable pattern in the distributions of the mean scores across levels of cohesion which could provide any support to the hypothesis.

Statistical Issues

Non-parametric tests may have been more appropriate because of the small number of patients in the disengaged and separated categories.

Relationship of Findings to Previous Research

Three published studies have examined family cohesion in the context of adjustment to cancer. Baider and Kaplan De-Nour

(1988) following up a cohort of postmastectomy women found a correlation between the cohesion subscale of the Family Environment Scale and anxiety. In the second study Spiegel (1983) failed to find a relationship between the cohesion subscale of the FES and psychological adjustment in a cohort of metastatic breast cancer patients. The findings from these studies are difficult to interpret because validity studies indicate that the FES does not measure family cohesion adequately (Olson 1991).

Friedman (1988) using FACES II found a strong relationship between family cohesion and psychological adjustment in group of breast cancer patients. Time from surgery to participation in the study ranged from three months to 14 years. The psychological adjustment measure they utilised was the Psychological Distress sub-scale of the Psychosocial adjustment to Illness Scale (Derogatis and Lopez 1983) which assesses disturbances in affect, self-esteem and body image attributable to the illness. The constructs tapped by this measure vary considerably from those of the MAC and could account for the differences in the study. Sixty-eight per-cent of the study population had more severe disease than stage I. It is possible that family cohesion is more important in more advanced stages of the disease.

A striking finding of the study was that 18(44%) of the families were considered to be enmeshed by FACES II criteria. In the Friedman study 23% of the families were described as enmeshed in terms of the FACES circumplex model. Thirty-four percent of Friedman's sample expressed a desire for greater

levels of cohesion. These findings suggest that greater levels of family cohesion may be adaptive for cancer patients in relation to characteristics which were not revealed by the MAC. It seems improbable that 44% of the families in the present study were enmeshed prior to the onset of cancer. That a shift to greater levels of family cohesion is an adaptive response to cancer in a family member appears more plausible.

4.3.2 Hypothesis (6)

"A curvilinear relationship will be identified between family adaptability and psychological adjustment such that adjustment will be better in the mid range of adaptability than at the extremes".

Correspondence Between Data and Hypothesis

No significant differences between group means on the MAC subscales were found. No suggestive trends were apparent. The hypothesis does not fit with the data and is therefore refuted.

Relationship of Findings to Previous Research

Friedman (1988) is the only other study to investigate family adaptability in the context of adult cancer. This study found no relationship between adaptability and adjustment. However 41% of the patients expressed a desire for greater adaptability in their family suggesting a shift towards greater adaptability may be an adaptive response to cancer. The distribution of levels of adaptability in the present study was skewed towards the rigid end of the dimension. Nineteen (46%) families in the present study were classed as rigid by the circumplex model. This also may have been caused by a shift in the family towards less adaptability subsequent to the onset of cancer.

4.3.3 Hypothesis (7)

"Patients from families identified as dysfunctional will report poorer psychological adjustment".

Correspondence Between Data and Hypothesis

There were no significant differences between the family types on the MAC sub-scales. No suggestive trends relevant to the hypothesis were apparent.

Relationship of Findings to Previous Research

No published studies could be identified which examined systematically assessed family dysfunction and psychological adjustment to cancer. Twenty nine per-cent of families in the present study were considered dysfunctional by the circumplex model. American general population norms are available for FACES which quotes a figure of 19% for family dysfunction in the general population. Twelve families (29%) of the present study were classified as rigidly enmeshed. Only 1.2% of families in the general population fall into this category. Friedman described the distribution of family types in his study as being comparable with the distribution found in the general population. In this study the mean time from surgery to participation in the study was three years. The distribution of family types in the present study may be a reflection of the temporal proximity of the patients to diagnosis and surgery. Patients and their families may try to compensate for the uncertainty which characterises this period by reinforcing

previous family structures and functioning with less flexibility.

4.3.4 Hypothesis (8)

"Patients from families identified as dysfunctional will report lower levels of social support from spouses than patients from dysfunctional families".

Correspondence Between Data and Hypothesis

The data did not reveal any significant differences in mean levels of social support across different levels of family functioning.

4.4 Predicting Caseness

Hypothesis (9)

"A linear combination of the study variables will significantly predict caseness".

Correspondence Between Data and Hypothesis

A linear combination of the study variables in the form of discriminant function equations predicted caseness at a significantly higher level than chance. The hypothesis was supported by the data.

