PSYCHOSOCIAL
NEEDS AND RESPONSES
IN BREAST CANCER RECOVERY

SANDRA J NEULING
B.A.(Hons.), Dip.T.

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PSYCHOSOCIAL NEEDS AND RESPONSES IN BREAST CANCER RECOVERY

Abstract

The aims of this thesis were to examine the psychosocial needs and responses of women recovering from recent breast cancer surgery, and also of their husbands; and to evaluate the support offered by family, friends, health professionals, and the Anti-Cancer Foundation's Breast Cancer Support Service (BCSS). The role of social support in coping with the stress of cancer was of prime interest.

Study 1. Fifty-eight breast cancer patients were interviewed in hospital within a few days of surgery, and were then followed up at 1, 3, and 6 months post surgery. It was found that the initial stress generated by the diagnosis and treatment of breast cancer did not remain, and by 6 months post surgery there were very few, if any, continuing psychosocial problems amongst the sample of patients in this study.

Study 2. As a result of indications from Study 1, of unmet informational and empathic support needs from surgeons, Study 2 ascertained whether the BCSS could help meet some of these needs. Postal questionnaires were answered by 42 BCSS hospital visitors and 67 patients who had recently been visited by them. Results indicated that BCSS visitors, being

previous breast cancer patients, were able to provide a valuable service mainly as a role-model of a survivor who looked "normal". However the BCSS did not take the place of medical professionals, husbands, or close confidants.

Study 3. As a result of indications from Study 1, of the importance of support from husbands, Study 3 investigated husbands' needs and responses. Postal questionnaires were answered by 86 husbands of recent breast cancer patients. A comparison of results with those of patients in Study 1 indicated that husbands' stress levels were similar to those of patients. Most husbands, however, received the support that they needed, and felt able to give their wives the support they required. This third study supported the findings from Study 1 that marriage relationships were brought closer together through the cancer experience.

STATEMENT

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university, and to the best of my knowledge and belief, contains no material previously published or written by another person, except when due reference is made in the text.

I consent to this thesis being made available for photocopying and loan if applicable, if accepted for the award of the degree.

Sandra J. Neuling
October, 1989.

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SECTION I

BACKGROUND RESEARCH

CHAPTER 1

Introduction

Breast cancer has probably existed as long as woman. The ancient Egyptians, Greeks, and Romans all had documented evidence of, and treatments for, breast cancer (Ray & Baum, 1985). However, it was not until the mid 19th century that reasonable records of treatments were kept, together with recurrence rates, and not until after 1930 that anything substantial was done in the selection of women for mastectomy. Today tests are performed to determine the degree of spread of the cancer and, where survival rates are similar, women are given the choice of mastectomy alone or of a less intensive surgical procedure with radiotherapy.

Breast cancer affects 1 in 11 women (Holland & Jacobs, 1986), and is the most common malignancy amongst women in the western world. It is not only a physical trauma but is also a psychological one, as the patient has to cope with a diagnosis of cancer and its implications, uncertainties, and treatments. This may also affect her family and friends as they attempt to give her support whilst coming to terms with the situation themselves. Thus it is probable that the patient and her confidants will suffer some degree of psychosocial morbidity. However, there is little agreement in the literature as the how much morbidity is experienced, and as to whether morbidity is due mainly to the diagnosis of cancer or the surgery used to treat it.

This research was undertaken to ascertain the amount and nature of distress caused by having breast cancer, and then to determine whether this can be alleviated either through the use of particular coping strategies or through social support. Lazarus and Folkman's (1984) notion of stress as being a function of cognitive appraisals was used as the basis of this research, and stress was defined as "any event in which environmental or internal demands (or both) tax or exceed the adaptive resources" (Lazarus & Folkman, 1984, p. 296).

Coping was defined as "what one does about a perceived problem in order to bring about relief, reward, quiescence, or equilibrium" (Weisman & Worden, 1976, p. 3), and was seen to act on, and interact with, stress appraisals. Coping may be aimed at changing the objective stressor (instrumental) or at regulating emotions (palliative), and as these aims are realised, a reappraisal of the demands of an event and/or the available resources may be made. The groups of coping strategies investigated in this research were avoidance/denial, active--behavioural, and active--cognitive. However, as no particular group of coping strategies was found to be more effective than any other in alleviating distress in Study 1, this research then concentrated on determining how support can be more satisfactorily provided for breast cancer patients in the early stages after surgery.

Social support was investigated with reference to four interrelated psychological theories: Attribution, Coping, Equity (Social Exchange), and Social Comparison. Attribution Theory emphasizes the importance of recipient views (a) of the intentions of support-givers and (b) of oneself as a support-receiver; Coping Theory emphasizes the influence of support on recipient views of stressors (primary appraisals) and available resources (secondary appraisals); Equity Theory emphasizes the notion of reciprocity and indebtedness, and Social Comparison Theory emphasizes the costs and benefits of comparing oneself with similar others. All of these theories help to clarify conceptual issues regarding the costs and benefits of social support, and assist in interpreting recipient evaluations of support and in predicting help-seeking activity. The Multi-Dimensional Support Scale (MDSS) was developed in order to capture the multidimensional nature of social support and to fully investigate (a) its functions in providing emotional, tangible, informational, and reassurance support; (b) the sources from which it is received, which in the case of cancer patients was family members, friends, and the surgeon; and (c) its frequency as well as recipient satisfaction with this frequency.

Study 1 demonstrated that the diagnosis of cancer and its attendant uncertainties was by far the most worrying problem facing breast cancer patients--more so than the fear of loss of femininity. There was some early psychosocial stress, but this was mostly dissipated by 6 months post surgery. Psychological adjustment was significantly related to satisfaction with support from family members at the time of surgery; from surgeons at 1 month post surgery; and from both family and surgeon at 3 months post surgery. Results from Study 1 also demonstrated that many patients had problems in eliciting the support they required from surgeons for two main reasons: (a) surgeons may not see providing support as a main part of their role, and (b) many patients did not ask for this help when they needed it. Results also indicated a balance in support needed from family members in that they were more likely than other sources to be resented for giving too much "support", and this could present families with a problem in attempting to give support whilst they are themselves under considerable stress. Some patients were also reluctant to express their feelings to those close to them for fear of worrying them.

Study 2 investigated the helpfulness of the Anti-Cancer Foundation Breast Cancer Support Service (BCSS), a group of volunteer hospital visitors who are ex-breast cancer patients, to ascertain whether they could fill part of patients' support needs. BCSS volunteers should be able to relate to patients' fears; would have more time available than surgeons; would be trained in hospital visiting; and would not be as emotionally involved as husbands or close friends. Results from Study 2 demonstrated that the BCSS had a definite part to play in the rehabilitation of the breast cancer patient, as they were a clear model to the patient that a full life can be led after breast cancer, and so offered hope and reassurance. However, they could not take the place of a supportive husband, or give the specific support that patients required of the surgeon.

Research has shown that the husband's reactions may be crucial to the breast cancer patient's adjustment (Wortman, 1984). Study 1 found that 42% of married subjects stated that their marriage had shown a marked improvement during the first 6 months after surgery; 68% confided in their husbands when they became worried about cancer-related problems; and over 90% nominated husbands as the most supportive family member. However, these men who were the main source of support for their wives were also under great stress themselves. Therefore Study 3 investigated the needs and responses of husbands of breast cancer patients, with the aim of identifying the assistance they may need in order to (a) alleviate their own stress and (b) support their wives. This study found that although husbands were subject to similar stress levels as their wives, most claimed that they received, and were able to give, what they considered to be adequate support. In fact, the overall pattern of responses in this study and Study 1 was that the quality of marriage relationships improved as a result of the cancer experience.

CHAPTER 2

Stress and Cancer

A diagnosis of cancer can evoke a high level of stress, as also can the methods used to treat it. A great deal of this stress is related to the uncertainties of the course of the illness and the efficacy of its treatments. This chapter reviews research findings in the areas of stress and cancer, with particular reference to breast cancer.

Theoretical perspective

The theoretical perspective adopted in this chapter is that of cognitive appraisal (Lazarus & Folkman, 1984). The notion of stress relies on appraisals of (a) the potential of an event problem specific to affect one's lifestyle disruptively and (b) the resources person specific available to combat this event. It is only when the demands of the event are appraised as taxing or exceeding available resources that stress results.

Stress and appraisal

Stress, of itself, is not inherently negative. It can be sought after as a challenge or a relief from boredom (Lazarus & Folkman, 1984). Lazarus and Launier (1978) defined stress as "any event in which environmental or internal demands (or both) tax or exceed the adaptive resources..." (p. 296). "Demands" refer to external events or internal goals or values which, if not met by suitable action, would result in negative consequences.

A person confronted with a major event may actually face two sources of stress: the situation may be threatening in itself; and so may one's reactions to it (Thoits, 1986). Developing a serious illness and undergoing medical treatment can be extremely stressful, not only physically but also psychologically (Cohen & Lazarus, 1979). The individual who previously took health for granted becomes faced with a sudden change in life-style which may threaten security and self-image. As this person responds to the threat or challenge, depending on how it is viewed, the situation changes and a new response is required. Thus stress represents a dynamic process, comprised of a complex set of changing conditions rather than a single event (Cohen, 1982; Folkman & Lazarus, 1985).

Stress, therefore is not definable merely as a stimulus, but as a relationship between the characteristics of the individual and the nature of the demand (Lazarus, DeLongis, Folkman, & Gruen, 1985). Hence, the notion of stress relies on cognitive appraisal (Lazarus & Folkman, 1984). If the demand is appraised as taxing or exceeding available resources, then stress results, and the individual will be required to activate extra resources to meet the challenge.

There are two types of cognitive appraisal, both of which influence the other: primary appraisal, or an evaluation of the significance of an event to one's well being; and secondary appraisal, or an evaluation of coping resources and options available (Cohen & Lazarus, 1979; Folkman, Schaefer, & Lazarus, 1979). This appraisal process may not be conscious or deliberate, and can occur without awareness (Lazarus & Launier, 1978). In fact, as Singer (1984) stated, "People coping with a serious problem or life-threatening illness make attributions about the problem, break down its elements, redefine their threat, search for positive elements, ignore base-rate information, misperceive characteristics of the illness, compare themselves to others, and distort the influence of their environment" (p. 2310).

Cancer

"Cancer is...a group of diseases that share the common characteristic of the uncontrolled growth of abnormal cells." (Kerson & Kerson, 1985, p. 36). A person diagnosed as having cancer experiences an enormous amount of stress--physical, psychological, and socioeconomic (Cohen, 1982; Stam, Bultz, & Pittman, 1986; Weisman, 1976). Probably no disease is viewed by the western world with as much fear as cancer (Haney, 1984; Wortman & Dunkel-Schetter, 1979). It has a profound psychological impact on patients' lives (Fobair, 1981; Jamison, Wellisch, & Pasnau, 1978), often beginning with a sense of helplessness and anxiety, and followed by depression (Gottesman & Lewis, 1982; Lewis, Gottesman, & Gutstein, 1979). Because it is such a stigmatizing illness, even the diagnosis itself has a negative affect on self image (Kerson & Kerson, 1985). Cancer rates high on the list of fears of prolonged death, and is associated with pain, dependence, isolation from family and friends, and loss of control (Fink et al., 1986), even though these may not be realistic aspects of an individual's illness (Raphael & Maddison, 1981). Cancer is not a short-term single stressor, but a complex set of changing conditions (Haney, 1984), requiring continual psychological readjustment (Greer & Burgess, 1987). First there is the trauma of diagnosis, and then treatment, which may include surgery, radiotherapy or chemotherapy. Then there are the inevitable periodic checkups accompanied by fears of recurrence and perhaps further treatment or a "death sentence", leaving the patient with little energy and often an altered physical state as well as a damaged psychological image.

Cancer treatments are stressful in their own right, and are often dreaded as much as the cancer itself. Treatment is relatively impersonal (Silberfarb, Maurer, & Crowthamel, 1980), as the patient is handed over to a new set of specialists in a new setting (Leventhal, Easterling, Coons, Luchterhand, & Love, 1986), leaving the sufferer feeling like a mere object in the medical setting (Fobair & Mages, 1981), whilst the family remains uninformed and helpless (Cox, 1986). Large technical equipment is used in radiotherapy and many patients fear being abandoned under the apparatus or receiving excessive doses. Some fear that radiotherapy will destroy healthy tissue (Maguire, 1985a) or even cause more cancer (Achte, Vauhkonen, Lindfors & Salokari, 1986). Radiotherapy and chemotherapy force patients to face the reality of their cancer (Vachon, Lyall, Rogers, Cochrane, & Freeman, 1982), not only because of their own treatment, but also because they find themselves in the presence of others who are suffering the effects of cancer or its treatments. This increases their distress. Possible side effects include nausea, vomiting, diarrhea, cutaneous irritation, hair loss and mouth sores, and if patients are not warned of these in advance, these or the resultant tiredness, weakness or pain, may be interpreted as a sign of the cancer's progression (Ray & Baum, 1985). All of this reduces patients' sense of control over events, and may increase their fear that treatment will fail to control the cancer.

However, the effect of radiotherapy on psychiatric morbidity is unclear. Fallowfield, Baum, & Maguire (1987a) pointed out the paradox that "although radiation 'cures' cancer, it is also linked to causing cancer" (p. 697). Some researchers claim that there is an increase in anxiety and depression levels amongst those undergoing radiotherapy (Maguire, 1985b; Peck & Boland, 1977). Yet Morris, Greer, and White (1977) found no difference in morbidity at 2 years post surgery between breast cancer patients who received radiotherapy and those who did not. In fact Vachon et al's. (1982) study demonstrated that the level of distress amongst patients receiving radiotherapy for breast cancer was lower than it was at surgery. Holland and Jacobs (1986) noted that patients undergoing radiotherapy felt reassured that something was being done and they were being looked after on a regular basis, adding that for this reason anxiety may increase when treatment was finished.

The effects of cancer and its treatments are not limited to those afflicted with it. The fear of cancer is widespread, as its impact on the community reflects a lack of understanding and a general "cancer phobia" (Feldman, 1987; Gotay, 1984). It is felt that information even from cancer education programs may serve to increase this fear (Faulder, 1985). The stigma associated with cancer is widely reported, often leading to withdrawal of support, as many healthy people have a great need to avoid identifying with a cancer patient (Jennings, 1982; Peters-Golden, 1982). This stigma, felt both within the patient and in society, is one of the central problems of the cancer sufferer (Fobair & Mages, 1981), who may be seen as being consumed alive (Kahn, 1978), evoking physical aversion and disgust (Peters-Golden, 1982).

Fear of cancer, however, is not purely 'lay ignorance', but is also a reflection of the problematic nature of the illness itself (Rosser, 1981). Just as the course taken by cancer is unpredictable, so is its response to treatment (Kerson & Kerson, 1985). This uncertainty can be a very important stressor for cancer patients (Pruyn, van den Borne, & Stringer, 1986), as unpleasant treatments with feared side effects come with no guarantee, and even "cured" patients are constantly monitored for recurrence. The uncertainty caused by the ambiguities of cancer can leave patients stressed and anxious (Morris, Blake, & Buckley, 1985), and perhaps more susceptible to complications of the disease and treatment as a result (Kusinitz, 1986).

Breast cancer

In 1982 the American Cancer Society stated that 1 in 11 women would develop breast cancer (Timko & Janoff-Bulman, 1985; Holland & Jacobs, 1986). It is the most common malignancy amongst women in the western world. Empirical research, clinical observations, and anecdotal reports suggest that breast cancer has more psychosocial impact than any other cancer (Meyerowitz, 1983). However, the risk of dying from breast cancer is less than 1 in 27 (Osteen, Henderson, Costanza, Wood, & Harris, 1986).

A woman's reaction to breast cancer and to mastectomy will depend considerably on her self-image before the operation (Goldberg, Stolzman, & Goldberg, 1984), and will be influenced by factors such as past experiences with cancer, age, cultural background, and the strength of her present relationships. Whilst most cancer patients develop the required adaptational resources, there appears to be a significant minority who experience high levels of distress (Farber, Weinerman, & Kuypers, 1984). Although an excess of anxiety can be debilitating, a certain amount is adaptive in that it motivates action towards adjustment (Klein, 1971). There are two kinds of anxiety distinguished in the literature: trait anxiety, a fairly stable personality factor indicating the propensity to become anxious; and state anxiety, a more fluctuating measurement of current anxiety (Newman, 1984; Spielberger, 1983). State anxiety is more likely than trait to be affected by a diagnosis of cancer (Temoshok & Heller, 1984).

Many studies have found breast cancer and its treatments to be psychologically traumatic for even the most stable woman (Meyerowitz, 1980). For many it represents a dreaded assault on the body (Leventhal et al., 1986), possibly awakening feelings of unworthiness, depression, and self-consciousness (Achte et al., 1986; Maguire, 1985c), and disrupting self concept and sexual identity (Derogatis, 1986). Feelings of guilt and anger may be transposed to other members of the family, straining the marriage relationship and also the relationship between mother and daughter (Jennings, 1982).

As western society tends to see the breasts as the ultimate signs of femininity (Maddison, 1976; Mantell, 1982), women faced with mastectomy have to cope with two major problems--the diagnosis of cancer and the loss of physical appearance (Tanner, Abraham, & Llewellyn-Jones, 1983). The experience of mastectomy may cause significant changes to life-style, and mar the quality of life for decades (Maguire, 1985d).

Most interpretations of women's emotional reactions to mastectomy revolve around the assumption that the loss of a breast threatens their sense of femininity (Holland & Jacobs, 1985; Timko & Janoff-Bulman, 1985). Some studies have found body image problems to predominate, with patients feeling less feminine and becoming preoccupied with how they appear to others and whether they are still acceptable (Katz, Weiner, Gallagher, & Hellman, 1970; Maguire 1985a; Polivy, 1977). Some women focus on their body as presented to the outside world and, with a good prosthesis, their self-image may well be restored. But for others, their body image is drastically changed following a mastectomy, regardless of the prosthesis (Ray & Baum, 1985). Special problems may also arise for women not in a stable relationship, as they may be discouraged from intimacy through embarrassment or a heightened fear of rejection. Other studies have found anxiety to be more related to the fact of having had cancer than the surgery used to treat it (Sanger & Reznikoff, 1981), and the predominant concern of the breast cancer patient to be with life and death (Peters-Golden, 1982; Worden & Weisman, 1977). However Rosser (1981) suggested that the two problems--having had a life threatening disease, and adjusting to the surgery--may be interrelated. That is, the response to the loss of a breast may be a reflection of beliefs about the efficacy (or otherwise) of the surgery in controlling the cancer.

Winick and Robbins (1977) claimed that the more mutilating the operation for breast cancer, the greater the psychological morbidity. Dean, Chetty, and Forrest's (1983) research into the effects of reduced psychosocial morbidity after breast reconstruction led them to suggest that less extensive surgery may result in less morbidity. Others, however, disagreed with the view that increased morbidity came with increased surgery (Greer & Moorey, 1987), as lumpectomy patients were sometimes concerned that the cancer had not all been removed and so worried about having received the "wrong" operation (Fallowfield, Baum, & Maguire, 1986).

Dean (1988) summarized some of the above views, concluding that overall psychological morbidity appeared to be reduced when women's preferences regarding the type of surgery were considered. This was supported by Morris and Ingham (1988), who compared the psychosocial adjustment of 20 women who had a choice of surgery (seven chosing mastectomy) with 10 who had a mastectomy, and found that having a choice was more important to adjustment than was the type of surgery performed. However, this in itself surely creates a different set of problems: treatment options are presented together with the information that (a) none offers 100% protection and (b) there is no clear indication as to which is most likely to prevent a recurrence. Depending on variables such as the size and position of the tumor and the size of the breast, some patients are given the choice of mastectomy, where the treatment is over sooner without the added possible side effects of radiotherapy; or segmental resection, which is less mutilating but which is accompanied by radiation. In the past the weight of medical opinion has been in favour of more rather than less extensive surgery (Ray & Baum, 1985), and so some women may fear that in nominating the latter they may be compromising survival for the sake of appearance (Faulder, 1985). Patients may also decide whether or not to accept the recommendations for adjuvant treatment following surgery (Kaplan, 1982). But any decision is subject to anxiety, self-doubt, and perhaps guilt, which adds more stress to an already problematic situation (Holland & Jacobs, 1986). Some people prefer to let others handle things, and so giving choices to such people may only serve to increase their stress (Folkman, 1984).

It seems contradictory to save a life by surgery and then not to provide the emotional support required to accept an altered body. In the past the outcome in cancer treatment trials was judged by survival and not quality of life, where quality of life is defined as both emotional and physical wellbeing (Greer, 1984). However, increased attention is now being paid to this latter aspect, as the psychological status of the patient can be an important factor in determining physical health (Derogatis, 1986). Emotion is the crucial link between psychosocial interaction and the neuroendocrine changes which can induce physiological abnormalities, possibly resulting in illness or, at least, retardation of recovery (Henry, 1982; Jemmott & Locke, 1984).

All physical outcomes short of mortality are also measures of psychosocial adjustment, (e.g. curtailment of activity, sleeping disturbances, and pain), and these affect illness behaviour, such as the number of visits to the doctor.

Stress induced by an assessment of a situation, together with an appraisal of available resources, can evoke feelings of helplessness and increased vulnerability, giving rise to anxiety and later depression. As Greer (1984) stated, the mind and body can be powerful allies in the fight for life, and patients may be lost through depression and lack of the will to live.

The term "psychosocial morbidity" describes the nature and intensity of distress experienced by cancer patients (Cohen, 1982). This morbidity is evident from anxiety, depression, and sexual problems, and has been found in many studies of breast cancer patients (Maguire et al., 1978; Rassaby & Hill, 1983). Yet up to 80% of this distress goes unrecognized (Maguire, 1985b), and this is partly due to patients not communicating psychological problems as they believe they are not their doctors' concern, or they don't want to be seen as inadequate. This lack of recognition of emotional problems is also partly due to doctors either assuming that patients with such problems will disclose them, or using "distancing tactics" to keep the focus away from these problems as they are unsure of how to deal with them (Maguire, 1985c).