Statistical Issues

One method of evaluating the discriminant function analysis is to compare the proportion of classification errors in the model with the proportion of errors that would occur if cases were classified randomly. The proportion of random errors expected on the basis of the numbers in the two groups is .44. The proportion of classification errors in the first discriminant function is .12. Expressing the reduction in error as a

proportion of the random error yields a figure of 72.7% For the second discriminant function the modal error is .11. This yields a reduction in error of 75%. The interpretation of the first function in terms of the variables which comprise it are problematic as there is no obvious underlying construct which connects them. The interpretation of the second function is somewhat clearer due to the large correlation between negative support and the discriminant function in comparison to the other variables. Negative support can be said to define this discriminant function. Both discriminant functions provide support to findings elsewhere in the study indicating that social support from a doctor and negative support are associated with psychological adjustment.

4.5 Service Implications

The Royal Cornwall Hospital(Treliske) treats approximately 150 new breast cancer patients per year. At the moment the breast nurse specialist is the only clinician with a remit to address the psychological needs of the patients although much of her time is occupied by fitting prothesis. She is therefore providing a service to a large number of women who have substantial unmet needs. The situation has recently been made more difficult by the local developments connected with the national reorganization of the health service. This has involved a split between the acute unit and the mental health unit which have become independent trusts. Prior to this an informal arrangement existed whereby a psychiatrist and a psychologist attached to a psychiatric unit based at the City site of the hospital would see a small number of inpatients

with physical illness if requested. Management has recently objected to this arrangement because acute hospital trust patients are no longer considered to be the responsibility of mental health services. This has meant that clinicians working with cancer patients have great difficulty in referring a patient to or obtaining advice from a psychiatrist or psychologist. Against this background the clinical nurse specialist in breast care finds it necessary to prioritise her activities given the overwhelming demands on her service. It was hoped that as a by product of the present study a screening instrument could be developed that would facilitate this. This was intended to have the following functions :-

- 1.To identify women with significant psychological disorder requiring intervention.
2. To obtain information which will help determine appropriate intervention
3. To ascertain the number of patients with significant psychological difficulties in order to inform management of the need to plan service provision in this area.

4.5.1 Development of a Screening Questionnaire

A number of 'off the shelf' screening questionnaires exist which are claimed to detect psychological disorder in cancer patients. Of these the Hospital Anxiety and Depression Scale(HADS) and the MAC have been the most extensively used. One of the problems facing a clinician using these instruments is deciding on the optimum cut-offs to use. If the cut-off is set too high then a proportion of cases will go undetected. If it is set too low a proportion of false positive cases will

identified which may defeat the purpose of using the instrument in the first place. Razavi et al. have adopted a useful approach to this problem using Relative Operating Characteristic (ROC) analysis in a study to determine optimum cut-offs for use with an oncology population. ROC analysis is a method for expressing the relationship between the true positive rate (sensitivity) and the false positive rate which can be represented graphically. Razavi et al. (1990) suggest that the optimum cut-off for the HADS is 13 for the combined scales which in their study gave a 75% true positive rate and a 25% false positive rate. Although Razavi and colleagues conclude that this score represents the optimum cut-off a false negative rate of 25% appears unacceptably high given the seriousness of the problem that is attempting to be detected. However, decreasing the cut-off to 11 resulted in an increase of the true positive rate to 82% but also an increase in the false positive rate to an impractical 40%. The study was done in an inpatient unit where a high base rate of psychological distress would be expected and may have inflated the false positive rate. For an outpatient setting the proposal is to use the HADS cut-off of 12 on the two scales combined with the fighting spirit and helplessness sub-scales of the MAC utilising cut-off scores of less than 47 and more than 12 respectively. The MAC will be used because it was acceptable to patients in the present study and data from it may suggest specific interventions for individual patients. The final screening questionnaire will also have a small number of items to obtain important relevant information regarding social

support, previous psychological adjustment, previous experience of cancer in a relative, and additional sources of stress. The timing of the assessment is important as patients often experience transient distress which tends to abate four to six weeks after diagnosis. This is probably an appropriate time to make an assessment with a view to determining the need for intervention. It is proposed to gain the cooperation of other clinicians in order to give the questionnaire to patients attending their first outpatient appointment after hospital discharge. Patients scoring above the cut-off will be invited for an appointment with the nurse specialist. As part of the assessment the nurse specialist will attempt to assess the presence of significant psychological symptoms using items from the Present State Examination (Wing et al., 1974) as probes.

4.6 Directions for Research and Theory

The pattern of change in case status between time one and two was surprising. It is well documented that psychological distress tends to diminish in the weeks following diagnosis. However a substantial proportion of women who were not significantly distressed at two months post diagnosis became so at eight months. It might be productive for research to investigate the characteristics which predict stability of case status over time. This would involve examining differences between patients who are; cases at time one and non-cases at time two, non-cases at time one and cases at time two, cases at time one and two, and non-cases at both times.

Further research is required to refine the sensitivity and specificity of screening instruments. ROC analysis is a

promising methodology for defining important parameters of a tests performance and as an aid to decision making in relation to screening methods. An ROC analysis of the MAC should be undertaken to determine if it offers any advantage over the HADS in reduction of false positive rates.

Although there is very strong evidence from the social support literature that interpersonal relationships are significantly related to aspects of physical and mental health the utility of the concept itself is questionable. This arises from an inability of researchers in the field to agree on definitions of what they are attempting to measure. As a result a plethora of instruments exist, many based on quite different theoretical assumptions. The result is that comparability across studies is seriously impaired. Comparability is crucial to progress in any scientific domain. The social support construct may actually be impeding progress as it has become identified as the primary means of studying the relationship between interpersonal relationships and health. It seems naive to think that a concept as broad and ill defined as social support could capture the complex, dynamic nature of human interactions. The social support construct has been important in drawing attention to the fact that relationships can influence health but it has not provided an elaborate knowledge base concerning how this occurs. Reducing the emphasis on social support in the research field might allow other methodologies to emerge which can answer some of the questions raised by two decades of social support research. In the

applied setting awareness of support issues should still be an important consideration in forming our responses.

Mental Adjustment to Cancer Scale.

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

	Definitely does not apply to me	Does not apply to me	Applies to me	Definitely applies to me
1. I have been doing things that I believe will improve my health, e.g.I changed my diet.	1	2	3	4
2. I feel I can't do anything to cheer myself up.	1	2	3	4
3. I feel that problems with my health prevent me from planning ahead.	1	2	3	4
4. I believe that my positive attitude will benefit my health.	1	2	3	4
5. I don't dwell on my illness	1	2	3	4
6. I firmly believe that I will get better	1	2	3	4
7. I feel that nothing I can do will make any difference	1	2	3	4
8. I've left it all to my doctors	1	2	3	4
9. I feel that life is hopeless	1	2	3	4
10. I have been doing things that I believe will improve my health, e.g.exercised	1	2	3	4
11. Since my cancer diagnosis I now realise how precious life is and I'm making the most of it	1	2	3	4
12. I've put myself in the hands of god	1	2	3	4
13. I have plans for the future, e.g. holiday, jobs, housing	1	2	3	4
14. I worry about the cancer returning or getting worse	1	2	3	4

	Definitely does not apply to me	Does not apply to me	Applies to me	Definitely applies to me
15. I've had a good life; what's left is a bonus	1	2	3	4
16. I think my state of mind can make a lot of difference to my health	1	2	3	4
17. I feel that there is nothing can do to help myself	1	2	3	4
18. I try to carry on my life as I've always done	1	2	3	4
19. I would like to make contact with others in the same boat	1	2	3	4
20. I am determined to put it all behind me	1	2	3	4
21. I have difficulty in believing that this has happened to me	1	2	3	4
22. I suffer great anxiety about it	1	2	3	4
23. I am not very hopeful about the future	1	2	3	4
24. At the moment I take one day at a time	1	2	3	4
25. I feel like giving up	1	2	3	4
26. I try to keep a sense of humour about it	1	2	3	4
27. Other people worry about me more than I do	1	2	3	4
28. I think of other people who are worse off	1	2	3	4
29. I am trying to get as much much information as I can about cancer	1	2	3	4
30. I feel that I can't control what is happening	1	2	3	4
31. I try to have a very positive attitude	1	2	3	4
32. I keep quite busy, so I don't have time to think about it	1	2	3	4
33. I avoid finding out more about it	1	2	3	4

	Definitely does not apply to me	Does not apply to me	Applies to me	Definitely applies to me
34. I see my illness as a challenge	1	2	3	4
35. I feel fatalistic about it	1	2	3	4
36. I feel completely at a loss about what to do	1	2	3	4
37. I feel very angry about what has happened to me	1	2	3	4
38. I don't really believe I had cancer	1	2	3	4
39. I count my blessings	1	2	3	4
40. I try to fight the illness	1	2	3	4

Family Adaptability and Cohesion Evaluation Scales.