Researchers have attempted to determine the time of greatest stress for patients. Hospitalization itself is stressful (Newman, 1984), and part of the anxiety generated at the time of surgery may be due to patients being separated from their family and familiar surroundings, and having to cope with hospital routine. Stam et al. (1986) cited studies indicating that for cancer patients the most stressful period was the first 3 months following diagnosis, as they have to cope with the shock of diagnosis, the surgery, and the beginning of treatment. Yet Ray and Baum (1985) claimed that only a few breast cancer patients saw the time immediately after surgery as the most stressful, as most were relieved that their surgery was over and the ambiguity resolved. This resolution of ambiguity, however, must be a temporary experience for many patients, as much has been written about the continuing stress caused by the unpredictability of the course of cancer and the efficacy of its treatments (Kerson & Kerson, 1985; Kusinitz, 1986; Molleman et al., 1984; Pruyn et al., 1986). Some see returning home as being the most difficult period, as the patient leaves the supportive hospital environment and attempts to re-establish normal routine (Froese, Hackett, Cassem, & Silverberg, 1974). Others put the most stressful time for mastectomees as later than any of the above, linking it with the relinquishing of denial and the resumption of normal life and "reality" (Polivy, 1977; Silberfarb et al., 1980).

It has been claimed that at least 20% of mastectomy patients become clinically anxious or depressed or develop sexual problems within a year of surgery (Maguire, 1985c; Maguire et al., 1978; Morris et al., 1977; Rosser, 1981). This emotional distress has been found to remain high for a year or more (Maguire, 1985a; Morris et al., 1977), and if not treated may impair daily functioning and cause family problems (Maguire 1985d). Most researchers found a lessening of distress as time from surgery passed (Cella & Tross, 1986). However, Polivy's (1977) results showed an increase in distress across time, together with a drop in self esteem at 6 to 11 months post surgery, which she attributed to the lifting of denial. Other researchers, however, found no prominence of depression or low self esteem amongst cancer patients (Penman et al., 1987; Silberfarb et al., 1980).

Holland and Jacobs (1986) described the stress reaction after surgical treatment of breast cancer as a form of normal grief, stating that patients who realize that they will probably feel more tearful, stressed, or depressed will adjust more readily. As the effects of depression, e.g., weight loss, constipation, lethargy, and sleep disturbance, may also result from the cancer itself or its treatments, it is often difficult to determine when depression is present (Silberfarb, 1988). Ray and Baum (1985) cited claims that the anxiety and depression evident amongst breast cancer patients is common to all cancer patients, and Greenberg, Abrams, and Cassem (1986) stated that even the severe depression claimed to have been found in 20% of cancer patients was no different from that found amongst general medical patients. Worden and Weisman (1977) found that the only response specific to mastectomy patients, when compared with other cancer patients, was an increase in emotional distress 2 to 3 months after starting treatment, and suggested that this was associated with the stresses of treatment and returning to normal routine rather than with breast loss. However, this suggestion is difficult to evaluate, as no details were given of the treatment received or for how long it continued. More recently prevailing conditions, such as patients having more say in their treatment; the trend towards breast conservation and reconstruction, and endocrine therapies; and the greater availability of information and support groups, are aimed to help patients to adjust.

Self esteem, which has been found to be negatively correlated with anxiety and depression (Greer & Burgess, 1987), is often an unstable measure, being affected by personal expectations and the expectations of others (Worden & Weisman, 1977). Thus serious illness, by threatening one's sense of identity may also threaten self esteem (Wood, Taylor, & Lichtman, 1985). Jamison et al. (1978) deduced from their data that younger women suffered more from the psychological effects of mastectomy than did older women. However, their subject pool was small (45 years or older, n = 25; under 45, n = 16), and measurement of emotional adjustment was comprised of (a) whether professional help had been sought for psychological problems relating to mastectomy, and (b) subjective ratings of post-mastectomy emotional adjustment on a 7-point scale ranging from excellent to very poor. It is probable that younger women were more open to professional psychological help, as 10 years ago this was less generally accepted and would have met strongest resistance from the older generation. Also, those receiving psychological help would be more comfortable with acknowledging their emotional problems. If this was the case, then the two measurements of emotional adjustment would have been both confounded and biased. Smith, Redman, Burns, and Sagert (1985) claimed that older women suffer less from cancer as they have developed a more philosophical outlook towards life, have more experience in adjusting to crises, and have had a longer time to build "durable sources of support" (p.77). However, this last claim is surely doubtful, as women move into old age and their friends die.

Reasons why research findings differ from each other may be the result of different measures used, or the way in which assessments were made (Stam et al., 1986). For example, researchers who use subjective case studies and small groups will no doubt have findings quite different from those who use objective mail surveys with large populations, especially if they are working with different variable definitions and measurements (Cella & Tross, 1986). Hence two studies may purport to be examining the same thing, but on closer scrutiny they may be seen to be so different that the results could not be expected to agree with each other. Research undertaken by Jenkins, Hurst and Rose (1979) indicated significant differences in reporting life change events as time from the events passed. This led them to dispute the reliability of event recall of 6 months or more, especially in the area of life change and illness, and points to the advisability of using prospective studies where possible. Further, the validity of measurements sometimes changes according to use. For example, psychiatric scales which include lack of sleep or appetite would not be valid measures of depression in cancer patients as these symptoms may also be due to the disease or its treatment (Derogatis & Spencer, 1984). Therefore the only effective way to separate the psychological responses from the somatic effects of cancer and its treatments is by long-term prospective studies on patients with early cancer as opposed to advanced disease (Greer, Morris, & Pettingale, 1979).

Summary

Cancer is a disease that evokes widespread fear in the community. This is probably due to its association with death and also the uncertainty both of the disease itself and the efficacy of its treatments. Treatment for breast cancer is either by mastectomy or by less extensive surgery and radiotherapy, but both of these options have their drawbacks. The first of these treatments may leave patients with self-image problems, whilst the second is more time-consuming and tiring and may leave some patients with the (medically unsubstantiated) worry that all of the cancer has not been removed. Research has shown that many breast cancer patients are susceptable to post-surgery psychological morbidity, yet a great deal of this goes unrecognized. Therefore it is important that psychosocial factors be included when considering the outcome of treatment given for cancer, as these factors can be important in determining physical health.

CHAPTER 3

Social Support and Cancer

Social support is a key concept to understanding psychological responses to severe stress. This chapter reviews some of the relevant research findings in this area.

Theoretical perspectives

Psychological theories which may be useful in predicting help-seeking behaviours and the psychological effects of receiving support are Attribution, Coping, Equity, and Social Comparison.

Attribution Theory "assumes that people attach causes and intentions to events in order to get control" (Pruyn et al., 1986, p. 50), and so may be useful in predicting reactions to help. Attribution theory also emphasizes the importance of recipient views on (a) the intentions of the support-giver and (b) oneself as support-receiver, and notes the necessity for congruence between the support models of the giver and receiver if the benefits of support are to be optimised. However, attributions about the intent of the support-giver are not usually made when that person's role prescribes the giving of aid (Fisher, Nadler, & Whitcher-Alagna, 1983), e.g., attributions are not made when surgeons perform surgery, but may be made when empathic support is offered by this source. Attributions about oneself as a receiver of help, i.e., internal attributions, may affect self esteem. Gross, Wallston, and Piliavin (1979) suggested that internal attributions of failure may be made when aid was sought rather than offered, and this may inhibit help-seeking behaviour. Therefore if attributions about (a) the giver of help, and (b) oneself as the receiver, are such that will enhance rather than threaten self esteem, then such help will be more readily accepted.

Coping Theory. Coping is a transactional process, determined by the relationship between the person and the environment (Stewart, 1989), and will be discussed in detail in Chapter 4. In the context of social support, coping theory focuses on the perspective of support as an element in appraising the potential of an event to cause harm and the availability of resources to combat this. Social support can affect Lazarus primary appraisals (assessing the meaning of a stressor) by assisting in understanding a potentially stressful event. This can be done by seeking information and by observing role-models (someone who has faced a similar stressor) and learning from that person's attitudes. Similarly, social support can affect secondary appraisals (assessing one's ability to deal with the stressor) by assisting in understanding what resources are available. This can be done by encouraging adaptive responses, by giving information about resources, or by role-models' identifying alternative problem solving techniques. Social support may also function directly as a coping strategy through the receipt of emotional, informational, or tangible support, or through reassurance. Such support would be an instance of "socially mediated coping" (Stewart, 1989, p. 1277). The practicality of coping theory is illustrated by self-help groups which assist in primary and secondary appraisals through the giving of information and through role-models.

Equity (Social Exchange) Theory describes social support as an exchange of resources (Shumaker & Brownell, 1984). This theory indicates the costs and benefits to both giver and receiver of support, with respect to reciprocity and feelings of indebtedness. Here, as with attribution theory, it is important that the support models of the giver and receiver are congruent, in order to allay feelings of resentment or the undermining of self esteem. This has implications for the ongoing relationship between the giver and receiver of help (Gross et al., 1979). Equity theory claims that the amount of distress experienced by the recipient will be positively related to that person's perception of the inequity (Fisher et al., 1983). This will affect help-seeking, as one who is unable to reciprocate will be less likely to ask for assistance. However, equity theory allows for the different "balance" in reciprocity when support is received from (a) professionals, (b) friends or acquaintances, and (c) close confidants, respectively. Reciprocity is much less formalized between intimate friends than with acquaintances, whilst monetary payment serves to restore equity when assistance is received from formal sources such as health professionals (Winefield, 1987). Self-help groups are an example of the practicality of equity theory, as they promote mutual support and encouragement and enable participants not only to receive but also to give.

Social Comparison "is the tendency of people to evaluate themselves and to elicit information about their characteristics, behavior, opinions, and abilities through comparison with similar others..." (Stewart, 1989, p. 1278). This strategy is most commonly used in resolving ambiguous situations and dealing with uncertainty. Upward comparisons (comparisons with those who are considered to be adjusting better than oneself) provide a role-model for coping, whilst downward comparisons (comparisons with those adjusting less well than oneself) enhance self esteem. Social comparison can influence primary and secondary apraisals through modelling and so may lead to reappraisals. In this manner social comparison theory is similar to coping theory. Social comparison theory assists in the interpretation of aid, i.e., whether it will be viewed as enhancing or threatening self esteem, and hence whether the individual will be likely to request support or not. One of the most obvious uses of social comparison can be found in self-help groups, where people facing similar crises gain mutual support through the resolution of ambiguity by sharing feelings, information, and coping strategies.

All of the above psychological theories help to clarify conceptual issues regarding the costs and benefits of social support, and assist in interpreting recipient evaluations of support. Attribution theory emphasizes the importance of recipient views of the intentions of the support giver; coping theory emphasizes the influence of support on recipient views of stressors and available resources; equity theory emphasizes the notions of reciprocity and indebtedness; and social comparison theory emphasizes the costs and benefits of comparing oneself with similar others. "Aid contains a mixture of self-threatening and -supportive elements" (Fisher et al., 1983, p. 64). It is possible to translate emphases from the above theories into whether the recipient will feel threatened or supported. If help implies that the recipient is inferior to, or dependent upon the giver, it will be viewed by the recipient as self-threatening. However if it shows a caring attitude it will be viewed as self-supportive. From this, predictions could reasonably be made as to the likelihood of a person engaging in help-seeking activity or accepting offers of help. Evidences of the use of these theories will be investigated.

The nature of social support

"Social support is in principle inherent in any interpersonal transaction" (Winefield, 1987, p. 633). Its territory has not yet been clearly defined (Coyne & Delongis, 1986; Orth-Gomer & Unden, 1987; Shisana & Celentano, 1987; Wortman, 1984). Definitions range from the global, in terms of social ties (Funch & Mettlin, 1982), to the multidimensional (Winefield & Neuling, 1987). Most current research focusses on two main components of support i.e., esteem-enhancing appraisals and practical aid (Heller, Swindle, & Dusenbury, 1986).

Walker, MacBride, and Vachon (1977) defined support networks as sets of "personal contacts through which the individual maintains his social identity and receives emotional support, material aids and services, information, and new social contacts" (p. 35).

Emotional support. This includes closeness with another person in whom the individual can confide and seek reassurance (Schaefer, Coyne, & Lazarus, 1981). It assures the individual of love and value regardless of achievement (Bloom, 1982a). The cancer patient has an intense need for emotional support, because the ambiguity of the disease, caused by possible spread and the uncertainty of treatment efficacy, results in fear and a loss of sense of control. One of the greatest fears of cancer patients in the early stages in the early stages of their disease is rejection or abandonment by the people to whom they were once closest (Wortman, 1984). This reflects the need for emotional support.

Tangible support. This involves direct aid, which may include loans, gifts of money or goods, and the provision of services such as driving the patient to an appointment or assisting with housework or babysitting.

Informational support. This helps to reduce the stress associated with threatening events, and is especially important in the early stages of cancer, as it provides a framework for appraisal. Patients are helped to organize their thoughts, as they come into contact with other people who may know of available help of which the patient is unaware. In this case, casual acquaintances may be more helpful than close friends or relatives, as they move in different circles and may therefore have different information from that which is normally available to the patient (Bloom, 1982a).

Social affiliation. This refers to the mutual dependence between people. Although this can provide opportunities to exchange information, obtain reassurance, and reduce feelings of isolation and loneliness, all of which have been mentioned before, the main function of this category is a mutuality, or reciprocity, which may act to reward and reassure both parties (Heller, 1979). Where reciprocity is not possible, the recipient may feel a burden of indebtedness, although this may not be the case when support is received from professionals, total strangers or very close friends.

Each type of support may be taken as evidence of others (Winefield, 1984). For example, tangible and informational support may also serve an emotional support function if they are a sign of caring (Schaefer et al., 1981). Further, as social interaction often involves mutual dependence, not only the recipient but also the provider may feel the benefit (Heller, 1979).

The social support system provides at least two types of feedback which assist in the maintenance of social identity (Bloom, 1982a). The knowledge that the experienced feelings are not unique but are common to others facing a similar situation, helps reduce the sense of isolation; and the knowledge of the appropriateness or otherwise of current behaviour patterns, reinforces the sense of identity and competence. Through discussing their plight with others who are sympathetic, cancer patients learn that it is quite normal to experience feelings of anger, depression, and fear, and this may be the first step in understanding what is happening and finding ways of coping with it (Dunkel-Schetter & Wortman, 1982).

It is important to view social support as a multidimensional construct, because of the possibility that each component may have independent effects on health and psychological functioning (Neuling & Winefield, 1988; Schaefer et al., 1981). When a threat is being appraised, informational support is required; whilst in time of bereavement, emotional support is most valued. The timing of support is also important, as needs change during the course of a crisis, and what may be appropriate at one stage may not be so later on (Walker et al., 1977).

The lack of valid and reliable measures of social support makes it difficult to compare research across studies (Lichtman & Taylor, 1986). If the definition of social support comprises multidimensionality, then research must tap this characteristic in order that measurement is related to theoretical perspectives. Although many recent researchers in this field have made some attempt to do this, research depending solely on global assessments such as network size and construction continues to be undertaken. Although it is reasonable to assume that with a large social network there would be more avenues for social contact, this does not answer questions regarding support. Recipient satisfaction with support is quite a separate entity from quantity of social interaction (Orth-Gomer & Unden, 1987). A stressed person may not feel able to tap social resources in time of need.

Social support and adjustment

Many studies have demonstrated that social support protects against illness and buffers its adverse effects when it does occur (Falke & Taylor, 1983; Winefield, 1982). Patients whose social support needs are met have more self-esteem and a higher level of emotional adjustment than those who lack this support (Peters-Golden, 1982). They also develop greater coping skills, which results in their suffering less emotional stress and having stronger feelings of control (Bloom, 1982b; Caplan, 1981). Lack of social support has been shown to contribute to physical illness and psychological pathology (Schaefer et al, 1981). However, research has not clearly indicated what it is about social support that makes people less vulnerable to illness (Bruhn & Philips, 1984). There is possibly both a main effect and a buffer effect mechanism (Orth-Gomer & Unden, 1987).

Social support may influence the occurrence of illness (Wortman, 1984). Those with adequate support may be more likely to engage in health-promoting behaviours; they may be encouraged to seek medical help before the problem becomes serious; or they may be protected from stress and so develop fewer stress-related illnesses. For example, Billings and Moos (1984) found that people with higher levels of social support experienced fewer negative life events.

Support may influence the initial appraisal of a stressful event. A stressful event is one in which demands are considered to exceed resources (Caplan, 1981; Lazarus & Launier, 1978). Therefore if the evaluation of demands is diminished, or if the evaluation of available resources is increased, so will the evaluation of threat be accordingly decreased. An event is a threat only if it is evaluated as such, therefore if other people provide information either about a situation or the resources available to help cope with it, this can influence the extent to which such a situation is stressful.

Social support may affect health and psychological functioning by its influence on coping mechanisms. This may occur by providing information on how to deal with a situation, or, more indirectly, by improving self-confidence. As a result the stressed person may take more control of the situation or may be less likely to develop depression. Support from others may also encourage a person to maintain coping efforts in times of extreme distress (Wortman, 1984).

The feelings of fear and helplessness generated by the uncertainty of cancer and its treatments results in the patient having an intense need for support. However, there appears to be a paradox for the cancer patient in that whilst social support is potentially a strong resource for adjustment, the disease of cancer interferes with its provision (Falke & Taylor, 1983; Peters-Golden, 1982). The stigma associated with cancer is felt both within the patient and in society, and the impact of cancer on the community reflects a lack of understanding (Gotay, 1984). This often leads to withdrawal of support. Some barriers to communication are self imposed, e.g. patients assume a cheerful facade so as not to stress those close to them; whilst other barriers arise because of reactions in loved ones (Lichtman & Taylor, 1986). Communication may force members of the cancer patient's social network to view their own helplessness in the situation, or even their own mortality. In order to avoid this threat, some may break off communication altogether, or at least avoid discussion of emotional topics. Further, many people fear interaction with those who may be depressed or anxious because they simply don't know what to say (Jennings, 1982). For the patient, therefore, being with others may become as distressing as being avoided, because the strain on communication may be seen as non-verbal rejection (Dunkel-Schetter, 1984). Patients may want to talk about their fears and anxieties, but avoid doing so in case this, in itself, would turn people away (Winefield & Neuling, 1987). It has been found that even with professionals many patients do not disclose emotional distress unless specifically asked (Greer, 1984).

Social interaction may also have stressful consequences (Revenson, Wollman, & Felton, 1983), which much research has tended to ignore (Innes, 1981). In fact, the amount of help provided has been found to be less important than the person who provided that help (Lieberman, 1986). Appropriate behaviour in one person may be quite inappropriate or even distressing in another. For example, information and advice is valued from medical staff, whilst it is often resented from family and friends (Dunkel-Schetter, 1984). Other behaviours from lay sources which have been cited as unhelpful were that of encouraging rapid recovery, being over-cheerful, and feigning identification with the patient's feelings (Lehman, Ellard, & Wortman, 1986). Thus there is a need to distinguish clearly between the number of relationships a person has and that person's perception of their supportive value (Schaefer et al., 1981). Quality of support has a stronger association with health outcomes than does quantity of social interaction (Billings & Moos, 1982; Winefield & Neuling, 1987).

Sources of support

The mere availability of support is not sufficient, unless the prospective recipient sees it as accessible (Weinberger, Hiner, & Tierney, 1986). Many patients, for example, are afraid to seek help from medical professionals for reasons to be discussed later. Further, when help is not received from the patient's preferred source, other sources may not be useful (Lieberman, 1986; Neuling & Winefield, 1988). In this respect, there is a need to consider the extent to which both the source of support and its frequency are related to recipient satisfaction. Some studies look at different components of social support and also different providers (Chesler & Barbarin, 1984), but do not specifically ask who provides what and in what quantities.

Natural support. This occurs spontaneously from close relationships, and is different from that which is sought from professional sources. Natural support is characterised mainly by its reciprocal and non-hierarchical nature (Rook & Dooley, 1985). This reciprocity can reward both the giver and the receiver of support (Heller, 1979). However, Greenberg (1980) noted that in cases where reciprocity was not possible, the recipient may feel the weight of obligation.

Family members and close friends are the most convincing source of empathic support for the cancer patient. In fact the reactions of intimate people may be critical to the patient's adjustment (Bloom, 1982a; Klein, 1971; Wortman, 1984). However, this may result in these support givers feeling somewhat overwhelmed by patients' needs and by their own lack of knowledge of how to meet these needs. Illness exerts a significant effect upon family members and close friends (Cohen, Goldenberg, & Goldenberg, 1977; Goldberg, Wool, Tull, & Boor, 1984), as they also feel threatened, not only by the possible loss of a loved one, but by thoughts of their own mortality. However, the literature suggests that, whilst communication problems may develop, most female cancer patients continue to receive support from their close relationships (Lichtman & Taylor, 1986).

Surgeons and medical staff. The surgeon has a key role in determining a patient's early adjustment to breast cancer (Klein, 1971). Informational and emotional support from this source is essential, as it is the only effective means of reducing uncertainty about cancer and its treatments (Winefield & Neuling, 1987). Although patients have a great need for informational and emotional support from the surgeon, many are afraid to seek this out. Some fear being seen by the doctor as neurotic or inadequate (Maguire, 1985c), whilst others fear appearing ignorant or taking up too much of the doctor's time (Eidinger & Shapira, 1984). To add to this, surgeons themselves feel a considerable amount of stress, not only in attempting to deal with the ambiguities of cancer (Amir, 1987), but also as they work out their relationship with patients, and decide to what extent they feel responsible for, and able to meet, their emotional needs (Ray, 1986). Because most patients are not qualified to assess their surgeon's technical ability, satisfacton tends to be based on the emotional and informational support offered (Ben-Sira, 1985; Dunkel-Schetter, 1984; Sechrest & Cohen, 1979; Winefield & Katsikitis, 1984).

Peers. Evidence suggests that when people are in extreme distress, those who have undergone a similar experience may be in a unique position to assist (Wortman, 1984). The Anti-Cancer Foundation of the Universities of South Australia provide support to breast cancer patients through the Breast Cancer Support Service, which is based on the American Reach to Recovery Program (Rogers, Bauman, & Metzger, 1985). Previous breast cancer patients visit current patients in hospital, give them a temporary breast prosthesis, and allow them to discuss any worries that they may have. This program has proved to be of benefit, mainly through the confidence instilled in patients by seeing someone who has been through a similar experience and who now lives a full life and looks "normal".