INSTRUCTIONS: below are a number of statements which describe some aspects of family life. Please circle the number to the right of each statement which best describes how you feel about your family now.

	Almost never	Once in a while	Sometimes	Frequently	Almost always
1. Family members are supportive	1	2	3	4	5
2. In our family, it is easy for everyone to express his/her opinion	1	2	3	4	5
3. It is easier to discuss problems with people outside the family than with other family members	1	2	3	4	5
4. Each family member has input in major family decisions	1	2	3	4	5
5. Our family gathers together in the same room	1	2	3	4	5
6. Children have a say in their discipline	1	2	3	4	5
7. Our family does things together	1	2	3	4	5
8. Family members discuss problems and feel good about the solutions in the same room	1	2	3	4	5
9. In our family everyone goes his/her way	1	2	3	4	5
10. We shift household responsibilities from person to person	1	2	3	4	5
11. Family members know each others close friends	1	2	3	4	5
12. It is hard to know what the rules are in our family	1	2	3	4	5
13. Family members consult other family members on their decisions	1	2	3	4	5
14. Family members say what they want	1	2	3	4	5
15. We have difficulty thinking of things to do as a family	1	2	3	4	5

	Almost never	Once in a while	Sometimes	Frequently	Almost always
16. In solving problems, the children's suggestions are followed	1	2	3	4	5
17. Family members feel very close	1	2	3	4	5
18. Discipline is fair in our family	1	2	3	4	5
19. Family members feel closer to people outside the family than to other family members	1	2	3	4	5
20. Our family tries new ways of dealing with problems	1	2	3	4	5
21. Family members go along with what the family decides to do	1	2	3	4	5
22. In our family, everyone shares responsibilities	1	2	3	4	5
23. Family members like to spend time together	1	2	3	4	5
24. It is difficult to get a rule changed in our family	1	2	3	4	5
25. Family members avoid each other at home	1	2	3	4	5
26. When problems arise we compromise	1	2	3	4	5
27. We approve of each others friends	1	2	3	4	5
28. Family members are afraid to say what is on their minds	1	2	3	4	5
29. Family members pair up rather than do things as a total family	1	2	3	4	5
30. Family members share interests and hobbies with each other compromise	1	2	3	4	5

Michigan Social Support Scale for Breast Cancer Patients.

INSTRUCTIONS: People frequently experience different amounts of support from various people in coping with a life stress. The following questions ask about your relationships with various people in your life, such as your spouse, relatives, friends, and health professionals and the amount of support you perceive from them in regard to the breast cancer experience. PLEASE INDICATE THE EXTENT TO WHICH YOU AGREE OR DISAGREE WITH EACH OF THE STATEMENTS.

For example if you strongly agree with the statement, circle number 5 in the strongly agree column. There are no right or wrong answers. This questionnaire is asking for your first impressions of the statements.

The following eight statements ask about your relationship with your spouse regarding the cancer experience.

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1. My spouse is willing to listen to me when I just need to talk	1	2	3	4	5
2. I feel comfortable discussing my concerns about this situation with my spouse	1	2	3	4	5
3. Sometimes my spouse ignores or makes light of my concerns	1	2	3	4	5
4. My spouse seems to understand what <u>I</u> am going through	1	2	3	4	5
5. I often feel as if I should put up a front around my spouse and pretend that things are going better than they really are	1	2	3	4	5
6. I am feeling a great deal of affection and warmth from my spouse	1	2	3	4	5
7. I often receive credit from my spouse for my attempt to cope with this situation	1	2	3	4	5
8. My spouse helps me put this experience into perspective	1	2	3	4	5

Comments:

The following eight statements ask about your relationship with a family member regarding the cancer experience. Think about one family member or relative (other than your spouse) who is important to you as you answer these statements.

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1. My family member is willing to listen to me when I just need to talk	1	2	3	4	5
2. I feel comfortable discussing my concerns about this situation with my family member	1	2	3	4	5
3. Sometimes my family member ignores or makes light of my concerns	1	2	3	4	5
4. My family member seems to understand what <u>I</u> am going through	1	2	3	4	5
5. I often feel as if I should put up a front around my family member and pretend that things are going better than they really are	1	2	3	4	5
6. I am feeling a great deal of affection and warmth from my family member	1	2	3	4	5
7. I often receive credit from my family member for my attempt to cope with this situation	1	2	3	4	5
8. My family member helps me put this experience into perspective	1	2	3	4	5

Comments:

The following eight statements ask about your relationship with your other people such as a friend (neighbour, work colleague, etc.) regarding the cancer experience. Think about one friend who is important to you as you think of these statements.

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1. My friend is willing to listen to me when I just need to talk	1	2	3	4	5
2. I feel comfortable discussing my concerns about this situation with my friend	1	2	3	4	5
3. Sometimes my friend ignores or makes light of my concerns	1	2	3	4	5
4. My friend seems to understand what <u>I</u> am going through	1	2	3	4	5
5. I often feel as if I should put up a front around my friend and pretend that things are going better than they really are	1	2	3	4	5
6. I am feeling a great deal of affection and warmth from my friend	1	2	3	4	5
7. I often receive credit from my friend for my attempt to cope with this situation	1	2	3	4	5
8. My friend helps me put this experience into perspective	1	2	3	4	5

Comments:

The following eight statements ask about your relationship with your nurses regarding the cancer experience.

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1. My nurse is willing to listen to me when I just need to talk	1	2	3	4	5
2. I feel comfortable discussing my concerns about this situation with my nurse	1	2	3	4	5
3. Sometimes my nurse ignores or makes light of my concerns	1	2	3	4	5
4. My nurse seems to understand what <u>I</u> am going through	1	2	3	4	5
5. I often feel as if I should put up a front around my nurse and pretend that things are going better than they really are	1	2	3	4	5
6. I am feeling a great deal of affection and warmth from my nurse	1	2	3	4	5
7. I often receive credit from my nurse for my attempt to cope with this situation	1	2	3	4	5
8. My nurse helps me put this experience into perspective	1	2	3	4	5

Comments:

The following eight statements ask about your relationship with your breast nurse specialist regarding the cancer experience.

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1. My nurse specialist is willing to listen to me when I just need to talk	1	2	3	4	5
2. I feel comfortable discussing my concerns about this situation with my nurse specialist	1	2	3	4	5
3. Sometimes my nurse specialist ignores or makes light of my concerns	1	2	3	4	5
4. My nurse specialist seems to understand what <u>I</u> am going through	1	2	3	4	5
5. I often feel as if I should put up a front around my nurse specialist and pretend that things are going better than they really are	1	2	3	4	5
6. I am feeling a great deal of affection and warmth from my nurse specialist	1	2	3	4	5
7. I often receive credit from my nurse specialist for my attempt to cope with this situation	1	2	3	4	5
8. My nurse specialist helps me put this experience into perspective	1	2	3	4	5

Comments:

The following eight statements ask about your relationship with your hospital doctor regarding the cancer experience.

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1. My doctor is willing to listen to me when I just need to talk	1	2	3	4	5
2. I feel comfortable discussing my concerns about this situation with my doctor	1	2	3	4	5
3. Sometimes my doctor ignores or makes light of my concerns	1	2	3	4	5
4. My doctor seems to understand what I am going through	1	2	3	4	5
5. I often feel as if I should put up a front around my doctor and pretend that things are going better than they really are	1	2	3	4	5
6. I am feeling a great deal of affection and warmth from my doctor	1	2	3	4	5
7. I often receive credit from my doctor for my attempt to cope with this situation	1	2	3	4	5
8. My doctor helps me put this experience into perspective	1	2	3	4	5

Comments:

ROYAL CORNWALL HOSPITAL(TRELISKE)
TRURO
CORNWALL

PATIENT CONSENT FORM

I am a clinical psychologist undergoing training at Polytechnic southwest, Plymouth and employed by the Cornwall and Isles of Scilly Health Authority. As part of my training I am required to undertake a research project. I am particularly concerned with some of the difficulties people with breast cancer may experience, and the nature of the support received from families and healthcare workers to help with these difficulties. As part of this study I would be very grateful if you would complete three short questionnaires which should take about 20 minutes of your time. This is all that will be required of you.