Another effective method of peer support is through groups which serve to introduce patients to similar others. Group counselling is one of the most potentially effective techniques (Ferlic, Goldman, & Kennedy, 1979), and is also economically attractive, making efficient use of limited staff (Rahe, Ward, & Hayes, 1979). Not only do participants gain from information made available to them, but they also receive emotional support from their peers, and learn coping strategies that have proved effective for others in a similar situation. Support groups enable patients to talk about their worries (Falke & Taylor, 1983), and so develop shared problem-solving techniques which result in an instillation of hope and a reduction of the feelings of helplessness (Spiegel, Bloom, & Yalom, 1981). The group is a safe place for the expression of concerns that the patient may be afraid to share with friends or relatives (Schwartz, 1977). The giving and receiving of help enhances self-worth and a sense of belonging, as the patient is no longer just a person in need, but is also a provider of information and support to others. Jennings (1982) claimed that a further benefit of cancer support groups was to create an awareness in the community that problems of cancer patients can be openly discussed, thus breaking down the stigma associated with cancer.

Admittedly the group situation is not for everyone, as not all experience significant psychosocial difficulties, and some people prefer to deal with their problems in other ways. Also, facing a group member who has had a recurrence may cause problems to some. Further, some people have difficulty identifying with cancer patients as they may be denying this reality in themselves. However, it has also been found that many who might benefit from the group situation do not attend because of lack of encouragement from doctors or family members (Falke & Taylor, 1983).

Counsellors. A number of studies indicate the lack of counselling felt by patients and their partners. Mathias (1984), an Australian mastectomee, related her problems in being a 'statistic', whilst Fobair & Mages (1981) reported that "patients with cancer may feel like bystanders in the medical setting as the physician uses multimodal attacks on the tumor, while inwardly they feel an enormous amount of stress" (p. 286). Research has shown that patients do not disclose emotional disturbances unless they are specifically asked (Battersby, 1977), whilst doctors assume that patients who need help will ask for it. Therefore a good deal of psychiatric morbidity amongst cancer patients is undetected (Maguire, 1985d). Wellisch (1984) noted cancer patients' need for psychiatric help, especially for depression.

Counsellors may assist patients through empathic understanding, by providing information or material aid, or by helping the patient to know where such aid can be obtained when necessary (Winefield & Neuling, 1987). A further benefit of counselling may well be the identification of those most at risk of psychosocial disorders (Maguire, Tait, Brooke, Thomas, & Sellwood, 1980). These people can then be referred to those who can help them, or support programs may be adapted to meet specific needs. Together with this may be the need for counsellors to assist patients to develop support elicitation skills. However, not all patients wish to discuss their problems, and research undertaken by Worden and Weisman (1980) indicated that some refused counselling, viewing the offer as a threat or an insult.

Support elicitation

The direction of causality between social support and adjustment needs clarification (Rook & Dooley, 1985). Some evidence favours the proposition that prognosis, coping, or prior adjustment can influence the amount of support received, rather than social support influencing adjustment (Wortman, 1984). Those who are poorly adjusted may underestimate the support available to them, and so not take advantage of it. Also, some patients do not effectively elicit care, respect or support (Winefield, 1984) and so, merely increasing the availability of support will not have the desired effect for these people. A person who is either self-reliant or who fears dependency may have less support than one who copes by actively seeking others for information, advice or company.

Many cancer patients are afraid to discuss their fears and feelings with their friends and relatives in case it upsets them. Further, they are afraid to discuss these problems with doctors and medical staff, as they fear their "unrealistic" worries may waste busy doctors' time, and result in eliciting a negative reaction from them. Winefield (1984) quoted Lorber's (1975) study of surgical inpatients where part of the description of a "good patient" was one who was stoical and uncomplaining, noting that it may be difficult to know how much complaining is adaptive when attention is required. Even when dealing with friends it takes a good deal of self-esteem and assertiveness to seek help, especially if one is unlikely to be able to return the favour.

Social support and coping

Caplan (1979) claimed that an important role played by social support was in helping (or perhaps hindering) people in their efforts to cope effectively. Empathic support enhances self-esteem and so leads to more positive coping responses; informational support assists in organizing coping responses; and tangible support dissipates some aspects of a stressor, so leaving fewer problems (Wilcox & Vernberg, 1985). Hence, social support might be usefully reconceptualized as coping assistance (Thoits, 1986). Conversely, the behaviour of an individual, in the form of social coping skills, affects the availability of support (Broadhead et al., 1983). Well-integrated individuals generally receive more assistance than those who are coping less well (Bruhn & Philips, 1984). From this can be seen the interdependent nature of social support and coping. Therefore, in order to understand the needs and responses of breast cancer patients, it will be necessary to study both of these aspects.

Summary

Cancer patients are subjected to a great deal of fear: fear of what the future may hold for them; fear of noxious treatments with unpleasant side effects; and fear of the reactions of their friends and family members. They are in great need of reassurance. They need to know that their surgeon has everything under control; that their family and friends will stand by them; and that they will be able to resume their responsibilities and look "normal". Many people, on being told that they have cancer, feel alone, angry, or depressed, or probably a mixture of these, and they need to be reassured that these feelings are common amongst cancer patients. Some patients will need information to enable them to cope with some of the uncertainties of cancer and its treatments. Others may require tangible support such as transport to radiotherapy clinics, or child care whilst in hospital. All of these forms of support have the potential to assist patients in coming to terms with what is happening.

However, fear of cancer is not confined to the patient. Close friends and family members also are prone to fear, with the result that they are sometimes hindered from giving patients the support and reassurance they require. Surgeons, also, are not immune from fear. Some surgeons who find it difficult to cope with patients for whom there is little that they can do, are unwilling to listen to their problems; some surgeons who do not like to admit that much about cancer remains a mystery to them, evade patients' questions about the future; and some surgeons who feel unequal to the task of listening to patients' fears, use "distancing tactics". This results in patients not receiving the support they need, and so suffering additional psychological distress.

As support is a key concept in understanding psychological responses to severe stress, it is important to take this wider framework into account. Therefore a high priority in this research was to develop a means of assessing social support which would capture its multidimentionality, and so to gain an understanding of its dynamics.

CHAPTER 4

Coping with Cancer

The other major mediating variable between stressful experiences and psychsocial outcomes which has been distinguished in the last two decades is the individual's coping skills. Therefore this chapter reviews relevant research findings in this area.

Theoretical perspective

Coping is a transactional process (Stewart, 1989), determined by the constantly changing relationship between the person and the environment. It arises from an evaluation that a potentially disruptive event may not be easily combatted by available resources, and is an attempt to deal with this.

Definition of coping

Definitions of coping vary greatly. "Coping remains the name of a file drawer, not a single theory, containing a variety of concerns" (Singer, 1984, p. 2310). Weisman and Worden's (1976) definition of coping as "what one does about a perceived problem in order to bring about relief, reward, quiescence, or equilibrium" (p. 3), is almost synonymous with adaptation; whilst Silver and Wortman (1980) include physiological responses and equate coping with responding: "any and all responses made by an individual who encounters a potentially harmful outcome....overt behaviors...

cognitions...emotional reactions...and physiological responses (e.g. nausea, sleep disturbances)" (p. 281), a definition which, particularly in the examples cited, may include outcomes which are far from adaptive.

Some researchers restrict the use of the word "coping". Ray and Baum (1985) claimed that coping is "directed toward the solution or mitigation of a problem" (p. 28), although this may not be a conscious direction, and added that "the term coping should not strictly speaking be used...to describe emotional responses that lack this purposive element" (p. 28). However, a non-consciously purposive response is problematic. They also stated that people cope "by using skills and habits that have been developed over a lifetime" (p. 28). This appears to be inconsistent with the views of Lazarus and Folkman (1984) who made a distinction between highly practised, almost involuntary, reactions and those which are more effortful, claiming that behaviours which "become automatized through the learning process" (p. 140) can no longer be considered as "coping".

However, Lazarus and Folkman's definition also presents problems. Two items in their "Ways of Coping" Checklist were "slept more than usual" and "tried to make myself feel better by eating, drinking, smoking...". These behaviours are more automatized than effortful, and therefore, by their definition, are not "coping". They also excluded "thoughts that do not require effort". Yet "wishful thinking", on their Checklist, surely needs very little effort. It is difficult to differentiate between effortful and effortless thought, and it appears that in effect, the nebulous nature of "coping" has merely been transferred to another equally nebulous area, with nothing being clarified by Lazarus and Folkman's views.

The study of coping should not be limited to responses resulting in successful adjustment (Kahn, Wolfe, Quinn, & Snoek, 1981; Silver & Wortman, 1980). Such a limitation often leads to equating "coping" with "mastery", but not all situations can be handled in this way. Whilst some responses are not helpful and some may be definitely harmful (e.g., denial, resulting in not seeking medical treatment), it is usually not true that certain responses are always "bad" whilst others are always "good". What may be useful at one time may be unhelpful at another (Moos & Schaefer, 1986).

Coping is sometimes confused with its effects. Folkman, Lazarus, Dunkel-Schetter, DeLongis, and Gruen's (1986) "Positive Reappraisal" category included "found new faith", "came out of the experience better than I went in", and "changed or grew as a person in a good way", all of which are descriptive of outcomes rather than of coping behaviour.

From the above, the most acceptable definition of coping is "what one does about a perceived problem in order to bring about relief, reward, quiescence, or equilibrium" (Weisman & Worden, 1976, p. 3). This definition is directed toward the solution or mitigation of the problem; does not confound the issue by distinguishing between effortful and automatized behaviours; is not limited to responses resulting in successful adjustment; and does not confuse coping with its effects.

Coping resources

A distinction should be made between coping resources, or that which can be mustered to assist in stress management, and coping responses, or the way in which these resources are utilized (Pearlin & Schooler, 1978). Coping resources include the following:

Belief systems. These affect the choice of responses (Moos & Schaefer, 1986). For example, one who believes it is degrading to appear needy is unlikely to seek assistance. Belief in the expertise of the doctor or the efficacy of treatment affects coping through increased sense of control.

Personal resources. Problem solving skills help with information seeking and understanding and using this information (Lazarus & Folkman, 1984). Social skills are invaluable when help or support from others is required. Good health and morale generate energy for coping.

Social resources. "Coping skills, motivation, and psychological comfort all depend upon the incentives and social support provided by the environment" (Heller, 1979, p. 373). The society in which we live shapes our belief system and most of our coping choices (Billings & Moos, 1982; Mechanic, 1974). A supportive family or confidant can provide information, tangible assistance, or emotional strength in times of stress (Wilcox & Vernberg, 1985). However, social support may hinder effective coping, in that supportive friends, on whom the stressed person relies, may render incorrect information resulting in a poor choice of coping response. Or they may encourage the use of palliative methods, such as smoking, which may run counter to medical advice.

Material resources. Those in a sound financial position, especially if they also know how to use this to advantage, are often able to increase their coping options (Lazarus & Folkman, 1984).

The specificity and multidimensionality of coping

Specificity. Each potential stress experience is responded to according to its specific meaning for the individual (Bard & Sutherland, 1955), and sometimes people react atypically to certain stressors (Ray & Baum, 1985). Therefore specific responses to particular stressors should be studied, rather than general coping style over a range of stressors.

Coping is "a function of continuous appraisals and reappraisals of the shifting person-environment relationship" (Lazarus & Folkman, 1984, p. 142). The situation is appraised and acted on, resulting in a change in the stressor or in the individual's subsequent reaction to it. This altered person-environment relationship is then appraised and acted on further. Moreover, the stressor presents different challenges over time. In breast cancer these may include finding a breast lump, having surgery and adjuvant therapy, and fearing recurrence. In addition, an individual's view of the stressor changes with time. For example, chemotherapy, initially viewed with fear, may be found not to be so bad once begun.

Multidimensionality. "Coping is not a single act but rather a constellation of many acts and thoughts, triggered by a complex set of demands that change with time" (Cohen & Lazarus, 1979, p. 225). If one response does not work then this should be varied. Therefore, "the greater the scope and variety of the individual's coping repertoire, the more protection coping affords" (Pearlin & Schooler, 1978, p. 18). When confronted with a serious illness there is a special need for a variety of responses, as one has to cope with physical, social, and psychological threats, together with environmental stressors imposed by hospital and treatment routines (Moos & Tsu, 1977). This may require a mixture of apparently incompatible responses, such as denying having the illness whilst at the same time carefully following medical instructions (Singer, 1984). For this to succeed, the patient must ignore the inconsistencies.

"There currently is a lack of well developed measures of cognitive strategies that consider the diversity of coping efforts used by people under stress" (Holahan & Moos, 1987, p. 11). Research into coping has the task of capturing the continuous movement between thoughts, feelings and responses. The only way to examine such a constantly changing process is by a longitudinal study which is process-oriented, concentrating on what the individual actually thought, felt or did, rather than what theoretically might have happened. Such research should also allow for people being unaware of the particular strategies they used (Silver & Wortman, 1980), by making questions and answer selections specific so that people can identify with them. Further, an individual will probably use a number of coping strategies at any one time, and so the only effective way to capture this process is by multiple measures.

The functions of coping

There are several functions of coping, which often exist side-by-side. The instrumental or problem-focused function is aimed at changing the objective stressor. This can be directed at the stressor itself (e.g. collecting information, considering possible solutions, and acting on these), or at the stressed person (e.g. learning new skills to combat the stressor). The palliative or emotion-focused function is aimed at regulating emotions (Baum, Fleming, & Singer, 1983), and includes all responses aimed at improving self esteem or viewing the environment less negatively. Moos and Schaefer, (1986) listed affective regulation, emotional discharge, and resigned acceptance in this group. The reappraisal function "serves to modify the meaning and comprehend the threat aroused by a situation" (Moos & Schaefer, 1986, p. 14). Reappraising a stressor may be achieved by ignoring stressful aspects; whilst reappraisal of resources includes changing personal characteristics which impede adjustment, or redefining goals or beliefs which are no longer viable. Pearlin and Schooler (1978) phrased this as "cognitively neutralizing the threats" (p. 6).

Although these three functions may seem well defined, examples are sometimes difficult to classify, as the following examples illustrate:

1. Pearlin and Schooler (1978) cited "avoid confrontation" as an example of EMOTION FOCUSED coping; Thoits (1986) claimed that avoiding or leaving the stressful situation was an example of PROBLEM FOCUSED coping; whilst Moos and Schaefer (1986) included avoidance or denial in REAPPRAISAL.

2. Pearlin and Schooler (1978) cited "count your blessings", "we're all in the same boat", and selectively ignoring that which is noxious as examples of cognitively neutralizing the threat (REAPPRAISAL); and "take the bad with the good" and "everything works out for the best" as examples of controlling the stress (EMOTION FOCUSED). These two functions are extremely difficult to separate on these examples.

3. Billings and Moos (1981, 1984) listed "prayed for guidance and strength" under EMOTION FOCUSED coping in 1981 and under PROBLEM FOCUSED coping in 1984, with no reason given for the change.

4. Some researchers did not view reappraisal as a category on its own. Singer (1984) claimed it is an instrumental (PROBLEM SOLVING) function, whilst Lazarus and Folkman (1984) divided it between EMOTION FOCUSED ("I decided there are more important things to worry about", "I decided I didn't need him nearly as much as I thought") and PROBLEM FOCUSED functions ("shifting the level of aspiration, reducing ego involvement, finding alternative channels of gratification").

Although these functions will often be mutually facilitative, they may sometimes conflict: for instance, an EMOTION FOCUSED response (denial) may prevent a PROBLEM

FOCUSED response (seeking medical treatment). Also, coping responses may serve more than one function, thus making it difficult to determine their main focus. When problems are solved, emotions are often regulated; and when emotions are regulated, problems are often solved. Therefore functions should be viewed as general guides rather than rigid divisions (Lazarus & Folkman, 1984).

Coping modes

"Efforts to classify coping responses into clusters or categories are at a preliminary stage, and no consensus has yet emerged" (Billings & Moos, 1984, p. 879). Folkman and Lazarus (1980) devised a "Ways of Coping" Checklist, revised it in 1985, and used it to rate a group of students coping with a college examination (Folkman & Lazarus, 1985); and to rate a group of middle-aged married couples on a wide range of stressors (Folkman et al., 1986). Factor analysis in these studies resulted in six and eight scales respectively, but these were not entirely consistent, as the following examples show.

1. The Confrontive scale (Folkman et al., 1986) included "Did something which I didn't think would work, but at least I was doing something". This item does not appear to involve Confrontive strategies.

2. "Let my feelings out somehow" was included in the Confrontive scale in 1986, and in Seeking Social Support in 1985, yet this may be the antithesis of confrontation, and does not seem to concern social support.

3. "I prayed" was listed in Seeking Social Support in 1985 and in Positive Reappraisal in 1986.

4. The 1986 study put "tried to forget the whole thing" into Distancing, and "refused to believe that it had happened" into Escape-Avoidance. The distinction between Distancing and Escape-Avoidance is difficult to make.

5. Coyne, Aldwin, and Lazarus (1981) used factor analysis on the same Checklist, and their Help-Seeking and Avoidance category included apparently conflicting responses such as "avoided being with people" and "sought advice".

6. Coyne et al. (1981) also included "thought about fantastic or unreal things which would solve the problem" in Help-Seeking and Avoidance, yet this would fit more comfortably in their Wishful Thinking category.

Groupings may also be devised theoretically and based on logical divisions, but as yet there is no agreement as to which set of groupings is most useful. Molleman et al. (1984) used four modes: ego defensive (adopting a passive attitude or avoiding thoughts about the stressor); social (seeking help from others); self instruction (adopting an active attitude which may not be apparent to others); and direct action (impulsive behaviour). Lazarus and Launier (1978) and Folkman, Schaefer, and Lazarus (1979) also used four modes, but different from the above: information seeking; direct action; inhibition of action (not engaging in impulsive or ill-informed acts); and intrapsychic defences. Cohen and Lazarus (1979) added turning to others for help and support to these.

Billings and Moos (1981) used a combination of cluster analyses, judges' ratings and previous research to arrive at three groups: avoidance/denial, active cognitive coping, and active behavioural coping. This system is described in some detail, because it was used as the basis of coping strategy groupings in this thesis.

Avoidance/denial covers a wide spectrum (Breznitz, 1983), and "is obviously a much overworked term with an underlying construct that needs clarification and specification" (Goldberger, 1983 p. 84).

Billings and Moo's (1981) avoidance group comprised two strategies: indirect efforts to reduce tension, e.g., smoking or drinking more than usual, and a refusal to confront the problem actively. An example of this latter strategy was given as "prepared for the worst" (p. 141), but it is conceptually difficult to include this in avoidance.

Most researchers agree that at least partial denial of the possible full implications of breast cancer can be beneficial in the initial stages (Bloom, 1986; Greer et al., 1979; Watson, Greer, Blake, & Shrapnell, 1984). Initial temporary denial provides time to ward off anxiety (Achte et al., 1986) and so protects until other forms of coping can be mustered (Polivy, 1977; Ray & Baum, 1985). However, denial of symptoms may be maladaptive before diagnosis, (e.g., ignoring a breast lump), and its continual use may hinder long-term adjustment.

Active cognitive coping is comprised of self-instructive strategies. This may entail treating the illness as a challenge, making optimistic comparisons such as thinking how much worse things could be, or generally looking on the bright side. Many people in stressful situations compared themselves with others in order to evaluate their reactions (Jenkins & Pargament, 1988; Taylor, 1983; Wood et al., 1985). The tendency was to make comparisons with those in a worse position or those who were not as well adjusted in order to enhance their own self esteem. Alternatively, active cognitive coping may include using a strong person as a model for handling the situation. Or it may involve accepting some responsibility for what has happened and perhaps thinking about how to act differently in the future. Molleman et al. (1984) found self-instruction, which is equivalent to cognitive coping, to be the most useful strategy against the uncertainties of cancer.

Active behavioural coping consists of overt attempts to control the problem or to control emotional reactions. This includes strategies such as information seeking, which lead to reappraisals. Gathering information is a way of establishing control (Ray & Baum, 1985), and is often effective in cases of ambiguity. However, it may be maladaptive when little can be done to change the situation (Cohen & Lazarus, 1979).

It is important to determine the source of information when considering its effect on adjustment. Social support research has indicated that information and advice were more appreciated from professional sources than from friends and relatives (Dunkel-Schetter, 1984). Further, some people prefer to let others handle things; to give information or increased choice to such people may cause them additional stress (Folkman, 1984).

The choice of coping responses

The individual's view of a stressor determines the strategy used to combat it. Believing something can be done results in problem-focused coping; whilst believing the situation must be accepted results in emotion-focused coping (Coyne, et al., 1981; Lazarus & Folkman, 1984). Also, viewing a stressor as a challenge encourages power and control, whilst viewing it as a threat may result in passivity and possibly helplessness.

Level of stress is another factor affecting strategy choice. Excessive threat interferes with information processing (Lazarus & Folkman, 1984). For example, patients adjusting to a diagnosis of serious illness may not take in information regarding treatment (Peck & Boland, 1977). However, Lazarus and Folkman distinguished between this inability and denial, "which also characterizes the response to threatening information" (p. 168). Yet surely this temporary interference with information processing could be a result of temporary denial.

Silver and Wortman (1980) questioned the advisability of keeping distress within manageable limits. Some research suggested that distressed individuals survived longer (Derogatis, Abeloff, & Melisaratos, 1979), or were less likely to suffer relapse (Rogentine et al., 1979). Perhaps distress safeguards people in some way, or motivates them to do something about their situation (Silver & Wortman, 1980). "Successful coping requires a balance between what one can accept and confront, and what can harmlessly be ignored or postponed" (Weisman & Worden, 1976, p. 13). When neither full acknowledgement nor full denial is really satisfactory, the perspective may shift according to the situation. This is described by Weisman (1972) as "middle knowledge".