Completion of the questionnaires is entirely voluntary and will not in any way affect your treatment.

All information obtained, recorded and analyzed will be confidential. Any resulting reports or publications will ensure complete anonymity and confidentiality. You as an individual will not be identifiable.

It is hoped that knowledge gained from the study may lead to an improved service for future patients.

The study has the approval of the Royal Cornwall Hospital's ethical committee and the approval of the Polytechnic Southwest Psychology Department. It meets the requirements of the ethical principles laid down in the Declaration of Helsinki and the British Psychological Society Code of Conduct for psychologists. It also conforms to the Data Protection Act 1984.

In signing this consent form I(Full name BLOCK CAPITALS) acknowledge that I have read this form and agree to be included in the study.

SIGNED.....

DATE.....

Research Protocol for Ethical Committee.

Applicant: Mr. M.E. Lunn.

Position: Clinical Psychologist in Training, Polytechnic South west, and Cornwall Health Authority.

Liaison Supervisor: Mr. D.J. Oxford.

Position: Principal Clinical Psychologist, Cornwall Health Authority.

Main Supervisor: Dr. A.T. Carr.

Position: Director, Clinical Teaching Unit, Polytechnic South West and Clinical Psychologist, Plymouth Health Authority.

Course: Postgraduate Professional Training in Clinical Psychology.

Institution: Polytechnic South West, Plymouth.

Title: Social Support, Family Cohesion, and Psychological Adjustment to Breast Cancer.

Introduction: Evidence suggests that a significant number of cancer patients experience psychological distress as a result of their disease (Derogatis et al. 1983). Other research indicates that the presence of perceived social support can buffer patients from the psychological stress of their illness (Wortman 1984). Recent attention has focused on aspects of patients family environment in relation to psychological outcome (Friedman et al. 1988).

Relevance to Management: Although most patients probably attain good outcome with existing services the present study will enable the identification of a subgroup of patients who may benefit from a more specialist counselling service. It is likely that such patients may have poorer support networks or require involvement of family members to optimise the supportive environment of the family. It is hoped that the proposed study will provide useful information on these issues.

Subjects: Women who have undergone assessment and the initial treatment for first incidence of breast cancer at the Royal Cornwall Hospital (Treliske) between March 1992 and January 1993.

Inclusion Criteria: Married woman who have undergone mastectomy, lumpectomy or radiotherapy aged 16-65, no history of psychosis, organic brain damage, or learning difficulty.

Instruments: A non-invasive psychosocial assessment, will be undertaken with subjects referred for inclusion in the study, by the applicant with the assistance of Sue Ferguson the clinical nurse specialist in breast care. This will consist of a semi-structured interview to obtain demographic data using the following questionnaires in common use.

1. The Family Adaptability and Cohesion Evaluation Scales (FACES) (Olson 1982). This is a 30-item scale assessing both family cohesion and family adaptability. Internal consistency, using Cronbach Alpha, was 0.87 for cohesion and 0.78 for adaptability.
2. Social Support for Breast Cancer Patients Questionnaire (Wortman 1988). This eight item scale allows the quantification of perceived emotional support from a variety of others, including spouse, friend, nurse and doctor. The scale uses a five point Likert type response. A typical item is "My spouse listens to my concerns".
3. Mental Adjustment to Cancer Scale (Watson and Greer 1988). A 40 item scale using a 4 point Likert format.

Procedure: It is intended that the applicant will liaise with the consultant oncologist who will ask patients fulfilling the entry criteria if they would be willing to be interviewed by Sue Ferguson or the applicant during their next outpatient appointment. Patients who have given their initial agreement will be approached before their outpatient appointment. The nature of the study will be explained and informed consent will then be obtained. Following this the psychosocial assessment will then be undertaken. This will take about 20 minutes. The research will run for one year.

Data Analysis: Multivariate analysis of variance will be performed on the data using the S.P.S.S. PC+ computerised package.

Patient Care: In the event of any adverse reactions the interview will be stopped and the patient will be counselled and debriefed. A follow-up counselling session will be arranged if required.

Data Protection: The data will be stored on a Dell 212n personal computer located in the applicants room in the staff quarters of the Royal Cornwall Hospital (City). Patients entered to the study will be assigned an identification number to enable data to be stored without using patients names or addresses. Only the applicant and supervisors named above will have access to the data. The study has been approved by the Polytechnic Southwest Psychology Department. It meets the ethical requirements of the Helsinki Declaration of ethical principles and the British Psychological Society Code of Conduct for Psychologists. It also conforms to the Data Protection Act 1984.