Coping and adjustment

Adjustment is a multi-dimensional construct, and may refer to social, physical, or psychological wellbeing. As success in one of these facets may preclude another, a judgement must be made as to their importance. For example, a cancer patient may have the possibility of treatment with chemotherapy, radiation, and surgery. All of these treatments have side effects which may have a serious impact on quality of life. There may be a vast difference of opinion as to whether coping should focus on physical health and life span, or quality of life. Would the same judgement of coping success be made of a 80 year old who refuses chemotherapy, concentrating on quality of life for a shorter period of time, and a 25 year old patient with a similar diagnosis? The question of when it is reasonable to reject treatment and avoid side effects has no general answer, and illustrates that an evaluation of coping style is not independent of value judgements. Singer (1984) refered to this as the "criterion problem". Lazarus and Launier (1978) stated that "effective coping must strike a reasonable balance between these concerns" (p. 316), but this entails value judgements which may reflect on the evaluation of adjustment. "What is adaptive for one person may not be so for another, and what is appropriate in one situation may be inappropriate in a different context" (Ray & Baum, 1985, p. 37).

Successful adjustment can only be assessed by matching achievement against goals, and so personal satisfaction with adjustment depends on expectations. People sometimes help themselves in this by making favourable comparisons with others. However, "adaptive coping includes knowing when to stop trying to achieve a goal that is unattainable" (Lazarus & Folkman, 1984, p. 169). Coyne et al. (1981) demonstrated that coping patterns differed between depressed and non-depressed subjects, and this points to the unresolved question of whether ineffective coping causes depression or is the result of prior depression. Also, as coping responses are essentially chosen from the models provided by the surrounding social and physical environment (Cohen, 1982), a poor adjustment may be a reflection of the insufficiencies in the social system rather than of personal inadequacy (Pearlin & Schooler, 1978).

Care must also be taken in interpreting results as it is not easy to determine causal relationships between correlated variables. Felton and Revenson (1984, p. 350) found that the "unique effects of adjustment on coping proved approximately equal in strength to the unique effects of coping on adjustment". And Aldwin and Revenson's (1987) longitudinal survey of 291 adults who completed the revised Ways of Coping Scale for a self-named stressful episode, found coping and psychological symptoms to be interrelated, both affecting the other.

Summary

Research into the area of coping is by no means complete. Definitions of both coping and adjustment need to be carefully worked out. If coping is confused with adjustment, problems arise because both are multi-dimensional constructs. Adjustment may refer to physical, social, or psychological well-being. Coping may be directed towards the stressor itself in an attempt to modify it, or may be directed towards the stressed person in an effort to learn new skills to combat the stressor or to control aroused emotions. If coping and adjustment are confused, incorrect evaluations may result. For example, an individual who rates life in terms of quality rather than quantity may decide against having noxious treatment and so may be rated as "not coping" by one who would have chosen differently. Likewise, coping must not be equated with mastery, as not all situations are amenable to this.

Coping attempts are influenced by resources such as belief systems, personality style, problem solving and social skills, and the availability of social and material resources. Coping responses are specific for each individual as they depend on the resources available and also the meaning of each stressor for that individual. Therefore successful adjustment depends on the individual's aim in coping, which may well change with changing circumstances and with continuing evaluations and re-evaluations of the stressor. This is the multidimensionality of coping--the true nature of coping that is yet to be fully captured by research.

SECTION II

STUDY 1

A 6-MONTH PROSPECTIVE STUDY OF BREAST CANCER PATIENTS

CHAPTER FIVE

An Overview of Study 1

Breast cancer affects 1 woman in 11 (Holland & Jacobs, 1986), and is the most common malignancy amongst women in the western world. The trauma it presents is both physical and psychological, as those affected have to contend with the uncertainties of the illness and its treatments as well as possible surgical disfiguration. There is little agreement amongst researchers as to whether breast cancer causes psychosocial morbidity. Although many have claimed to have found this (Maguire, 1985c; Rosser, 1981), some did not (Penman et al., 1987), whilst others claimed that any such morbidity was merely a form of normal grief (Holland & Jacobs, 1986). Some claimed that less extensive surgery decreased psychological morbidity (Dean, 1988), or that being given a choice in surgery or treatment could have this effect. There was likewise little agreement as to the cause of this morbidity, if it exists. Some found breast cancer patients to be preoccupied with physical appearance (Maguire, 1985a), whilst others found issues of life and death to be more problematic (Sanger & Reznikoff, 1981). However, there was general agreement with the principle that it is unsatisfactory to undergo surgery in order to live with very little quality of life.

Research into social support and coping has indicated that these two related areas may have some effect on psychosocial morbidity. Social support has been shown to have some protective or buffering effect against illness (Falke & Taylor, 1983). Each area of support, i.e., empathic, informational, tangible, and reassurance, has a specific value for the patient, as also does the source from which support is received. The way people deal with a stressor is also important, and this is often related to the support received.

The aim of this study, therefore, was to determine the physical, social, and psychological adjustment of recent breast cancer patients who had not had any previous life-threatening disease, and to evaluate their coping strategies and the support they (a) received and (b) required. The purpose was to determine how much (if any) psychosocial morbidity existed amongst breast cancer patients and to consider ways of alleviating this, such as through social support or the use of more productive coping strategies. In order to get accurate assessments, this research took the form of a prospective study, where breast cancer patients were given structured interviews in hospital within a few days of surgery and were then interviewed or sent postal questionnaires at 1, 3, and 6 months post surgery.

Hypotheses

1. There will be a positive relationship between anxiety and depression, and a negative relationship between self esteem and both anxiety and depression (Greer & Burgess, 1987).

2. There will be a lessening of anxiety and depression as time from surgery passes (Cella & Tross, 1986), and also a lessening in the number of cancer related physical difficulties experienced. At the same time there will be an increase in self esteem and social activity levels.

3. Uncertainty generates stress (Morris et al., 1985; Pruyn et al., 1986). Therefore patients who have less tolerance for ambiguity will be less able to cope with the "unknowns" of cancer and its treatment, and hence will become more stressed. This should lead to a positive correlation between both anxiety and depression and scores on the Intolerance of Ambiguity Scale.

4. Subjects whose support needs are met will have higher levels of psychological adjustment (Peters-Golden, 1982; Zemore & Shepel, 1989) and less physical illness (Schaefer et al., 1981) than those who lack this support.

5. The subject's perceived quality of support received will have a stronger association with health outcomes than will frequency of support received (Billings & Moos, 1982; Winefield & Neuling, 1987).

6. As the source of support is more important than the amount of help provided (Lieberman, 1986), patients will require informational support from their surgeons, but may resent this from non-professional sources (Dunkel-Schetter, 1984). This will be shown by subjects (a) being satisfied with significantly less information from family and friends than from surgeons, or (b) stating that they would have appreciated more information from surgeons and less from family and friends.

7. The husband's reactions to his wife's breast cancer may be crucial to her adjustment (Wortman, 1984). Therefore patients will require more empathic support from husbands and family members than from other sources. This will be shown by subjects either (a) receiving more empathic support from family members than from other sources, or (b) stating that they would have appreciated more empathy from their families.

8. As indicated above, specific kinds of support are required from the surgeon and family. Further, if help is not received from the source from which it is required, other sources may not be useful (Neuling & Winefield, 1988). Therefore, patients will be satisfied with less support from friends than from family members and surgeons.

9. There will be some non-materialization of expected support, as people have a fear of identifying with cancer patients (Peters-Golden, 1982). This will be noticed mainly amongst friends, as it is easier for them to avoid contact with the patient than it is for families.

10. Some patients, not wanting to worry people or to appear complaining, will impose barriers to communication with friends, relatives (Lichtman & Taylor, 1986), and doctors (Eidinger & Shapira, 1984; Maguire, 1985c). As a result, they will not receive the support they require. This will be indicated by a lack of satisfaction with support from these sources, together with comments as to why there was lack of communication.

11. The more coping strategies used, the less depressed and anxious the subject will be (Pearlin & Schooler, 1978; Moos & Tsu, 1977).

12. Rather than any one particular group of coping strategies being used more than others, subjects will either tend to use a wide range of strategies or else use few of any kind. This will lead to a high positive correlation between coping strategy groups (Aldwin & Revenson, 1987; Folkman & Lazarus, 1985).

13. There will be high positive correlations between coping and social support, indicating that these two variables are inter-related (Thoits, 1986).

Experimental variables

Control:
1. Demographic: age, religiosity, marital status, number of children, education, and employment.
2. Other stressful events.
3. Medical:
    - Pre-operative awareness of malignancy.
    - Time since surgery.
    - Type of mastectomy.
    - Adjuvant therapy given.
    - Reconstruction.
    - Public/private patient.
4. Intolerance of Ambiguity.

Dependent:
1. Psychological adjustment:
    - Anxiety.
    - Depression.
    - Self esteem.
2. Social activity level.
3. Physical adjustment:
    - Surgical complications.
    - Perceived recovery.
    - Resumption of activity.

Independent:
1. Frequency of support received and satisfaction with this frequency, from:
    - Family members.
    - Close friends and confidants.
    - Surgeon and medical staff.
    - Peers--other cancer patients.
2. Coping strategies.

Consultations about the questionnaire

A preliminary draft questionnaire was distributed to 14 surgeons, two nursing sisters (breast cancer ward supervisors), and three Anti-Cancer Foundation social workers, each of whom was later interviewed for a critical evaluation of the questionnaire's content and clarity. The questionnaire was then administered as an interview on three separate occasions with middle-aged women. Changes made as a result of this feedback and practice administration are noted in the relevant sections.

Ethical considerations

Approval was granted by the Human Ethics Committee of the University of Adelaide and the Research Review Boards of the Royal Adelaide Hospital, the Flinders Medical Centre, and Calvary, Ashford, Memorial, and St. Andrew's Hospitals. Surgeons were informed of the research, and patients were only approached with the prior consent of their surgeon. Patients were informed of the nature and aims of the research, and were also made aware that participation was voluntary and that they were free to withdraw at any time without prejudice to their treatment. A sheet explaining the above was given to patients and signed by them as an indication that they agreed to take part. (This explanatory sheet can be seen in Appendix A-1).

CHAPTER SIX

Adjustment to Breast Cancer in the Prospective Study

Method

Subjects

Subjects were all English-speaking breast cancer patients from the breast clinics of two large metropolitan teaching hospitals, the Royal Adelaide Hospital and the Flinders Medical Centre, between June-December 1986. No-one had had any previous life-threatening illness. Surgeons at these hospitals also allowed access to their patients in private hospitals.

Of the 60 women invited to take part, 59 agreed, but 1 was later excluded on the grounds of revised histology. At the 1 month follow-up 57 of the 58 took part; at 3 months 55 of the 57 responded; and at 6 months all of the 56 subjects contacted took part; thus the response rate over the 6 months was 98.3%.

The 58 subjects ranged in age from 34 to 82 years (median age 54), and 43 were married or living in a permanent de-facto relationship. Thirty-five subjects had a mastectomy (modified radical or extended simple), whilst the other 23 had less extensive surgery (i.e., simple local excision, wide local excision, or quadrantectomy). Thirty-six were public patients. Only 1 patient did not know that she had a malignancy before she went into the operating theatre;

5 patients knew of the malignancy only 1 to 2 days prior to their surgery; and a further 12 knew only 3 to 7 days prior to surgery. The other 40 patients had known they had cancer for longer than a week. Of the 35 who had mastectomies, 1 was bilateral, and 8 had immediate reconstructions. At the time of the first interview 20 subjects were already aware of the results of their pathology tests, and 5 of these had evidence of cancer spread, whilst 15 did not. One month later it was determined that a total of 17 of the 57 subjects had cancer spread. Adjuvant therapy was given to 33 subjects: 8 had chemotherapy alone; 5 had radiotherapy alone; 14 had hormone manipulation alone; 3 had both chemotherapy and hormone manipulation; and 3 had both radiotherapy and hormone manipulation. Radiotherapy was given on 5 days a week for 5 weeks, and chemotherapy was given for 3 months.

Distribution by "cancer staging" was not a part of this study. This was considered irrelevant as patients did not normally have this information and so it would not have influenced their perceptions in any way. However, patients were separated according to information readily available to them, i.e., nodal spread, type of operation, and recommended adjuvant therapy. This information was more likely to have influenced their attitude. Also, a control group was not considered a necessary part of this study, as the psychological scales used provided norms for various populations, and other studies (Gottesman & Lewis, 1982) have already done comparative studies using similar scales to the ones used in this study. The purpose of the present study was not to replicate studies previously done in determining the difference between breast cancer patients and normal populations, or between breast cancer patients and other patient groups, but to go from this to investigate, prospectively, the relationships between psychosocial adjustment, social support, and coping, in breast cancer patients.

Measures

Psychological adjustment

Anxiety was measured by the state-anxiety scale from the Spielberger State-Trait Anxiety Inventory, Form X. This consisted of 20 items, each evaluated on a 4-point scale, and has been shown to be sensitive to situational stress (Spielberger, Auerbach, Wadsworth, Dunn, & Taulbee, 1973). A high score indicated a high level of anxiety. Means and standard deviations for the state-anxiety scale were given by Spielberger as M = 36.03; SD = 11.07 for females aged 40-49, and M = 32.20; SD = 8.67 for females aged 50-69 (Spielberger, 1983).

Depression was measured by the Wakefield Self-Assessment Depression Inventory (Snaith, Ahmed, Mehta, & Hamilton, 1971). This consisted of 12 items, each evaluated on a 4-point scale, and measured feelings of depression rather than depressive illness. As the subjects were surgical rather than psychiatric patients, this was considered more suitable than a psychiatric instrument. A high score indicated a high level of depression. Mean depression score was given in the test manual as 6.75 for females. One minor change was made to the wording of this scale after the questionnaire was distributed for feedback. The words, "before my operation" were added to the item "I find it easy to do the things I used to". This change was made because it was thought that older subjects might compare what they could do now with what they were capable of doing in their younger days.

Self esteem was measured by the Rosenberg Self-Esteem Scale (Rosenberg, 1972, 1979; Wylie, 1974). This consisted of 10 items, each evaluated on a 4-point scale, with a score of 20 or above being regarded as extremely high self esteem, and 5 or below as extremely low (Gottesman & Lewis, 1982). A minor change made in this questionnaire after distribution for feedback was the addition of "at daytime" to "I feel anxious when I go out of the house on my own", as most women feel anxious when outside, alone, at night.

Social adjustment was assessed through the use of 7 items which have been found to indicate subjective health status during the early stages of recovery from serious illness (Winefield & Cormack, 1986). A high score indicated an active social life.

Physical adjustment was not assessed at the first interview, as all subjects were in hospital having recently undergone surgery. At the second interview subjects were asked 4 questions relating to surgical complications (i.e., healing of the wound, and weakness or stiffness in the arm due to axillary node sampling), and 12 questions specifically relating to discomfort or difficulty when performing tasks such as dressing, laundering and driving a car (Funch & Mettlin, 1982). A high score on this scale indicated a great number of physical difficulties. Subjects also rated, on a 4-point scale, the extent to which they had returned to their pre-operation level of activity. A change made to Funch & Mettlin's questionnaire, after distribution for feedback, was that the words "Please cross a line through any of the items below that you never do even when in good health", were added to the directions. This was to cater for those who never drive, do heavy cleaning, or wash their hair.

Control variables included demographic (age, religiosity, marital status, number of children, education, and employment) and medical (type of surgery undergone; whether or not there was any nodal cancer spread, or adjuvant therapy given; whether the subject was a private or public patient; and how long she had been aware of a malignancy prior to her operation). The Intolerance of Ambiguity Scale (Rump, 1985; Skene, 1983) was also included in order to determine whether subjects' ability to handle uncertainty affected their adjustment. This was an 18-item true/false scale where a high score indicated a high intolerance of ambiguity. Eleven items which seemed appropriate to breast cancer patients were also selected from Tennant and Andrews' (1976) Life Events Inventory. These applied to the subject and those close to her, and concerned events unrelated to having had breast cancer, and which had happened in the past month, or since the subject had known that she had breast cancer, whichever was the shorter. One positive event, "There has been a marked improvement in the way you and your husband are getting on", was included in this list.

Independent variables were: (a) the frequency of, and satisfaction with, social support; and (b) the coping strategies used. These will be discussed in detail in Chapters 7 and 8 respectively.

The most difficult cancer-related problem. Subjects were asked, at the time of surgery and at 1 and 3 months post surgery, to indicate which of five problems they considered to be the most difficult or troubling, and how stressful they had found this problem (Taylor, Falke, Shoptaw, & Lichtman, 1986). They were also given the opportunity to list a problem of their own if their most difficult problem was not one of those listed. A change made to this questionnaire after distribution for feedback was that the single item "limitations in physical ability, appearance or lifestyle due to cancer" was separated into the two items, "limitations in physical abilities or lifestyle due to cancer" and "change in appearance due to cancer". This questionnaire was not presented at 6 months post surgery, as by the 3-month interview many had indicated a lessening of stress and reported having trouble selecting a problem.

Reactions to taking part in the research. There is often some reluctance on the part of doctors to allow psychological studies to be undertaken with their patients for fear that it may upset them (Fallowfield, Baum, & Maguire, 1987b). For this reason, on completion of the last questionnaire, subjects were asked their reactions to taking part in the 6-month study, and were given the choice of three possible replies: "I wish I hadn't been asked, but someone has to do it";

"I feel I gained something positive for myself by the experience"; and "I really didn't care either way--I didn't mind doing them, but I also don't think I gained anything personally from them". Subjects were then asked for their motivation in taking part, and were given a choice of five possible answers: "To help other breast cancer patients"; "To show my appreciation for the care I have received from my doctor"; "To express thoughts and feelings that I didn't feel I could tell other people about"; "To make me feel less alone--the questionnaires helped me to believe that others were also having the same experiences"; and "I didn't really want to do the questionnaires, but didn't know how to say 'no' politely". There was also space for any other reason in case their motivation was not covered.

Procedure

The women were interviewed in hospital from 2 to 7 days after having had surgery performed for breast cancer, and were then followed up at 1, 3 and 6 months post-surgery with home interviews (if living in the inner metropolitan area) or with postal questionnaires. A copy of the four questionnaires can be seen in Appendices A-2 to A-5 inclusive. Interviews lasted 30-40 minutes. At the initial interview the interviewer wore a white hospital coat with an identification tag marked "research", and in introducing herself mentioned that she was a previous breast cancer patient.

As a validity check, a significant other--usually the husband, and always someone living in the same house--was asked for his or her opinion of the subject's physical and social adjustment 1 month after surgery, using the same questions and scales as was given to subjects. (This questionnaire can be seen in Appendix A-6). These questionnaires were posted with the subject's follow-up questionnaire, or were left at the house if the subject was visited. In cases where the subject lived alone, these questionnaires were not given. Forty-four of these questionnaires were given out and 36 (82%) were returned.

Statistical analyses

A total score for each measure was calculated for each adjustment variable after making the necessary reversals for negative questions. This method was also used to compute scores from the Rosenberg Self-Esteem Scale, in order to compare the results with those of Gottesman and Lewis (1982), who scored self esteem for breast cancer patients in this manner. However, as Rosenberg (1972, 1979) used "contrived items", Pearsons correlations were computed to ascertain whether there was any significant difference obtained between the two ways of scoring. Total adjustment scores were then analyzed by a multivariate analysis of variance (MANOVA) (SPSS Incorporated, 1983). Manova uses matrix algebra to examine multiple adjustment variables simultaneously, whilst preventing highly correlated variables from artificially inflating the *F* ratio (Sanger & Reznikoff, 1981). This program took into account the variability in time between interviews.

A repeated measures MANOVA program ascertained whether there was any relationship between any control variable and any of the adjustment variables. As the range of ages was 34-82, the mean age was 55.7, and the SD was 13.8, a cut-off point for the "old" group was made at 70 years of age (i.e., 1 SD above the mean) and a further division was made at 50 years of age (i.e., the median of subjects younger than 70). The effects of age, marital status, and type of surgery were investigated together from the time of surgery to 6 months post surgery. As the pathology results had not been received for most subjects at the time of the first interview, the effects of nodal cancer spread and planned adjuvant therapy were investigated from 1 month post surgery. These latter two variables were each examined separately in order to avoid confounding effects due to the interrelationships between them and the type of surgery given: no radiotherapy was given to any patient who had a mastectomy; and all patients found to have nodal cancer spread were given adjuvant therapy.

Planned comparisons computed on the MANOVA program determined the extent of any changes in adjustment variables over time. This was done by comparing adjustment variables as measured (a) at 1 month post surgery with those at the time of surgery; (b) at 3 months post surgery with the combined measurements taken previous to this; and (c) at 6 months post surgery with the combined measurements taken prior to this.

It was planned to use an Analysis of Variance in order to determine whether adjustment was adversely affected by any particular cancer-related stressor. However, as few subjects selected problems other than "fear and uncertainty about the future" as their most worrying concern, individual cell numbers were too small for computational analysis. Therefore, the means for all other problems were combined and Student's t-tests compared the means on adjustment variables for those who selected "fear and uncertainty about the future" with the combined means of subjects who chose any other problem. Then, as an indication of how aware subjects were of their stress levels, Pearson's correlations determined whether there was any association between subjects' evaluation of the stress generated by their most difficult problem and their anxiety and depression levels as measured on the scales.

For the follow-up questionnaires, 37 subjects living in the inner metropolitan area were interviewed whilst the other 21 received postal questionnaires. Student's t-tests indicated whether there were any response differences which may be accounted for by these different methods of presentation or by distance from hospital and surgeon.

Missing data. There was no missing data for any questionnaires administered by interview, with the exception of the Intolerance of Ambiguity Scale which some subjects found too difficult to understand. There was very little missing data in postal questionnaires, and where it did occur the subjects were contacted by telephone or the relevant pages were photocopied and re-sent to respondents, with the following exceptions: the Intolerance of Ambiguity Scale, which proved too difficult for some subjects, and the questionnaire on cancer support groups (Chap. 6), as so few attended these groups and many may not have had an opinion as to the important aspects.

Results

Student's t-tests computed as a check on response differences from postal questionnaires versus interviews demonstrated no significant difference in any of the adjustment variables either at the time of surgery, or at 1, 3, or 6 months post surgery.

Of the 20 subjects who were employed before having breast cancer, 3 had returned within a fortnight, and by 3 months 12 were back at work. Four subjects did not answer the question on returning to work.

The Intolerance of Ambiguity Scale had an alpha reliability coefficient of .28 with a corrected item-total correlation ranging from -.15 to .37. As this was not considered to be sufficiently reliable, the scale was excluded from further analysis.

Adjustment variables

In the validity check for responses on physical and social adjustment, Pearson correlations between subjects' replies and those of husbands were all significant at $p < .01$: perceived recovery $r = .53$; surgical complications $r = .50$; discomfort or difficulty $r = .81$; and social activity $r = .77$.

Table 6.1 shows the means and standard deviations on adjustment variables over the 6-month period.

Table 6.1

Means and Standard Deviations of Measures of Psychological, Social, and Physical Adjustment, as measured at each Interview

	In hospital (N = 58)		1 month post-op. (N = 57)		3 months post-op. (N = 55)		6 months post-op. (N = 56)	
	M	SD	M	SD	M	SD	M	SD
Anxiety	43.0	(13.9)	39.4	(12.2)	36.1	(11.9)	37.8	(11.9)
Depression	11.3	(7.8)	10.2	(7.7)	8.2	(7.0)	8.3	(7.2)
Self esteem	23.7	(6.1)	24.1	(6.0)	24.3	(5.9)	23.9	(5.4)
Social activities	9.1	(4.6)	9.3	(4.4)	10.2	(4.4)	11.2	(4.0)
Physical problems	--	--	10.7	(7.2)	4.3	(5.6)	--	--

Pearson correlations between total scores on the Rosenberg Self-Esteem Scale and "contrived items" were all significant at $p < .01$: in hospital $r = .89$; 1 month post surgery $r = .89$; 3 months post surgery $r = .86$; and 6 months post surgery $r = .73$. As the scores were so highly correlated, the total score was used in all computations.

There was a significant positive correlation between anxiety and depression and a significant negative correlation between self esteem and both anxiety and depression, as is shown in Table 6.2.

Table 6.2

Pearson Correlations Comparing Anxiety, Depression, and Self Esteem Measures at each Interview

	In hospital (N = 58)		1 month post-op. (N = 57)		3 months post-op. (N = 55)		6 months post-op. (N = 56)	
	depr.	s.esteem	depr.	s.esteem	depr.	s.esteem	depr.	s.esteem
Anxiety	.70 *	-.53 *	.87 *	-.65 *	.87 *	-.66 *	.89 *	-.57 *
Depression		-.54 *		-.66 *		-.64 *		-.66 *

* $p < .01$

Subjects' reported stress levels related to their most difficult problem were compared with anxiety and depression measures, and these were found to be consistently highly correlated, as shown in Table 6.3.

Table 6.3

Reported Stress Levels at each Interview, and Pearson Correlations Comparing these Stress Levels with Anxiety and Depression Measures

	In hospital (N = 58)	1 month post-op. (N = 57)	3 months post-op. (N = 55)	6 months post-op. (N = 56)
Slightly stressed	14 (24%)	30 (53%)	33 (60%)	43 (77%)
Quite stressed	20 (35%)	19 (33%)	16 (29%)	8 (14%)
Extremely stressed	24 (41%)	8 (14%)	6 (11%)	5 (9%)
Correlations between stress and:				
Anxiety	.66 *	.47 *	.51 *	.59 *
Depression	.48 *	.53 *	.46 *	.53 *

* $p < .01$

Planned comparisons demonstrated a significant decrease in anxiety across time when measurements taken at (a) 1 month post surgery were compared with those taken at the time of surgery, $F(1, 162) = 7.25$, $p < .01$, and (b) 3 months post surgery were compared with the two measurements taken prior to this, $F(1, 162) = 23.88$, $p < .01$. A significant decrease was also found in depression when measurements taken at (a) 3 months post surgery were compared with the two measurements taken prior to this, $F(1, 162) = 13.02$, $p < .01$, and (b) 6 months post surgery were compared with the three measurements taken prior to this, $F(1, 162) = 7.54$, $p < .01$.

There were no significant differences in measurements of self esteem across time. There was a significant increase in social activities when measurements taken at (a) 3 months post surgery were compared with the two measurements taken prior to this, $F(1, 162) = 4.73$, $p < .05$, and (b) 6 months post surgery were compared with the three measurements taken prior to this, $F(1, 162) = 17.72$, $p < .01$. The number of physical difficulties encountered decreased from 1 month to 3 months post surgery, $F(1, 54) = 9.10$, $p < .01$.

Table 6.4 breaks down the means for anxiety, depression and self esteem at the hospital interview according to whether biopsy results were known to the subject at the time of the interview or not; and, if known, whether there had been any evidence of cancer spread or not. None of these differences was significant.

Table 6.4

Means and Standard Deviations of Psychological Measures Taken at the Hospital Interview when not all Subjects Knew their Biopsy Results

	Results not known (*n* = 38)		Results known (*n* = 20)		Results known			
					Spread (*n* = 5)		No spread (*n* = 15)	
	M	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*
Anxiety	44.7	(13.5)	39.8	(14.2)	45.2	(17.0)	37.9	(13.4)
Depression	11.5	(7.3)	10.9	(8.8)	11.0	(7.5)	10.8	(9.5)
Self esteem	23.1	(6.5)	25.0	(5.3)	24.2	(5.8)	25.2	(5.3)

Table 6.5 breaks down the means for anxiety, depression and self esteem at the hospital interview according to age, marital status, type of surgery, nodal cancer spread or adjuvant therapy given.

Table 6.5

Adjustment Measures at each Interview, Showing Demographic Differences

In hospital	n	Anxiety M	Depres-sion M	Self esteem M	Social activ. M	Physical probs. M
Age:						
50 years or younger	23	42.3	9.8	24.6	10.3	--
between 50 and 70	24	45.3	12.7	22.3	9.0	--
70 years or older	11	39.5	11.0	24.8	6.8	--
Marital status:						
married	43	42.6	11.2	24.2	9.6	--
not married	15	44.2	11.5	22.2	7.6	--
Type of surgery:						
mastectomy	35	40.7	10.4	24.6	8.9	--
less extensive surg.	23	46.5	12.5	22.3	9.4	--
1 month post surgery						
mastectomy	34	38.4	9.7	25.0	9.2	12.1
less extensive surg.	23	40.8	10.8	22.7	9.5	9.3
Evidence of spread:						
no spread	40	39.4	10.0	23.9	8.9	11.4
spread	17	39.3	10.6	24.5	10.3	10.0
Adjuvant therapy:						
no therapy	24	38.1	10.2	23.5	8.6	12.5
† hormone manipulation	14	41.3	10.1	26.3	9.6	8.3
radiotherapy	8	39.0	9.3	20.9	10.8	10.9
chemotherapy	11	39.9	10.9	24.8	9.5	11.1
3 months post surgery						
mastectomy	32	33.7	7.1	25.7	10.7	4.8
less extensive surg.	23	39.5	9.6	22.3	9.6	3.6
Evidence of spread:						
no spread	38	36.3	8.2	24.0	10.0	4.7
spread	17	35.6	8.0	24.9	10.7	3.3
Adjuvant therapy:						
no therapy	28	34.3	7.4	24.4	9.8	4.5
† hormone manipulation	17	39.2	8.7	23.8	10.1	4.1
chemotherapy	10	36.0	9.2	24.7	11.8	4.1
6 months post surgery						
mastectomy	33	36.9	7.5	24.3	11.1	--
less extensive surg.	23	39.1	9.5	23.5	11.3	--
Evidence of spread:						
no spread	39	38.4	8.5	23.3	10.7	--
spread	17	36.4	7.8	25.4	12.4	--
Adjuvant therapy:						
no therapy	37	39.2	8.5	23.9	11.2	--
hormone manipulation	19	35.1	7.9	24.0	11.2	--

† Hormone manipulation included only those having this treatment and no other treatment at the stated time. Three subjects having radiotherapy and two having chemotherapy were also having hormone therapy.

The MANOVA program indicated that the control variables, of themselves, made no significant difference to any of the adjustment variables measured over the 6-month period. However, there was a significant interaction effect of age by marital status on depression at the time of surgery, $F(2, 47) = 4.4$, $p < .05$, as shown on Table 6.6. Also, there was no significant relationship between adjustment and the length of time a subject had known she had cancer; her pre-operative employment status; religiosity; or education.

Table 6.6

Cell Numbers and Means for the Interaction Effect of Age by Marital Status on Depression at the Time of Surgery

Age	Married		Not married	
	n	M	n	M
<50	20	8.8	3	17.0
50-70	20	12.5	4	14.0
>70	3	18.3	8	8.3

In response to the positive question in the Life Events Inventory, 18 subjects indicated a marked improvement in their relationship with their husbands. Nine first noticed this improvement at the time of surgery; three noticed it 1 month later; five at 3 months; and one at 6 months post surgery.

The most difficult cancer-related problem

Table 6.7 lists cancer-related problems together with the number of subjects choosing each one as their most difficult.

Table 6.7

The Number of Subjects Selecting Certain Cancer-Related Problems as their Most Difficult or Troubling in the Past Month

- I Fear and uncertainty about the future, due to cancer.
- II Limitations in physical abilities or lifestyle due to cancer.
- III Change in appearance due to cancer.
- IV Pain, symptoms, or discomfort from illness or treatment.
- V Problems with family or friends related to cancer.

	Problem number				
In hospital	I	II	III	IV	V
Nodal involvement (n = 5)	3	1	0	1	0
No nodal involvement (n = 15)	10	3	1	1	0
Awaiting results (n = 38)	32	1	0	4	1
Mastectomy (n = 35)	27	4	1	2	1
< mastectomy (n = 23)	18	1	0	4	0
Total (N = 58)	45	5	1	6	1
1 month post surgery					
Nodal involvement (n = 17)	12	1	1	3	0
No nodal involvement (n = 40)	26	6	4	4	0
Mastectomy (n = 34)	22	4	3	5	0
< mastectomy (n = 23)	16	3	2	2	0
No adjuvant therapy (n = 24)	13	6	3	2	0
Chemotherapy (n = 11)	5	1	1	4	0
Radiotherapy (n = 8)	8	0	0	0	0
Hormone therapy alone (n = 14)	12	0	1	1	0
Total (N = 57)	38	7	5	7	0
3 months post surgery					
Nodal involvement (n = 17)	11	0	1	5	0
No nodal involvement (n = 38)	24	6	4	4	0
Mastectomy (n = 32)	18	4	5	5	0
< mastectomy (n = 23)	17	2	0	4	0
No adjuvant therapy (n = 28)	16	6	4	2	0
Chemotherapy (n = 10)	4	0	1	5	0
Hormone therapy alone (n = 17)	15	0	0	2	0
Total (N = 55)	35	6	5	9	0

Table 6.8 gives the means when the sample has been divided according to the cancer related problem chosen as the most worrying over the past month. Student's *t*-tests compared the mean for subjects choosing problem I with the combined means of those choosing all other problems. Results indicated no significant differences at the time of surgery or 1 month later, but at 3 months post surgery those choosing fear and uncertainty about the future as their most difficult problem had significantly higher anxiety levels than those who were more worried about other problems, *F*(1, 53) = 5.29, $p < .05$.

Table 6.8

Psychological, Social, and Physical Adjustment Measures Associated with the Choice of each Most Stressful Problem

In hospital	*n*	Anxiety *M*	Depression *M*	Self esteem *M*	Social activ. *M*	Physical probs. *M*
Fear of the future	45	44.3	11.4	23.2	9.2	--
Limitations in abilities	5	38.0	15.2	22.6	9.2	--
Change in appearance	1	23.0	2.0	30.0	7.0	--
Pain or discomfort	6	43.0	8.7	26.3	9.2	--
Probs. with fam./friends	1	30.0	9.0	30.0	6.0	--
1 month post surgery						
Fear of the future	38	41.0	10.7	23.7	9.5	10.8
Limitations in abilities	7	37.0	9.9	21.4	9.4	13.7
Change in appearance	5	37.0	9.0	27.0	5.4	5.4
Pain or discomfort	7	34.4	8.3	26.7	11.3	13.1
Probs. with fam./friends	0	--	--	--	--	--
3 months post surgery						
Fear of the future	35	38.8	9.3	23.3	10.5	3.6
Limitations in abilities	6	34.3	7.3	24.2	7.7	9.2
Change in appearance	5	27.6	4.8	28.6	9.0	0.8
Pain or discomfort	9	31.7	6.1	25.7	11.8	5.7
Probs. with fam./friends	0	--	--	--	--	--

Reactions to taking part in the research

When subjects were asked for their reactions to taking part in the research over the past 6 months, 34 (61%) of the 56 who responded to this question said that they felt they had gained something positive for themselves by the experience; one subject said she wished she hadn't been asked; whilst the other 21 (38%) said they didn't care either way. The questionnaire on motivation was answered by 55 subjects, with five of them selecting two options. Table 6.9 gives the options and the number of subjects choosing each.

Table 6.9

Reasons Why Subjects Chose to Take Part in the Research

No. selected	Motivation
0	I didn't really want to do the questionnaires, but didn't know how to say "no" politely.
5 (9%)	I wanted to do the questionnaires because I was able to express thoughts and feelings that I didn't feel I could tell other people about.
11 (20%)	I was pleased to do the questionnaires because somehow they made me feel less alone--they helped me to believe that others were also having the same experiences.
21 (38%)	I wanted to do the questionnaires to help other breast cancer patients.
23 (42%)	I wanted to do the questionnaires because it was a way of showing my appreciation for the care I had received from my doctor.

During the course of this research, many unsolicited comments were made by subjects about (a) having cancer and (b) taking part in the research, and these, together with notes included with questionnaires, are recorded in Appendices C-1 and C-2 respectively.

Discussion

The response rate of over 98% for the four interviews taken over 6 months is extremely high. This may have been due to the fact that the researcher was a previous breast cancer patient, and introduced herself as such. Although the researcher took care not to be a support provider, there was obviously some element of patient identification, and it was of course quite impossible for the researcher not to be seen as a role model by at least some of the patients. Comments such as that from subject no. 45, "How good you were for me. You were wonderful, because you had been through it yourself. I don't have much time for people with questionnaires etc., who don't know what it's really like.", and also those from subjects 9, 14, 30, 32, 39, 40, 57, and 58 (Appendix C-1), indicate the unintentional support role played by the researcher. However, although this may have resulted in a high response rate, it is doubtful that it would have contaminated the replies in any way. This is indicated by the fact that when answers from those who were interviewed were compared with those who were sent postal questionnaires, there were no significant differences at any time in psychological, social, or physical adjustment. If anything, women who identified with the researcher may have been more honest in their replies, as they knew they would be understood.

Although many of the results did not reach statistical significance, definite trends can be found. This leads to the problem of how large a sample size would be required to demonstrate that true differences, when they exist, are significant. Sokal and Rohlf (1969, p. 247) provided a formula for this, which when applied to the results of depression as measured in the present study, indicated that a minimum of 84 subjects would be required in order to give a probability of .8 that a significant difference at $\underline{P} < .05$ level would be found when it exists. The same formula applied to the results of anxiety in the present study indicated that a minimum of 250 subjects would be required to demonstrate a significant difference at the same levels. The difference in the sample sizes required to indicate significance in the depression and anxiety scales respectively relates to the greater variability shown between subjects when measured on anxiety. Assuming that the true size of the effect is roughly as estimated from sample means in the present study, as the number of subjects interviewed was only 58, it can be inferred that there may well be significant differences which have not emerged due to the small sample size.

Responses to breast cancer

The comments (Appendix C-2) indicated that there were a variety of responses to breast cancer. Two subjects (Ss. 37 & 49) just wanted to put the illness behind them and get on with their normal routine. However, the sense of unfairness expressed overtly by subjects nos. 9, 16, 24 & 38 would no doubt be the experience of many (Achte et al., 1986), as part of the initial shock of having cancer. For some, this sense of unfairness was expressed in anger.

It is obvious from the comments made by patients that fear had become a major factor of their lives since contracting cancer. For example, "Fear is a dreadful thing....Every small pain worries me" (S. 24), and also comments made by subjects nos. 4, 8, 12, 14, 35, 38, 39, 48, and 57. This fear manifested itself in various ways, including sleeplessness, feeling the need for support, not being able to talk about the situation, not being able to consult the doctor when a breast lump was found, eating too much, not being able to eat, getting upset, becoming tearful, not being able to look at the scar, using diets and alternative methods, and losing interest in things. Many of these symptoms were also reported by Maguire (1985c). Feelings of despair were also evident, as indicated by subjects nos. 40, 44, 48, and 55, and no. 41 who said, "Who am I to survive when so many haven't?" Some subjects felt this despair so deeply that they expressed thoughts of suicide or euthanasia (Ss. 41, 28, 51). Others obviously denied the fact that they had cancer. For example, "I still say it was a big mistake, and not really cancer" (S. 9), and "I still don't know if I had cancer" (S. 34).

Seven (12%) of the 58 subjects used alternative methods whilst continuing to comply with the medical regimen. Four were using some form of meditation, and two of these were going to a Cancer Care group where meditation was taught. Two subjects were practising yoga, and three were investigating special diets. One subject was engaged in all three activities mentioned above, whilst another was actively participating in various alternative methods, including coffee enemas, visiting a psychologist, going on a special diet, visualization, relaxation, and reflexology. This subject investigated alternative methods for 7 weeks after finding her breast lump and before consulting a doctor. Brown (1986) and Cassileth and Brown (1988) suggested that one of the reasons for patients seeking unproven remedies is to maintain a sense of control over what is happening to them by actively participating in their cure.

Adjustment variables

Table 6.3 demonstrates that subjects seemed to be aware of their stress levels. On all occasions the stress level reported by subjects in answer to the one question, "how stressed have you felt", had a significant correlation with both anxiety and depression measures.

Anxiety. Means for the state-anxiety subtest have been given by Spielberger (1983) as ranging from 32-36 depending on age. Therefore it appears (Table 6.1) that subjects in the present study had very high levels of anxiety when measured within a week of their operation. In fact, they were similar to Gottesman and Lewis' (1982) breast cancer group. However, there was a significant drop in anxiety from in-hospital levels to 1 month post surgery. This was also evident when measurements taken at 3 months were compared with the previous two levels together. In fact, by 3 months post surgery, anxiety levels were similar to the means given by Spielberger (1983) for normal females.

Table 6.4 divides the means for anxiety, depression and self esteem at the hospital interview according to whether or not biopsy results were known to the subject at the time of the interview; and, if known, whether there had been any evidence of cancer spread or not. Although none of these differences was significant, it is interesting to note the drop in anxiety once the biopsy results were known; and also the very small difference in anxiety levels between those who didn't know their results and those who had been told that their biopsy had indicated nodal cancer spread. Thus it appears that awaiting results caused almost as much anxiety as being told that the cancer had spread.

The anxiety level at 1 month post surgery (Table 6.1) was very close to that at the hospital interview for those who knew the result of their biopsy (Table 6.4). This was expected, as all patients knew their results at 1 month post operation.

Table 6.5 divides subjects into demographic groups in order to compare the means on adjustment variables for each group. Although none of these variables had a significant effect on anxiety levels, it is interesting to note that at each interview those who had a mastectomy experienced less anxiety than those who had less intrusive surgery. In fact, the anxiety level for the group who had less extensive surgery was very high at the hospital interview, even higher than that of subjects who had been told that their biopsy had given evidence of cancer spread (Table 6.4). These results support Fallowfield et al. (1986), who claimed that lumpectomy patients sometimes became concerned that all the cancer had not been removed. It appears that fear of recurrence may be so high that patients feel less anxious if the whole breast has been removed, believing that this minimizes the chance of cancer cells remaining, even although there is no medical evidence to support this.

Table 6.8 explores anxiety levels according to the problem that subjects found most difficult or troubling. The only statistically significant finding was that at 3 months post surgery those nominating fear and uncertainty about the future as their worst problem had significantly higher anxiety levels than those who were more worried about other problems. This finding supports Peters-Golden (1982) and Worden and Weisman (1977) in that the predominant concern of the breast cancer patient is with life and death. Not only was this nominated by most women as their most troubling problem (Table 6.7), but at all interviews the group nominating fear and anxiety about the future registered the highest anxiety levels, although this was not always significantly so (Table 6.8).

Depression. Average depression score, using the Wakefield Depression Scale, has been given by the test authors as 6.75 for females. The levels for the present study were considerably higher than this, and were similar to those found by Gottesman and Lewis (1982) in their breast cancer group.

A significant drop in depression was evident when levels measured at 3 months post surgery were compared with those measured prior to this, and when measurements taken at 6 months post surgery were compared with those taken up to and including 3 months post surgery (Table 6.1). When this was divided into those who had a mastectomy and those who had a less extensive surgical procedure (Table 6.5) mastectomees were seen to be less depressed at each interview (although not significantly so). This follows the same pattern as anxiety.

Amongst adjuvant therapy groups, those undergoing chemotherapy were the most depressed (although, again, not significantly so). The only significant demographic effect on depression was found at the time of surgery in the interaction between age and marital status (Table 6.6). This indicated that younger unmarried, and older married breast cancer patients were the most susceptible to depression. High depression in the younger unmarried group may be a result of feeling insecure, as fear of unacceptability may prevent those not in a relationship from beginning a new one (Jennings, 1983). The older married group may be depressed at the possibility of leaving their husbands to fend for themselves. However, depression in this group may simply be a reflection of the general population, where marriage has been found to have a depressive effect on women over time (Weissman & Klerman, 1977). Thus those who have been married for many years were prone to depression, whilst this would not yet have affected the younger married group.

Self esteem did not show any significant change over the 6-month period, and all means were in the "extremely high" range, even when measured in hospital (Table 6.1). These measurements were also similar to those of Gottesman and Lewis (1982), which, in turn, were not significantly different from their "normal" control group. Therefore it appears that either self esteem did not change significantly with breast cancer surgery, or the Rosenberg Self-Esteem scale was measuring something more stable than did the state-anxiety or depression scales.

It is interesting to note that throughout the 6-month period, self esteem was higher for subjects who had a mastectomy than for those who had less extensive surgery (Table 6.5). Although this difference was not significant, it shows a trend which, coupled with the consistently lower anxiety and depression for this group, may point to subjects feeling more secure with the more extensive operation. Although caution is needed in interpreting these results, as they were non-significant, it can at least be said that they do not support Winick and Robbins' (1977) view that less extensive surgery results in less psychological morbidity.