CORNWALL AND ISLES OF SCILLY HEALTH AUTHORITY

MEDICAL AND DENTAL ADVISORY COMMITTEES

ETHICAL COMMITTEE

INFORMATION TO ACCOMPANY PROTOCOL - DETAILS TO BE TYPEWRITTEN

1. **DATE:** 9:2:92
2. **TITLE OF STUDY:** Social Support, Family Cohesion, and Psychological Adjustment to Breast Cancer.
3. **MAIN INVESTIGATOR:** Martin E. Lunn
(SUMMARY OF PREVIOUS RESEARCH EXPERIENCE)
 1. Position: Postgraduate Student, University College and Middlesex School of Medicine, Univ. of London.
Nature of Research: Cross sectional study of psychometrically assessed hostility and angiographically documented coronary artery disease.
Location: Cardiac Department, Kings College Hospital, London.
Date: 1989/90.
 2. Position: Research Psychologist, Institute of Psychiatry, Univ. of London.
Nature of Research: Randomised controlled trial of community v. hospital treatment of severe mental illness.
Location: Royal Bethlem and Maudsley hospitals, London.
Date: 1989/90.
4. **OTHER INVESTIGATORS** See attached.
5. **IS THIS A MULTICENTRE STUDY?** No

6. IS THIS STUDY SPONSORED BY A PHARMACEUTICAL OR OTHER MEDICAL COMPANY? No.

7. IF YES, NAME OF COMPANY:

8. WILL THE INVESTIGATOR OBTAIN FINANCIAL BENEFIT FROM THIS STUDY? (PLEASE SPECIFY) No.

9. TRIAL STATUS FOR MEDICAL PRODUCTS: N/A.

a) Clinical Trial Certificate Exemption Reference Number:

b) Clinical Trial Certificate Reference Number:

c) Other - please specify:

10. DOES THIS COMPANY ACCEPT THE APBI GUIDELINES FOR COMPENSATION? N/A.

11. ESTIMATED NUMBER AND AGE RANGE OF ENTRANTS: 50 patients
(Has statistical advice been taken?)
aged 18 to 65. Statistical advice has been taken.

12. ESTIMATED DURATION OF STUDY: 10 months.

13. **OUTLINE OF PROTOCOL INCLUDING PRACTICAL BENEFITS ENVISAGED FROM THE SUCCESSFUL COMPLETION OF THE PROJECT-**
(In lay terms please): See attached.

14. **SUBSTANCES TO BE GIVEN TO PATIENTS. INDICATE THOSE EXTRA TO NORMAL CLINICAL MANAGEMENT:** None.

Drugs -

Radioactive Substances -

Route of Administration -

Amount -

Frequency -

20. ARE MOST OF THESE UNLIKELY OR POSSIBLE?

21. INFORMATION SHEET (Please enclose a copy of the patient information sheet).

22. CONSENT - Method of obtaining consent plus copy of consent form if applicable. (N.B THE ORIGINAL PATIENT CONSENT FORM MUST BE FILED WITHIN THE HOSPITAL PATIENT CASE FOLDER.)

Patients who fulfil the entry criteria will be approached by Sue Ferguson (Clinical Nurse Specialist in Breast Care), the nature of the study will be explained and the patient's views and concerns will be elicited. If the response is favourable the patient will be asked to read and sign the information and consent form.

23. STORAGE OF INFORMATION -

Will Computer be used to Store Information? Yes.

If YES, has provision been made to comply with the data protection act? Yes.

24. HAVE YOU READ THE HELSINKI DECLARATION 1989 AND DOES THIS STUDY CONFORM? Yes.

25. HAVE YOU READ THE CPMP GUIDELINES ON GOOD CLINICAL PRACTICE FOR TRIALS ON MEDICINAL PRODUCTS IN THE EUROPEAN COMMUNITY?

(A COPY CAN BE OBTAINED FROM Mrs REYNOLDS)

N/A.

15 COPIES OF THE FULL PROTOCOL FOR THE STUDY SHOULD BE SENT WITH THIS FORM TO:

Mrs M M Reynolds
Administrator
Medical & Dental Advisory Committees
Royal Cornwall Hospital (Treliske)
TRURO

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