Another unexpected trend was that the group with the highest mean score on self esteem were consistently those who selected change in appearance as their most stressful problem (Table 6.8). From the literature (Maguire, 1985c) one would be led to believe that damage to body image would cause a lowering of self esteem, yet these results do not support this.

Social activities. There was a significant increase in the frequency of social activities when measurements taken at 3 months and 6 months post surgery were compared with those taken earlier (Table 6.1). This is as would be expected with a lessening of anxiety and depression and an increase in physical strength as time from surgery passed.

Physical difficulties. A greater amount of physical difficulty was experienced by subjects who had a mastectomy, as was expected with a more intrusive operation (Table 6.5). Silberfarb et al. (1980) also found a prevalence of arm weakness and chest wall tightness in patients who had recently had a mastectomy, and as in the present study, there was no relationship between these difficulties and age, marital status, or employment history. There was a significant drop in the number of cancer related physical difficulties experienced from 1 month to 3 months post surgery (Table 6.1). Table 6.8 demonstrates that those who most feared limitations in abilities registered the greatest number of physical difficulties, particularly at 3 months post surgery. As only one of the five who most feared such limitations in hospital still listed this as her greatest worry 1 month later, and none of them did 3 months later, it appears that the severity of physical limitations was the cause of the fear at 3 months post surgery, rather than the other way around.

Other events which may influence adjustment

Many things may affect adjustment, hence it is advisable to include questions on other life events. Subjects whose post surgical scores of anxiety and depression rose at any time to be greater than two standard deviations above the mean, or whose self esteem dropped to less than two standard deviations below the mean, were considered separately to see if there was any reason for this.

Subject no. 4 registered very low self esteem throughout the 6 months. This subject was divorced and lived alone, and by comments made at interviews, her low self esteem was considered to be related to her loneliness and unhappiness in her work situation rather than her cancer. Subject no. 27 measured high anxiety and depression at 6 months post surgery, when her husband had a serious (unspecified) illness or injury. Subject no. 28 found an abcess on her other breast at 3 months post surgery and her (country) doctor wanted to give her a second mastectomy, but the Adelaide surgeon opposed this treatment. This subject's anxiety and depression levels rose and her self esteem dropped at 3 months post surgery. At 6 months post surgery her anxiety and depression had abated, but self esteem remained low. Subject no. 33, who registered high in anxiety at 1 month post surgery, and low in self esteem at 1 and 3 months post surgery, was adversely affected by radiotherapy. She returned the second questionniare 3 weeks late, with the note "Sorry I've been so long-winded in getting this back to you. Been backwards and forwards for radiotherapy for past 6 weeks and just haven't had the time nor quite frankly the inclination to get any further involved with the subject in general." Subject no. 55 didn't answer the questionnaire at 3 months post surgery, as she had just heard that her brother had cancer. He died 2 months later. This subject had high depression throughout the 6-month period, but her anxiety levels also rose at 6 months post surgery.

The above indicates that of the five subjects who were least well adjusted over the 6-month period following breast cancer surgery, three had problems unrelated to their illness; one found radiotherapy difficult; and the other had her fear heightened by an abcess on her other breast and her doctor's reaction to this.

The effects of adjuvant therapy

Adjuvant therapy was a major concern for some subjects. Comments such as those made by subjects nos. 8 and 9 (Appendix C-2) expressed the fear felt by some before beginning treatment. However, in many cases this was fear of the unknown rather than any actual unpleasantness from the treatment, as most negative comments were made before treatment began. A notable comment in this regard was that made by subject no. 17, who at the time of surgery said she'd rather die than have chemotherapy, but 3 months later remarked that it was not as bad as she thought. In fact, not all subjects were negative about adjuvant therapy. As one subject claimed, "I'm having side effects already from chemotherapy, and that's good because I know it's working" (S. 50).

Researchers have differing views on the effect of adjuvant therapy on adjustment. Radiotherapy has been claimed to have a detrimental effect on anxiety and depression (Peck & Boland, 1977); no difference (Morris et al., 1977); and a reassuring effect (Holland & Jacobs, 1986). This reassuring effect was indicated by subject no. 48 who said, "I miss radiotherapy. I felt more safe, like someone was looking after me. Now I feel on my own." The present study did not show any significant effect of any type of adjuvant therapy on any adjustment variable (Table 6.5). Also, no patient undergoing radiotherapy selected pain, symptoms, or discomfort from illness or treatment as their most difficult problem (Table 6.7), yet approximately half of those undergoing chemotherapy nominated this as their major concern. As most patients having chemotherapy had to cope with hair loss and nausea, this, together with the fact that chemotherapy lasted for 3 months whilst radiotherapy was only given for 5 weeks, would have made the discomfort more problematic.

In the light of Dean's (1988) belief that being given a choice of treatments may reduce psychological morbidity, it was interesting to note that three subjects asked the interviewer whether they should go in chemotherapy trials or not. It appears that having to cope with decision-making on top of having to cope with what is happening to them, merely adds extra stress to some subjects. There are no doubt a number of subjects who just like to be in the hands of someone capable who can make all of these decisions for them, e.g., "He makes me feel wonderful, like everything's under control" (S. 16).

Marital relationships

It has been claimed that marriage reduces stress from mastectomy (Smith et al., 1985), and although this research showed no significant effect of marital status on adjustment, there were indications that the effect may have been directionally opposite to that claimed by Smith et al., i.e., having a mastectomy may reduce the stress from marriage! The life events questionnaire included one positive item: "There has been a marked improvement in the way you and your husband are getting on". Over the 6-month period, 18 (42%) of the 43 married subjects said that their marriage had shown a marked improvement, whilst others commented that they have always had a good relationship and it has remained so. Of these 18 whose marriages improved markedly, 9 first reported this improvement at the time of surgery; 3 reported it 1 month later; 5 at 3 months; and 1 at 6 months post surgery. Added to this is the fact that only one subject's main worry was problems with family or friends related to cancer at the time of surgery, and none were worried about this at any time post surgery. This provides evidence that the cancer experience is more likely to bring spouses closer together than to cause stress in the relationship. This finding supports Zemore and Shepel (1989), who found an increase in marital closeness and an improvement in interpersonal relationships following cancer.

Employment

Results on returning to work supported other findings in this area. In the present study 12 (75%) of the 16 subjects who replied to this section of the questionnaire had returned to their pre-operation employment by 3 months post surgery. Dean (1988) reported a number of studies where over 50% had resumed work within 3 to 4 months. Morris et al. (1977) reported that 54% of their 64 subjects were working to the same degree as they were prior to having their breast cancer operation. However, they used only subjects under 70 years of age and included the ability to carry out household tasks in their work adjustment variable. Silberfarb et al. (1980) stated that 13 (54%) of their 24 primary stage breast cancer patients had returned to work after 4 months. The reason why the present study reflects a higher rate of rapid return to work could be a function of the less intrusive surgery, as all of Silberfarb's subjects and 92% of Morris' had a mastectomy, whereas only 60% in the present study had a mastectomy.

A further reason for the present study's apparent higher rate of return to work within 3 months may be that the 4 subjects who did not reply to this question may not have returned to work. If this were the case, the present study would show a return to work rate of 12 out of 20 subjects (i.e., 60%), which is comparable with the other studies.

The most difficult cancer related problem

Silberfarb et al. (1980) studied breast cancer patients who were in either primary, recurrent, or final treatment stages, and found the first recurrence of breast cancer to be the most emotionally distressing time. The findings of the present study, together with the comments made by subjects, support Silberfarb's results, as by far the most worrying problem was fear of recurrence (Table 6.7). Amongst those choosing fear of recurrence were 32 (84%) of the 38 who were awaiting biopsy results, hence it was predictable that this would be uppermost in their minds. Yet, even amongst the 15 subjects who had been told that their biopsy results showed no evidence of cancer spread, 10 (67%) stated that fear of recurrence was their major source of stress. However, this could be due to the fact that they had been asked for the most stressful problem in the past month, or since they knew they had cancer, whichever was the shorter, and so, even though they may not have been worried about cancer spread at the time of the interview, this may have been their main worry over most of that time.

It is surprising to find that at 1 month post surgery, when all subjects had known the results of their biopsy for some weeks, 38 (67%) of the 57 subjects in the study still worried most about cancer spread, even though 26 (68%) of these 38 had been assured that there was no evidence of spread. Further, at 3 months post surgery, 35 (64%) of the 55 subjects continued to select fear and uncertainty about the future above the other problems. Some comments made by subjects illustrated this fear. For example, "My friend had breast cancer and...she died" (S. 8), and also those from subjects nos. 6, 12, 14, 24, 41, 51, and 55 (Appendix C-2).

There is little doubt that mastectomy patients in the present study were more concerned with preventing recurrence than they were with preserving body image. This is in direct contradiction to Polivy (1977), who stated that "the principle psychological reactions to mastectomy seem to center on the threat to femininity it presents, possibly even more than fear of death from the disease itself" (p. 78). Rather, the results of the present research support Peters-Golden (1982), Sanger and Reznikoff (1981), and Worden and Weisman (1977). At the hospital interview, only 1 (3%) of 35 mastectomy patients stated that change in appearance was her main concern; at 1 month post surgery there were only 3 (9% of 34); and at 3 months post surgery there were 5 (28% of 32). The percentages of mastectomy patients most concerned with recurrence were 77%, 65%, and 56% at the time of surgery, 1 month, and 3 months post surgery respectively. This increase in worry about change in appearance and decrease in fear of the future amongst mastectomy patients seems to indicate that as time from surgery passed and some patients became more secure that their cancer had been cured by surgery, they then began to focus on their "mutilation".

There may be a hierarchy of fears, such that as one lessens it makes way for another, which was initially less pressing, to emerge.

Morris et al. (1977) found that 31 (49%) of their 63 subjects (59 of whom had had a mastectomy) claimed to be not stressed at all by their operation at 3 months post surgery. At this time 15 (24%) were most stressed by breast loss or disfigurement, whilst 10 (16%) were most stressed by the diagnosis of cancer. At 12 months post surgery, 37 (70%) of Morris et al's. 53 subjects were not stressed; 10 (19%) were most stressed by breast loss/disfigurement; and 5 (9%) were most stressed by the diagnosis. The findings from the present research differ from Morris et al., in that stress from diagnosis of cancer was more often reported to be a major difficulty than was stress from breast loss or disfigurement. Also, in the present study the subjects were not given the option of saying that they were not stressed at all, but were required to choose the most stressful aspect, even although it may have been seen as a very slight stressor. At 3 months post surgery, 60% claimed to be only slightly stressed, and this is comparable with Morris et al's. 49% who were not stressed. It would have been interesting to know how many would have selected "no stress" if it were an option, in the light of the fact that so many subjects had difficulty in selecting an area of stress at 3 months that this question was omitted at the next interview.

Reactions to taking part in the research

Answers to this section demonstrated that people desired to help others and also appreciated the opportunity to reciprocate the help they had received. This is an example of one of the principles of equity theory, especially as discussed by Fisher et al. (1983), where reciprocation may be made to a third party. Forty-two percent of the subjects indicated that the main reason why they chose to take part in the research was to show their appreciation for the care they had received from their doctors.

Although most subjects claimed to have taken part in the research for altruistic reasons, the greater majority also admitted to gaining something positive for themselves. This supports Fallowfield et al. (1987b), who found that breast cancer patients taking part in their psychological study viewed it as a "helpful extension to their treatment" as it had the therapeutic effect of allowing the patient "to express the emotional traumas that she is experiencing" (p. 59). Comments made by subjects in the present study were a further indication that they were more than pleased to have taken part (Appendix C-1). Twenty-five subjects made favourable comments about taking part in the research and seven offered to take part in further studies. Remarks indicated that subjects felt "cared for" by taking part. Only two subjects (Ss. 19 & 41) were perhaps slightly irritated by the questionnaires, but no-one was upset by them. These comments, together with a response rate of 98% over the 6 months of the research, should reassure those doctors who, as reported by Fallowfield et al. (1987b), are reluctant to allow psychological studies to be undertaken with their patients in case it upsets them.

Summary

This study demonstrated that by 6 months post surgery, the initial stress generated by the diagnosis and treatment of breast cancer had largely dissipated. By 3 months post surgery the mean anxiety and depression levels were close to those given for normal populations. Also by 3 months post surgery 60% of subjects claimed to be, at most, only slightly stressed by cancer-related problems, and 60%-75% had returned to work. The few whose anxiety or depression levels were high were found to have been affected by situations other than breast cancer, except for two subjects, one who was adversely affected by radiotherapy and one who had an abcess on her other breast. Therefore this research supported the findings of Penman et al. (1987) and Silberfarb et al. (1980) that there was no prominence of psychosocial problems amongst cancer patients.

CHAPTER 7

Social Support in the Prospective Study

As reviewed in Chapter 3, social support is a set of "personal contacts through which the individual maintains his social identity and receives emotional support, material aids and services, information, and new social contacts" (Walker et al., 1977, p. 35). As such, it is a multidimensional construct, where each component may have independent effects on health and psychological well-being (Neuling & Winefield, 1988).

Social support has been demonstrated to have the effect of protecting people from illness and shielding them from many of its adverse effects when it does occur (Falke & Taylor, 1983; Winefield, 1982). Although research has not clearly indicated how this occurs (Bruhn & Philips, 1984), it appears that adequate support may influence the occurrence of illness (Wortman, 1984) by (a) decreasing recipients' vulnerability to stress, or (b) increasing their resistance to it (Broadhead et al., 1983). It may be that social support assists in dealing effectively with stress (Bloom, 1982b; Caplan, 1981), or it may be a basic human requirement such that lack of social support is a stressor in itself (Orth-Gomer & Unden, 1987), and so contributes to the effects of illness (Schaefer et al., 1981).

There is a need to distinguish between the quantity of support received and the recipient's perception of its quality (Schaefer et al., 1981), as some social interaction actually increases stress levels (Innes, 1981). It is not uncommon for friends or relatives to offer "support" which is found by the recipient to be unhelpful (Lehman et al., 1986). Further, the source from which support is received has been found to be more important than the amount of support offered (Lieberman, 1986). For example, patients require information from their surgeon, but may resent it from non-professionals (Dunkel-Schetter, 1984).

To date there is a lack of valid and reliable measures of social support (Lichtman & Taylor, 1986). Hence the present study will develop a questionnaire encompassing the essential multidimensionality of support with its elements of empathic, informational and tangible support together with the reassurance it offers, and will also include the source from which each type of support is received. The sources covered will be those most pertinent to breast cancer sufferers, i.e., the surgeon, family members, close friends, and peers (other breast cancer patients). It will not only investigate the frequency at which each type of support is received from each source, but also the recipient's perception of its helpfulness. This will all then be related to the patient's psychological, physical, and social adjustment.

Hypotheses

1. Subjects whose support needs are met will have higher levels of psychological adjustment (Peters-Golden, 1982; Zemore & Shepel, 1989) and less physical illness (Schaefer et al., 1981) than those who lack this support.

2. The subject's perceived quality of support received will have a stronger association with health outcomes than will frequency of support received (Billings & Moos, 1982; Winefield & Neuling, 1987).

3. As the source of support is more important than the amount of help provided (Lieberman, 1986), patients will require informational support from their surgeons, but may resent this from non-professional sources (Dunkel-Schetter, 1984). This will be shown by subjects either (a) being satisfied with significantly less information from family and friends than from surgeons, or (b) stating that they would have appreciated more information from surgeons and less from family and friends.

4. The husband's reactions to his wife's breast cancer may be crucial to her adjustment (Wortman, 1984). Therefore patients will require more empathic support from husbands and family members than from other sources. This will be shown by subjects either (a) receiving more empathic support from family members than from other sources, or (b) stating that they would have appreciated more information from their families.

5. As indicated above, specific kinds of support are required from the surgeon and family. Further, if help is not received from the source from which it is required, other sources may not be useful (Neuling & Winefield, 1988). Therefore, patients will be satisfied with less support from friends than from family members and surgeons.

6. There will be some non-materialization of expected support, as people have a fear of identifying with cancer patients (Peters-Golden, 1982). This will be noticed mainly amongst friends, as it is easier for them to avoid contact with the patient than it is for families.

7. Some patients, not wanting to worry people or to appear complaining, will impose barriers to communication with friends, relatives (Lichtman & Taylor, 1986), and doctors (Eidinger & Shapira, 1984; Maguire, 1985c). As a result, they will not receive the support they require. This will be indicated by a lack of satisfaction with support from these sources, together with comments as to why there was lack of communication.

Method

Measures and procedure

Multi-Dimensional Support Scale. The support received during the month preceding and the 3 months following surgery was evaluated by designing a new scale, the Multi-Dimensional Support Scale (MDSS), which specified the source, type, and frequency of supportive behaviours towards the subject, and included the recipient's rating of the adequacy of each behaviour from each person. This extended the work of Funch and Mettlin (1982), in which multiple support systems were considered with respect to multiple outcomes of breast cancer surgery.

In order to encompass the multidimensionality of social support, the MDSS included four aspects: emotional support, which involves closeness with others in an environment of acceptance or love (Bloom & Spiegel, 1984); informational support, which allows for organization of thoughts and provides a framework for appraisal; tangible support, which involves direct aid; and reassurance support, which leads to increased confidence (Dunkel-Schetter, 1984; Wortman, 1984). The items comprising these areas are listed in Table 7.1.

Table 7.1

<u>Social Support Groupings</u>

Empathic support
    Encouraged you to talk about your (emotional) feelings about your illness
    Encouraged you to talk about your illness experience (physical)
    Listened carefully to what you said and tried to understand
    Told you they loved you, or made you feel loved (family and friends only)

Informational support
    Offered advice about how you could help yourself
    Suggested new ways of looking at your illness
    Offered advice about treatments available
    Told you what to expect
    Answered all your questions (surgeon only)

Tangible support (family and friends only)
    Helped with chores, transport or childcare
    Took over all your duties and did everything for you

Reassurance
    Told you to count your blessings
    Told you not to worry as everything would be all right
    Told jokes and chattered to keep your mind off your illness

Although some behaviours intended to distract or cheer up the patient may not be seen as helpful by the recipient, it was important that the MDSS include such behaviours in order to determine when and by whom they failed to have the desired effect.

The sources of support investigated were family members, friends, and the surgeon. In order to make answers specific, subjects were asked to nominate one family member and one friend who had been the most supportive in the last month, or since they knew they had cancer, whichever was the shorter. In this way they could then concentrate more directly on the support received, rather than giving some sort of global estimate of what had been received from a group of people (Wortman, 1984). Provision was also made for subjects to describe any additional support received from persons other than the one nominated. In this way a complete picture of the support received was gained, together with any unmet expectations from the person seen as most supportive. Subjects were also asked to describe any additional support received from health professionals other than surgeons. This gave an indication of total support received from this source, but, for comparison purposes, subjects were required to answer the questionnaire with respect to their main surgeon. At the time of surgery, and at 1 and 3 months post surgery, subjects rated, on a 4-point scale ranging from "never" to "often", how frequently in the past month they experienced each behaviour from each source.

The MDSS not only measured the frequency with which each type of support was given by each source, but also, on a separate scale, recipient satisfaction. This enabled a distinction to be made between quantity and quality of social support so that it could be determined how much of each type of support was seen as supportive from each source. Subjects indicated their level of satisfaction by marking whether they were satisfied or whether they would have preferred to experience this behaviour more often or less often from the nominated person. This method was considered more likely to result in honest answers than merely asking subjects whether they were satisfied or dissatisfied with the various behaviours. Subjects may have been unwilling to indicate dissatisfaction with the behaviour of a close friend or family member who was attempting to be supportive.

Other measures of support from family, friends, and surgeon. In order to get a more complete description of the support given (or withheld), together with the kinds of behaviour perceived by the recipient as supportive (or unhelpful), subjects were asked, at the time of surgery, to describe the most (a) helpful and (b) unhelpful or upsetting thing that was said or done since they knew they had cancer, and to give the relationship or position of the person who had said or done this. They were also asked what type of support was most appreciated from their family, friends, and surgeon.

A short questionnaire was included at 6 months post surgery, in order to find out who, if anyone, subjects confided in when they were worried or upset. Subjects marked on a 4-point scale, ranging from "never/no such relationship" to "often", the frequency with which they confided in their husband, children, parents, siblings, or close friends. This was followed by five possible reasons why a person might not confide in anyone about their cancer-related worries, together with a place for "other reasons" in case the listed ones were not sufficient. Subjects who did not share their worries with others, marked their reasons for not doing so on this list.

Responses to peer support. The Anti-Cancer Foundation of the Universities of South Australia provide a support service for breast cancer patients through the Breast Cancer Support Service (BCSS). This service is available at many country hospitals as well as all of those in Adelaide except the Flinders Medical Centre, which run their own support service. Previous breast cancer patients visit current patients, give them a temporary breast prosthesis, and discuss with them any problems that the patient may wish to discuss. At 1 month post surgery a short questionnaire was included in order to evaluate the services provided by these volunteer hospital visitors. Questions related to how the visit was arranged; the timing of the visit; and the helpfulness of different areas of information and advice. Subjects rated the above on a 4-point scale ranging from "not applicable" to "very helpful".

The role of cancer support groups was investigated by asking subjects to rate, on a 4-point scale ranging from "no time" to "a lot of time", how much time they consider an ideal cancer support group should devote to each of the listed items. Subjects were then asked whether they would prefer talking about their cancer related problems (a) to one similar patient; (b) with a group of breast cancer patients; or (c) neither. Following this was a questionnaire on experiences in a cancer support group, to be filled out only by those who had attended such a group. All of the questions in this section were adapted from Dunkel-Schetter's (1984) Social Support Questionnaire.

Statistical analyses

Cronbach's Alpha was calculated using the SPSSx program "Reliability" (SPSS Incorporated, 1983), in order to examine the internal reliability of the MDSS. It was not appropriate to do test-retest reliability, as it was expected that subjects' emotional and physical state would change considerably between hospitalization and the follow-up interview 1 month later. Pearsons correlations indicated the level of association between the frequency of support received and satisfaction with this frequency. Student's t-tests determined whether there were any response differences which could be accounted for either by distance from hospital and surgeon or by the different methods of questionnaire presentation due to this distance factor (i.e., interview or postal).

Each subject's frequency ratings for each type of support (i.e., empathic, informational, tangible, and reassurance) were averaged, resulting in scores ranging from 0-3 for each type of support from each source. These scores were then analysed by a repeated measures multivariate analysis of variance (MANOVA) with trend analyses to determine the overall pattern of change over the 3 months. This program took into account the variability in time between interviews.

Research has indicated that breast cancer patients rely mainly on family members, particularly husbands, for empathic support, but often resent informational support from this source, requiring this from professional sources. Therefore this study used planned comparisons to compare the amount of each type of support given by surgeons and families respectively, with the hypothesis that surgeons would give more information whilst families would give more empathy. Planned comparisons then compared the amount of each type of support given by friends with that given by family and surgeons. Research has indicated that patients' psychological adjustment is more dependent on the support given by family members and surgeons than on that given by friends. Therefore it was expected that friends would give less support than families or surgeons, and that patients would be satisfied with this. Planned comparisons also compared, in the same manner, the amount of overall support given by family, friends and surgeons.

Satisfaction with support received from the various sources was measured in three categories: too little support; too much; and satisfactory. As the numbers in some sections were small, the two categories of dissatisfaction were combined for purposes of statistical analyses.

An analysis of variance ascertained whether there was any relationship between any control variable and (a) the amount of support received, or (b) satisfaction with this frequency. The relationships were examined as described in Chapter 6, in order to avoid confounding effects due to interrelationships between them and the type of surgery given. Student's *t*-tests then compared the amount of support given by surgeons to private and public patients respectively, whilst Chi-squared tests compared private with public patients' satisfaction with the support received from surgeons.

A division was made at the median frequency for each type of support from each source at each interview An analysis of variance then determined whether there was any effect on adjustment variables attributable to support frequency. As there were no significant three-way interactions, all three-way interaction terms were pooled into the error (residual) sum of squares.

An analysis of variance also ascertained whether there were any effects on adjustment variables attributable to subjects' satisfaction with the support received. As there was so little dissatisfaction with support from friends, this resulted in empty cells and hence an inability to compute interaction effects. Therefore, as there was also no significant interaction between satisfaction with support from family and surgeons, interaction sums of squares were pooled into the error (residual) sum of squares.

Cross-lagged correlations were used to detect any association between (a) the amount of support received from each source at the time of surgery, and psychological adjustment 1 month later; or (b) psychological adjustment at the time of surgery, and the amount of support received from each source 1 month later. Similar correlations were also used to detect any association between psychological adjustment and satisfaction with support. A z-test employing Fisher's logarithmic transformation of r to Z (Diem, 1962; Sheskin, 1984) then ascertained whether there was any significant difference between these pairs of cross-lagged correlations. If any differences are found, and if there are storage processes which spread out causation in time, it may be inferred that the stronger correlation indicates a greater causal effect (Cook & Campbell, 1976).

Results

Reliability coefficients for the MDSS are shown in Table 7.2, together with correlations between frequency of support and satisfaction with this frequency from the three sources investigated.

Table 7.2

Reliability Coefficients for Social Support Groupings (Frequency) Averaged across the Three Interviews, and Correlations between Frequency of Support and Satisfaction with this Frequency from Family, Friends, and Surgeon, at each Interview

	No. of items	Chronbach's Alpha	Pearson's correlations		
			In hospital	1 month post-op.	3 months post-op.
Family					
Empathic	4	.71	.55 +	.54 +	.29 *
Information	4	.69	-.01	-.35 +	-.19
Reassurance	3	.64	.04	-.06	-.30 *
Tangible	2	.61	.32 +	.34 +	.17
Friends					
Empathic	4	.70	.16	.01	-.20
Information	4	.66	-.09	-.12	--
Reassurance	3	.57	.03	-.02	--
Tangible	2	.51	--	--	--
Surgeon					
Empathic	3	.68	.42 +	.55 +	.62 +
Information	5	.60	.44 +	.56 +	.39 +
Reassurance	3	.56	.08	.13	-.11

* $p < .05$; + $p < .01$

Note. Some scores for friends were unable to be calculated, as there were no subjects dissatisfied with this support.

Pearson's correlations indicated that there were significant correlations between frequency of family support and satisfaction with this frequency with respect to empathic support at all three interviews: in hospital $r = .55$, $p < .01$; 1 month post surgery $r = .54$, $p < .01$; 3 months post surgery $r = .29$, $p < .05$; informational support at 1 month post surgery, $r = -.35$, $p < .01$; reassurance support at 3 months post surgery, $r = -.30$, $p < .05$; and tangible support in hospital, $r = .32$, $p < .01$, and at 1 month post surgery, $r = .34$, $p < .01$. There were significant correlations between frequency of surgeons' support and satisfaction with this frequency in the areas of empathic and informational support at all three interviews at $p < .01$: empathic, in hospital $r = .42$; 1 month post surgery $r = .55$; and 3 months post surgery $r = .62$; and informational, in hospital $r = .44$; 1 month post surgery $r = .56$; and 3 months post surgery $r = .39$. There were no significant correlations between frequency of surgeons' reassurance and satisfaction with this, or between frequency of friends' support in any area and satisfaction with this.

Student's t-tests computed as a check on response differences from postal questionnaires versus interviews demonstrated that subjects living outside the Adelaide metropolitan area had significantly more support from their family at the time of surgery than did subjects living within the metropolitan area, $F(1, 53) = 4.04$, $p = .05$, and that these same subjects were significantly more satisfied with the support provided by their surgeons at this time, $F(1, 56) = 4.24$, $p < .05$. There were no other significant differences at the time of surgery, and no significant differences in either the frequency with which social support was received from any source, or satisfaction with this frequency at 1 or 3 months post surgery.

Support from family, friends, and surgeon

Frequency of support. Not all subjects had support available from each source. Three subjects did not have any family support readily available to them, two subjects decided not to tell anyone outside the family and therefore did not have the support of a close friend or confidant, and 11 subjects did not see their surgeon between leaving hospital and 1 month post surgery. Four of the latter as well as a further 14 did not see their surgeon between 1 month and 3 months post surgery. This resulted in smaller numbers for some of the analyses.

Table 7.3 shows the mean frequency of each group of potentially supportive behaviours from the three sources at each interview, together with results of trend analyses performed on each source. Appendix B-1 divides this further into the frequency with which each item of potentially supportive behaviour was received from each source at each interview. Overall support from family and surgeon decreased over time, resulting in significant linear trends: family $F(1, 104) = 49.07$, $p < .01$, and surgeon $F(1, 66) = 37.25$, $p < .01$, whilst overall support from friends increased in the first month after surgery and then decreased, resulting in a significant quadratic trend, $F(1, 94) = 5.63$, $p < .05$.

Table 7.3

Mean Frequency of Potentially Supportive Behaviours from each Source, as Reported at each Interview

	In hospital	1 month post op.	3 months post op.
Family	(n = 55)	(n = 54)	(n = 52)
empathic	2.24	1.85	1.51
information	0.29	0.39	0.25
tangible	1.72	1.80	1.26
reassurance	1.16	0.98	0.57
Friends	(n = 56)	(n = 52)	(n = 49)
empathic	1.83	1.79	1.26
information	0.15	0.32	0.14
tangible	0.41	0.53	0.31
reassurance	0.75	0.78	0.36
Surgeon	(n = 58)	(n = 47)	(n = 40)
empathic	1.78	1.45	1.14
information	1.46	1.10	0.87
reassurance	0.60	0.52	0.18

Note. Maximum score = 3.

Planned comparisons between the amount of support received from each source demonstrated that on all three occasions friends provided significantly less overall support than did family and surgeons: in hospital $F(1, 614) = 34.77$, $p < .01$; 1 month post surgery $F(1, 561) = 10.00$, $p < .01$; and 3 months post surgery $F(1, 521) = 14.65$, $p < .01$. There were no significant differences between the amount of support provided by families and surgeons respectively. However, when support was divided into different components, the difference between the amounts provided by families and surgeons was significant for each type for each interview. Families provided significantly more reassurance and empathic support than did surgeons: in hospital, reassurance $F(1, 166) = 3.98$, $p < .01$, and empathic $F(1, 166) = 7.03$, $p < .01$; 1 month post surgery, reassurance $F(1, 150) = 3.08$, $p < .01$, and empathic $F(1, 150) = 6.01$, $p < .01$; and 3 months post surgery, reassurance $F(1, 138) = 3.27$, $p < .01$, and empathic $F(1, 138) = 4.70$, $p < .01$. However, at all three interviews, surgeons provided significantly more information than did families: in hospital $F(1, 166) = 15.71$, $p < .01$; 1 month post surgery $F(1, 150) = 8.40$, $p <01$; and 3 months post surgery $F(1, 138) = 7.73$, $p < .01$.

A significantly greater amount of tangible support was given by family members to those who were found to have nodal cancer spread, $F(1, 50) = 4.98$, $p < .05$. There was no other significant effect from age, marital status, type of surgery, nodal cancer spread or adjuvant therapy on either the amount of support received from any source or satisfaction with this amount.

Satisfaction with support. Table 7.4 gives the subjects' reported satisfaction with each type of support received from the three sources at each interview, and Appendix B-2 divides this further into satisfaction with each item of support.

Table 7.4

Percentages of Subjects Dissatisfied with the Frequency of Potentially Supportive Behaviours Received from each Source, as Reported at each Interview

	In hospital		1 month post-op.		3 months post-op.	
	Needed more	Needed less	Needed more	Needed less	Needed more	Needed less
	%	%	%	%	%	%
Family	(N = 55)		(N = 54)		(N = 52)	
empathic	15	4	11	-	10	-
information	7	2	-	4	2	2
tangible	4	-	6	4	6	4
reassurance	5	5	4	7	4	2
Friends	(N = 56)		(N = 52)		(N = 49)	
empathic	7	2	-	2	2	-
information	4	2	-	2	-	-
tangible	-	-	-	-	-	-
reassurance	1	1	2	2	-	-
Surgeon	(N = 58)		(N = 47)		(N = 40)	
empathic	19	-	34	-	30	-
information	16	2	26	-	23	5
reassurance	3	-	6	4	5	-

Note. Percentages have been rounded to the nearest whole number.

Numerous comments were made on the support received during the course of the research. These came from three sources: (a) subjects' responses to the questionnaire on what was the most helpful or unhelpful thing that was said or done since they knew they had cancer; (b) subjects' unsolicited comments recorded by the interviewer during interviews; and (c) notes included with the return of postal questionnaires. These comments are recorded in the Appendices: Support from family members in Appendix C-3; friends in Appendix C-4; medical practitioners in Appendix C-5; and volunteer hospital visitors in Appendix C-6. Comments on hospital staff and conditions are recorded in Appendix C-7.

Of the 43 married subjects, 39 (90.7%) selected husbands as the most supportive family members. One chose a son who had had cancer, another chose her mother, and the other two chose daughters. Of the 15 unmarried subjects, two selected a sister, six chose a daughter, and four chose a son as the most supportive, whilst three relied on friends.

When asked to describe any additional support received from health professionals other than surgeons, nine subjects mentioned hospital sisters, three mentioned general practitioners, one named a hospital social worker, and eight found hospital doctors particularly supportive.

Table 7.5 shows the choices made by subjects when they were asked at the time of surgery what type of behaviour was most appreciated from their most supportive family member, closest friend, and surgeon. Fifty-one subjects answered this question with respect to families, and 49 answered with respect to friends and surgeons, the other subjects claiming that they found it too difficult to choose.

Table 7.5

Number of Subjects Selecting each of the Most Supportive Behaviours from Family Members, Friends, and Surgeons

	Family (*N* = 51)	Friend (*N* = 49)	Surgeon (*N* = 49)
They did nothing very helpful	2 (4%)	1 (2%)	8 (16%)
Talked about your feelings (emotional)	0	2 (4%)	0
Talked about your feelings (physical)	0	1 (2%)	2 (4%)
Listened, and tried to understand	8 (16%)	15 (31%)	9 (18%)
Suggested new ways of viewing your illness	1 (2%)	0	0
Offered advice about treatments	1 (2%)	0	3 (6%)
Told you what to expect	0	1 (2%)	9 (18%)
Told you to count your blessings	1 (2%)	0	0
Told you not to worry	0	2 (4%)	2 (4%)
Told jokes and chattered	1 (2%)	3 (6%)	0
Made you feel loved	17 (33%)	17 (33%)	--
Helped with chores, transport or childcare	19 (37%)	7 (14%)	--
Did everything for you	2 (4%)	0	--
Answered all your questions	--	--	16 (33%)

Table 7.6 indicates the people with whom subjects shared their cancer-related concerns. Seventeen subjects said that they talked about these concerns fairly often, whilst a further 38 gave reasons for not doing so (three subjects gave two reasons):

Table 7.6

Number of Subjects Sharing their Cancer-Related Problems with each of the Listed People

(*N* = 54)	Rarely	Sometimes	Often
Husband	8 (15%)	21 (39%)	6 (11%) ‡
A close friend	12 (22%)	17 (32%)	5 (9%)
A parent	3 (6%)	6 (11%)	1 (2%)
A brother or sister	9 (17%)	13 (24%)	1 (2%)
One of my children	12 (22%)	19 (35%)	6 (11%) +

	(*N* = 55)
I'm a private person and don't want others to know	6 (11%)
I don't want to worry or upset anyone	10 (18%)
I don't really need to talk about my worries	15 (27%)
I don't want to upset myself by thinking about my worries	2 (4%)
I don't want to seem like someone who is self-pitying	8 (15%)
None of the above applies because I do talk fairly often about cancer with others	17 (31%)

‡ 40 respondents were married

+ 50 respondents had children

Public vs. private patients

Frequency of support. Table 7.7 compares potentially supportive behaviours as given by surgeons to public and private patients respectively. At 3 months post surgery private patients received significantly more empathic support than did public patients, $F(1, 38) = 3.76$, $p < .05$.

Table 7.7

Mean Frequency of Potentially Supportive Behaviours from Surgeons, Comparing Public with Private Patients

	In hospital	1 month post-op.	3 months post-op.
	public (_n_ = 36) private (_n_ = 22)	public (_n_ = 29) private (_n_ = 18)	public (_n_ = 25) private (_n_ = 15)
	_M_	_M_	_M_
Empathic support			
Public patients	1.77	1.30	0.96
Private patients	1.79	1.70	1.44 *
Informational support			
Public patients	1.47	1.06	0.81
Private patients	1.44	1.17	0.97
Reassurance			
Public patients	0.63	0.59	0.20
Private patients	0.56	0.41	0.13

* < .05 (one-tailed _t_-test). Difference in support given to public patients and private patients.

Satisfaction with support. Table 7.8 compares the satisfaction felt by public and private patients with the support received over the 3 months. The Chi-squared tests revealed no significant differences between public and private patients' satisfaction with support given by surgeons.

Table 7.8

Percentages of Patients Reporting Dissatisfaction with the Amount of Potentially Supportive Behaviours Received from Surgeons, Comparing Public with Private Patients

	In hospital		1 month post-op.		3 months post-op.	
	public (n = 36) private (n = 22)		public (n = 29) private (n = 18)		public (n = 25) private (n = 15)	
	Needed more %	Needed less %	Needed more %	Needed less %	Needed more %	Needed less %
Empathic support						
Public patients	22	-	41	-	36	-
Private patients	14	-	22	-	20	-
Informational support						
Public patients	19	-	34	-	32	4
Private patients	9	5	11	-	7	7
Reassurance						
Public patients	6	-	7	3	8	-
Private patients	-	-	6	6	-	-

Note. Percentages have been rounded to the nearest whole number.

Social support and adjustment

Frequency of support. A division was made at the median frequency of support given by each source in order to ascertain the psychological, social, and physical adjustment of subjects according to the amount of support received (Table 7.9). Table 7.10 gives the results from the analyses of variance performed on these adjustment variables to determine whether there was any effect attributable to the frequency of support received from each source at the time of surgery or at 1 or 3 months post surgery respectively.

Table 7.9

Cell Numbers and Means on Psychological, Social, and Physical Adjustment According to Frequency of Social Support Received from Each Source

		Anxiety	Depress.	Self esteem	Social activ.	Physical probs.
In hospital	*n*	*M*	*M*	*M*	*M*	*M*
Family						
low frequency	22	42.3	10.5	23.8	9.6	--
high frequency	33	43.6	12.0	24.1	9.0	--
Friends						
low frequency	27	40.0	9.0	25.0	8.7	--
high frequency	29	45.7	13.2	22.7	9.7	--
Surgeon						
low frequency	27	44.9	11.9	22.5	8.7	--
high frequency	31	41.3	10.7	24.8	9.4	--
1 month post surgery						
Family						
low frequency	27	36.7	8.0	24.7	9.3	9.1
high frequency	27	41.1	12.1	24.1	9.5	11.7
Friends						
low frequency	25	35.2	7.7	24.7	8.5	9.6
high frequency	27	42.9	12.7	23.7	10.5	12.3
Surgeon						
low frequency	23	41.1	10.8	23.3	7.8	10.0
high frequency	24	36.8	9.1	25.4	10.5	12.0
3 months post surgery						
Family						
low frequency	26	34.0	6.6	25.5	8.8	3.3
high frequency	26	37.4	9.4	23.8	12.3	4.7
Friends						
low frequency	17	33.4	6.5	24.5	8.9	3.8
high frequency	32	37.2	9.1	24.4	11.5	4.1
Surgeon						
low frequency	19	39.2	10.3	24.3	10.4	2.6
high frequency	21	34.1	6.7	25.3	10.4	6.3

Note. The division between low and high frequency was made at the median.

Table 7.10

Analyses of Variance on Adjustment Variables, by Frequency of Support Received from each Source at each Interview

	In hospital		1 month post-op.		3 months post-op.	
	MS	*F*	*MS*	*F*	*MS*	*F*
Anxiety						
Family	77.9	0.42	123.7	1.12	35.9	0.33
Friend	1067.9	5.81 *	699.2	6.33 *	1.0	0.01
Surgeon	688.6	3.75	253.5	2.29	322.5	2.95
Family x friend	100.7	0.55	22.2	0.20	0.1	0.00
Family x surgeon	1.4	0.01	14.3	0.13	75.8	0.69
Friend x surgeon	337.6	1.84	8.8	0.08	33.1	0.30
Depression						
Family	0.6	0.01	4.2	0.08	1.1	0.03
Friend	381.1	6.15 *	161.8	3.19	0.7	0.02
Surgeon	184.0	2.97	113.7	2.24	152.6	3.53
Family x friend	3.5	0.06	15.3	0.30	11.1	0.26
Family x surgeon	9.1	0.15	21.6	0.43	0.0	0.00
Friend x surgeon	3.9	0.06	52.3	1.03	1.5	0.04
Self esteem						
Family	0.4	0.02	15.4	0.61	0.6	0.03
Friend	322.0	11.48 +	8.6	0.34	14.0	0.70
Surgeon	319.0	11.38 +	2.1	0.08	0.5	0.02
Family x friend	55.4	1.98	33.7	1.33	11.5	0.58
Family x surgeon	4.1	0.15	20.1	0.79	71.6	3.59
Friend x surgeon	2.8	0.10	39.6	1.56	77.7	3.90
Social activities						
Family	3.3	0.14	1.2	0.07	120.8	5.79 *
Friend	10.0	0.44	42.3	2.43	35.3	1.69
Surgeon	3.3	0.14	54.6	3.14	2.9	0.14
Family x friend	6.6	0.29	1.5	0.09	0.2	0.01
Family x surgeon	2.9	0.13	38.8	2.23	0.0	0.00
Friend x surgeon	23.6	1.03	49.6	2.85	8.8	0.42
Physical difficulties						
Family	--	--	7.1	0.16	1.4	0.04
Friend	--	--	217.9	5.02 *	0.8	0.04
Surgeon	--	--	165.7	3.82	20.8	0.68
Family x friend	--	--	1.3	0.03	0.3	0.01
Family x surgeon	--	--	5.6	0.13	5.3	0.17
Friend x surgeon	--	--	11.0	0.25	5.9	0.20

* $p < .05$; + $p < .01$.

Note. As there were no significant three-way interactions, the three-way interaction terms were pooled into the error (residual) sum of squares.

Satisfaction with support. Table 7.11 shows psychological, social, and physical adjustment according to satisfaction with support received from each source, whilst Table 7.12 gives the results from the analyses of variance on these variables.

Table 7.11

Cell Numbers and Means on Psychological, Social, and Physical Adjustment According to Satisfaction with Social Support Received from each Source.

In hospital	*n*	Anxiety *M*	Depress. *M*	Self esteem *M*	Social activ. *M*	Physical probs. *M*
Family						
not satisfied	13	50.7	16.0	19.8	9.2	--
satisfied	42	40.7	9.9	25.3	9.2	--
Friends						
not satisfied	7	44.1	11.1	21.1	8.1	--
satisfied	49	42.8	11.2	24.2	9.4	--
Surgeon						
not satisfied	17	48.1	12.6	23.6	10.6	--
satisfied	41	40.9	10.7	23.8	8.5	--
1 month post surgery						
Family						
not satisfied	10	43.9	14.1	22.8	8.9	14.4
satisfied	44	37.8	9.1	24.8	9.5	9.5
Friends						
not satisfied	2	27.0	5.0	29.0	11.5	10.5
satisfied	50	39.7	10.5	24.0	9.5	11.0
Surgeon						
not satisfied	17	46.1	14.9	22.6	8.1	11.5
satisfied	30	34.8	7.1	25.4	9.8	10.8
3 months post surgery						
Family						
not satisfied	9	45.9	13.3	22.7	7.7	13.0
satisfied	43	33.6	6.9	25.1	11.2	9.4
Friends						
not satisfied	1	43.0	11.0	19.0	5.0	20.0
satisfied	48	35.7	8.1	24.5	10.7	3.7
Surgeon						
not satisfied	12	41.2	13.0	23.3	10.6	9.4
satisfied	28	34.6	6.5	25.5	10.4	11.5

Table 7.12

Analyses of Variance on Adjustment Variables, by Satisfaction with Support Received from each Source at each Interview

	In hospital		1 month post-op.		3 months post-op.	
	_MS_	_F_	_MS_	_F_	_MS_	_F_
Anxiety						
Family	886.8	5.02 *	282.2	2.98	668.8	8.23 +
Friend	31.0	0.18	189.8	2.01	0.0	0.00
Surgeon	564.4	3.19	775.1	8.19 +	500.8	6.16 *
Depression						
Family	350.5	6.01 *	137.7	3.44	177.4	7.32 *
Friend	2.3	0.04	27.3	0.68	0.0	0.00
Surgeon	50.9	0.87	413.2	10.33 +	536.7	22.13 +
Self esteem						
Family	324.6	10.79 +	33.5	1.34	2.3	0.12
Friend	5.5	0.18	35.4	1.42	33.0	1.68
Surgeon	0.6	0.02	10.8	0.43	34.1	1.74
Social activities						
Family	1.6	0.08	0.3	0.02	118.7	5.63 *
Friend	6.7	0.32	4.5	0.23	2.8	0.13
Surgeon	62.5	2.95	34.2	1.74	0.2	0.01
Physical difficulties						
Family			68.0	1.41	7.3	0.37
Friend			2.7	0.06	184.7	9.23 +
Surgeon			0.1	0.00	20.6	1.03

* $p < .05$; + $p < .01$.

Note. As there was so little dissatisfaction with support from friends, this resulted in empty cells and hence an inability to compute interaction effects. Therefore interaction sums of squares were pooled into the error (residual) sum of squares. There was no significant interaction between satisfaction with support from family and surgeons at any time.

Anxiety. From Tables 7.9 to 7.12 inclusive it can be seen that anxiety was significantly related to the amount of support received from friends at the time of surgery, $F(1, 46) = 5.81$, $p < .05$, in that those who received more support had higher anxiety levels than those who received less support from their friends. However, at the same time those who were more satisfied with support from family members had significantly lower levels of anxiety, $F(1, 49) = 5.02$, $p < .05$. One month later anxiety was similarly related to the amount of support received from friends, $F(1, 34) = 6.33$, $p < .05$, whilst those who were satisfied with support from their surgeon were significantly less anxious than those who were dissatisfied, $F(1, 37) = 8.19$, $p < .01$. At 3 months, anxiety levels were not significantly related to frequency of support from any source, but lower anxiety was related to satisfaction with support from both family, $F(1, 32) = 8.23$, $p < .01$, and surgeons, $F(1, 32) = 6.16$, $p < .05$.

Depression. Tables 7.9 to 7.12 inclusive indicate that depression levels were related to amount of, and satisfaction with, support in much the same way as were anxiety levels. In hospital, the significant factors were amount of support from friends, $F(1, 46) = 6.15$, $p < .05$ and satisfaction with family support, $F(1, 49) = 6.01$, $p < .05$; 1 month later it was satisfaction with support from surgeons, $F(1, 37) = 10.33$, $p < .01$; and at 3 months post surgery, the significant factors were satisfaction with support from family members, $F(1, 32) = 7.32$, $p < .05$, and surgeon, $F(1, 32) = 22.13$, $p < .01$.

Self esteem. From Tables 7.9 to 7.12 inclusive it can be seen that self esteem levels remained fairly constant throughout the 3-month period, and were only minimally related to amount of and satisfaction with support, with the exception of measures taken at the time of surgery. Self esteem was significantly lower for those receiving a greater amount of support from friends than for those who did not, $F(1, 46) = 11.48$, $p < .01$, and significantly higher for those receiving a greater amount of support from surgeons, $F(1, 46) = 11.38$, $p < .01$. Also, those who were satisfied with support received from family members at the time of surgery had significantly higher levels of self esteem than did those who were dissatisfied with support received from this source, $F(1, 49) = 10.79$, $p < .01$.

Social activities. Tables 7.9 to 7.12 inclusive indicate that social activities were also only minimally related to amount of and satisfaction with support, with the exception that in the third month after surgery those who received greater amounts of support from family members engaged in significantly more social activities, $F(1, 29) = 5.79$, $p < .05$, as also did those who were satisfied with support from this source, $F(1, 32) = 5.63$, $p < .05$.

Physical difficulties. From Tables 7.9 to 7.12 inclusive it can be seen that physical difficulties were experienced significantly more by subjects who received greater amounts of support from friends at 1 month post surgery, $F(1, 34) = 5.02$, $p < .05$, but there were no differences related to frequency of support at 3 months post surgery. However at 3 months post surgery, satisfaction with support from friends was significantly related to experiencing fewer physical difficulties, $F(1, 32) = 9.23$, $p < .01$.

Direction of causality between social support and adjustment

Frequency of support. Table 7.13 shows the correlations between the amount of support received at the time of surgery and psychological variables 1 month later; and between psychological variables at the time of surgery and frequency of support received 1 month later. A significant association was found between anxiety at the time of surgery and the amount of support given by family and friends 1 month later: family $r = .25$, $p < .05$; and friends $r = .31$, $p < .05$; and between depression at the time of surgery and the amount of support given by friends and surgeon 1 month later: friends $r = .32$, $p < .05$; and surgeons $r = -.27$, $p < .05$. However, the z-test performed on these pairs of cross-lagged correlations demonstrated a significant difference over time only between anxiety and the amount of support received from the family, $z = 2.31$, $p < .05$. In order to determine whether this trend between anxiety and family support continued after 1 month post surgery, correlations were calculated between anxiety at 1 month and family support at 3 months post surgery, $r = .17$, $n = 52$; and between family support at 1 month and anxiety at 3 months post surgery, $r = .21$, $n = 52$. There was no significant difference between these correlations, $z = 0.24$.

Table 7.13

Cross-lagged Correlations Between Anxiety and Depression and Frequency of Social Support Received at the Time of Surgery and at 1 Month Post Surgery, and z-tests on these Pairs of Correlations.

Variable at time of surgery	Variable at 1 month post-op.	N	Pearson's correlation	Fisher's Z transformation	z
Anxiety	Family support	54	.25 ‡	.26)	2.31+
Family support	Anxiety	54	-.20	-.20)	
Depression	Family support	54	.17	.17)	1.49
Family support	Depression	54	-.12	-.12)	
Anxiety	Friend support	52	.31 ‡	.32)	1.31
Friend support	Anxiety	55	.06	.06)	
Depression	Friend support	52	.32 ‡	.33)	1.17
Friend support	Depression	55	.10	.10)	
Anxiety	Surgeon support	47	-.05	-.05)	0.39
Surgeon support	Anxiety	57	-.13	-.13)	
Depression	Surgeon support	47	-.27 ‡	-.28)	1.32
Surgeon support	Depression	57	-.01	-.01)	

‡ $p < .05$, Pearson's correlation.
\+ $p < .05$, z-test.

Satisfaction with support. Table 7.14 is similar to 7.13 except that satisfaction with support received is considered instead of frequency. A significant association was found between satisfaction with support received from families at the time of surgery and anxiety and depression levels 1 month later: anxiety $r = -.29$, $p < .05$; and depression $r = -.28$, $p < .05$; and between anxiety and depression at the time of surgery and satisfaction with support received from surgeons 1 month later: anxiety $r = -.30$, $p < .05$; and depression $r = -.46$, $p < .01$. The z-test performed on these pairs of cross-lagged correlations demonstrated a significant difference over time between only one pair of variables, i.e., depression and satisfaction with support from surgeons, $z = 2.06$, $p < .05$. In order to determine whether this trend between depression and surgeon's support continued after 1 month post surgery, correlations were calculated between depression at 1 month and surgeon's support at 3 months post surgery, $r = -.21$, $n = 52$; and between surgeon's support at 1 month and depression at 3 months post surgery, $r = -.53$, $n = 45$. There was no significant difference between these correlations, $z = 1.67$.

Table 7.14

Cross-lagged Correlations Between Anxiety and Depression and Satisfaction with Social Support Received at the Time of Surgery and at 1 Month Post Surgery, and z-tests on these Pairs of Correlations

Variable at time of surgery	Variable at 1 month post-op.	N	Pearson's correlation	Fisher's Z transformation	z
Anxiety	Family support	54	-.11	-.11)	0.98
Family support	Anxiety	54	-.29 *	-.30)	
Depression	Family support	54	-.13	-.13)	0.79
Family support	Depression	54	-.28 *	-.29)	
Anxiety	Friend support	52	-.03	-.03)	0.52
Friend support	Anxiety	55	-.14	-.14)	
Depression	Friend support	52	.11	.11)	1.49
Friend support	Depression	55	-.19	-.19)	
Anxiety	Surgeon support	47	-.30 *	-.31)	1.02
Surgeon support	Anxiety	57	-.10	-.10)	
Depression	Surgeon support	47	-.46 **	-.50)	2.06+
Surgeon support	Depression	57	-.08	-.08)	

* $p < .05$; ** $p < .01$, Pearson's correlation.
\+ $p < .05$, z-test.

Volunteer hospital visitors and peer support

Fifty subjects had interviewed a hospital visitor who had previously had similar surgery. Of these interviews, 36 were arranged by the surgeon or hospital staff and the other 14 were with friends of the subject or with someone introduced to her through her friends. Twenty-one subjects had spoken with this person prior to their surgery; whilst the number of days post surgery when subjects spoke to such a person ranged from the day of surgery to 14 days later, the mean number of days being 5. Most subjects were satisfied with the timing of the visit, with the exception of six who had seen their hospital visitor from 2 to 5 days post surgery and complained that this was too early; and one who saw her visitor at 4 days post surgery and said that this was too late.

Table 7.15 shows how the 50 subjects who were visited by a volunteer hospital visitor rated the helpfulness of the visit on each of the areas listed.

Table 7.15

Areas of Potential Helpfulness from Volunteer Hospital Visitors, and the Percentage of Subjects Finding each Area Helpful

N = 50	Not Applicable	Not very helpful	Quite helpful	Very helpful
Advice about:	%	%	%	%
communicating with doctor	90	2	2	6
communicating with husband	86	4	8	2
communicating with children	92	4	2	2
what treatment to have	90	0	8	2
side effects of treatment	86	2	8	4
exercising of arm	50	10	26	14
prostheses	64	6	10	20
financial matters	94	4	2	0
resuming work	88	2	4	6
playing sport	88	4	4	4
resuming social life	76	4	10	10

Fortytwo (84%) subjects stated that they would recommend that other patients see a volunteer hospital visitor; two (4%) said they would not recommend this; and six (12%) did not answer this question. Eleven subjects included comments about the visit in the space provided, and these can be seen in Appendix C-6.

Cancer support groups

Of the 56 subjects who were sent the fourth questionnaire, only six had attended a cancer support group, and of those, one rated her experience as "extremely positive"; three rated it as "quite positive"; one as "neither positive nor negative"; and one didn't answer this question. Because so few subjects attended cancer support groups, this data can not be analysed further. However, 45 subjects answered the questionnaire on how much time they considered should be devoted to aspects of an ideal cancer support group, and Table 7.16 gives their answers:

Table 7.16

Areas of Discussion in Cancer Support Groups, and the Percentage of Subjects Allocating Time to Each

N = 45	No time	A little time	Moderate time	A lot of time
	%	%	%	%
Providing medical information	0	4	38	58
Alternative treatments (eg diets)	4	11	33	51
Sharing feelings and emotions	2	11	51	36
Solving specific problems	4	4	38	53
Companionship	7	18	53	22
Talking with similar others	4	18	42	36
Dealing with pain or nausea	4	11	38	47
Information on coping	7	9	33	51
Dealing with cancer related crises	2	11	36	51
A place to give and receive love	13	13	51	22
A place from the harshness of the health care system	13	13	53	20
Learning how others solve similar problems	4	13	49	33
Offering advice	7	18	51	24
Offering reassurance (hope)	4	11	36	49

Fourteen (26%) of 54 subjects said they would prefer discussing their cancer-related problems with one patient with a similar diagnosis and treatment; 20 (37%) preferred meeting with a group of breast cancer patients; and 20 (37%) had no desire to do either of these. The first 34 replies were as follows:

I prefer talking to one similar patient	6 (18%)
I prefer meeting with a group	19 (56%)
I would not like to do either	9 (26%)

These results seemed unusual, as 56% claimed to prefer meeting with a group, and yet only five (14%) had attended a cancer support group, although information regarding these had been provided to all patients. Therefore it was hypothesized that the positioning of the question may have had an effect on the answers. In order to check whether this was so, this question was moved from immediately after the question on what an ideal cancer group should spend time on, to the previous page. It now followed questions on why some people do not share their concerns with others. After this repositioning, the remaining 20 subjects answered in the following manner:

I prefer talking to one similar patient	8 (40%)
I prefer meeting with a group	1 (5%)
I would not like to do either	11 (55%)

Crosstabs computed on the number of subjects who preferred meeting with a group of breast cancer patients, as indicated in the two different formats, resulted in a significant difference, Chi-squared (2) = 14.79; $p < .01$.

Discussion

There were two significant differences shown when subjects who were interviewed (i.e., those living in the inner metropolitan area) were compared with those who were sent postal questionnaires (i.e., those living outside the inner metropolitan area). These were: subjects living outside the metropolitan area (a) had more support from their family members at the time of surgery; and, at the same time, (b) were more satisfied with the support they received from their surgeons. However, at the time of surgery there was no difference in the method of presentation of the questionnaire, as all were completed by interview whilst subjects were in hospital. Therefore the two differences found must be a function of subjects' living further from the city rather than of questionnaire presentation.

Frequency and satisfaction

The correlations betweeen frequency of support and recipient satisfaction with this frequency (Table 7.2) give some idea of how much value is put on each type of support from each source. Satisfaction with empathic support from family members and surgeons was significantly positively related to frequency at all three interviews, indicating a desire for a great deal of empathic support from these sources. However, informational support displayed a different pattern, with a positive correlation when given by surgeons, significant at all three interviews, but with a negative correlation, significant only at 1 month post surgery, when given by families. Thus the most satisfied subjects were those who received (a) a great amount of information from surgeons, and (b) a small amount of information from family members. This supports the findings of Dunkel-Schetter (1984), who found that cancer patients required information from professional sources, but often resented this from families and friends.

Satisfaction with reassurance from surgeons resulted in low correlations with frequency. On the other hand, there was a negative correlation between satisfaction and frequency of reassurance from families at 3 months post surgery, indicating that patients often did not find such reassurance to be helpful. In fact it was sometimes seen as a "fobbing off"; a way of trying to calm a person whose reactions or whose questions were upsetting the care-giver. Satisfaction with tangible support from families correlated positively with frequency at the time of surgery and 1 month post surgery, indicating a need and a desire for this type of support from this source. Generally there was satisfaction with all types of support given from friends (Table 7.4), and from the low correlations it appears that some subjects required more than others from this source, but most subjects received what they needed.

Although it is of interest to compare frequency with satisfaction, satisfaction is more pertinent to adjustment, because some people prefer more/less support than others. The question of whether people's needs are being met is more important than the number of potentially supportive behaviours towards them. Further, as the amount may be excessive, but never the satisfaction, it is easier to quantify satisfaction with respect to whether needs are being met.

Support from family, friends, and surgeon

Family members provided significantly less support as time from surgery passed (Table 7.3). The main type of support provided by families was empathic, particularly in the period immediately before the operation. Yet empathic support was most widely criticised at all three interviews as being the most insufficient type of family support (Table 7.4). Moreover, informational support was given least often, yet at both 1 month and 3 months post operation it generated the greatest amount of satisfaction. This supports findings from other studies showing that cancer patients require significant amounts of empathic support from family members, yet do not look for advice and information from this source (Dunkel-Schetter, 1984).

Cancer does not necessarily cause stress on family relationships. In fact, many families were brought closer together by the experience, as was indicated by the number of subjects who noticed a marked improvement in the relationship between themselves and their husbands (Chapter 6). In Table 7.6 the two columns indicating with whom subjects shared their concerns, demonstrated that 27 (68%) of the 40 married subjects confided in their husbands. Children were also a high priority for sharing of confidence, as 25 (50%) of the 50 subjects who had children confided in them about their problems, and this would have excluded those with young infants.

Appendix C-3 contains comments made by subjects on the support they received from family members. Comments such as those from subjects no. 21 and 48, together with subject no. 29 regarding her husband, showed that cancer had a uniting effect on the family. Positive comments made by family members raised subjects' morale, such as those from the families of subjects no. 46 and 59. Subject no. 1 noted that her husband helped with chores, but the most helpful thing was that he "let me do what I could myself slowly", thus finding a formula of helpfulness without dependency.

One of the main problems in family support appeared to be in a blocking of communication. This was also illustrated in some of the comments recorded in Appendix C-3. Sometimes the subject herself felt uncomfortable about communicating her fears because of reactions anticipated in others. This may have originated from previous comments or non-verbal responses from family members. Two subjects didn't talk about their cancer to their husbands "because he gets upset" (S. 57), or for fear of scaring him (S. 48). One subject was so stressed at hearing that she had cancer in her lymph nodes that she hadn't told her husband 2 months later (S. 12). At other times family members refused to allow the subject to communicate her feelings (Ss. 2, 24, 40, and the parents and sister of S. 29). Sometimes, however, the most hurtful things were unsaid. This was illustrated by subject no. 41, who claimed that her husband and sister had her buried, and subject no. 39, whose son looked at her as if she were a stranger. Some family members, however, found more obvious ways to withhold support. One husband confined himself to bed when his wife felt ill (S. 14), whilst another asked "Are you going to make sandwiches for lunch?" on the day his wife arrived home from hospital (S. 55). As subject no. 35 commented about her family, "As soon as they see you up and about, they expect you to do things".

Friends provided significantly less support overall than did families and surgeons (Table 7.3), yet the reported satisfaction with support given by friends was greater than that from either of the other two sources (Table 7.4). As with family members, empathic support was by far the most frequently received, whilst information was least frequent. This again supports other findings regarding the importance of empathic support from close friends and confidants and the relative lack of need for information from non-professional sources (Dunkel-Schetter, 1984).

Appendix C-4 contains comments made by subjects on the support they received from friends, and indicates that many subjects were happiest just being with someone with whom they felt comfortable, without necessarily having things done for them (Ss. 7, 24, & 53, and the workmates of S. 4). Perhaps this just represented a reassurance of their worth. Subject no. 48 pointed out the difference between the emotional sympathetic response of some friends and the understanding empathy of the one whom she found most supportive. Comments made by other subjects described some of the much appreciated services and information provided by friends (Ss. 1 & 5), especially those friends who had had cancer themselves (S. 3). Attitudes expressed by friends also often proved helpful (Ss. 6, 8, 26, 36, & 43).

Some friends, however, were mentioned amongst the most unhelpful. There were those who visited but couldn't talk, such as the friend of subject no. 3, who "just sat and looked upset; then she cried", and subject no. 12 who just watched television when she visited. Other friends said the wrong things, as illustrated by the comments of subjects no. 48 and 20. Subject no. 32's friend not only treated her as though she were already dead, but also habitually rang her mother to see how she was, instead of ringing her. Some people said things which were unkind (S. 44) or unthoughtful, such as comparing subjects with people they know who have died of cancer (Ss. 35 & 55). Also, friends who gave medical advice were generally not appreciated (Ss. 4 & 14). This supports Dunkel-Schetter's (1984) finding that cancer patients do not look for advice from non-professional sources.

People don't like being pitied but they do need to be understood (S. 48). The non-materialization of expected support, referred to by Peters-Golden (1982), was experienced by some (Ss. 4 & 8). But it appears from most comments and also from Table 7.4 that, although some potentially supportive behaviours were not seen as supportive by the recipients, there was not much actual withdrawal of support. However, some subjects felt that they were not able to talk to their friends for various reasons, such as not wanting to frighten them (S. 30), to be a burden (S. 35), or to appear to be whinging (S. 55).

Smith et al. (1985) noted that one of the reasons why older people suffer less from having cancer was because they have had a longer time to build "durable sources of support" (p. 77). However, Broadhead et al. (1983) noted that older people had fewer supports because of reduced social network size. This was illustrated by subject no. 30, who lost 23 friends from cancer or heart trouble in the last 3 years.

Surgeons provided significantly less support as time from surgery passed (Table 7.3). Their main areas of support were in listening to and trying to understand their patients, and in answering their questions (Appendix B-1). As the maximum frequency given in this table was 3, it can be seen that a great amount of these two areas of support was given. It is in this area that coping theory is most clearly applied to support seeking. One of the most effective ways for cancer patients to appraise their situation is through the information received from health professionals. By far the most sought after support from medical practitioners was that they have sufficient time to explain things fully so that subjects didn't feel rushed and under pressure.

Appendix C-5 contains comments made by subjects on the support they received from medical practitioners. Those whose surgeons explained what was happening and answered questions felt that they were understood and accepted (Ss. 12, 15, & 30). Subject no. 24 aptly commented, "Some doctors may as well be vets; they just feel around and don't talk"! Subjects no. 9 and 38 were grateful for the information given them by their surgeons, noting that they would rather know of possible side effects in advance, even if they do not experience them. Some surgeons had a lot of time for their patients, and this was greatly appreciated (Ss. 5, 9, & 14). Often it was merely the surgeon's general caring attitude which was found to be most reassuring (Ss. 16, 18, & 34).

Some subjects found their surgeons to be very busy, and although they did not see this as cause for complaint, it discouraged them from seeking assistance from them (Ss. 35, 51, & 58). This fear of taking up too much of the surgeon's time was also noticed by Eidinger and Shapira (1984). Others refrained from asking questions for different reasons, including fear of the surgeon (Ss. 22 & 57), being over-awed by the surgeon's superior education (S. 8), feeling stupid asking questions whilst the nurse was present (S. 14), and being afraid of the answers (Ss. 27 & 48).

Many subjects focussed their complaints on the rushed attitude of some surgeons (Ss. 39, 40, & 55). Others said that their surgeon was patronizing (S. 32), abrupt (S. 41), or evaded questions (S. 4). Medical practitioners other than surgeons also had complaints levelled against them. These included treating patients uncaringly (S. 44), evading questions (S. 8), lying (S. 49), and accusing a patient of being over-anxious when she presented with a breast lump that he did not recognise as cancer (S. 11).

However, the comments made by some subjects were a clear indication that in some respects it is impossible for surgeons to satisfy them all. It is generally taken for granted that subjects want information about their cancer, treatment, and possible side effects. This was illustrated in this study by the number who complained that this information was not forthcoming, and also those who expressed gratitude for surgeons who took the time and trouble to give this information. Yet subject no. 41 complained of having been told too much, commenting that "I don't want to know everything". Also, different subjects made contradictory statements about the same surgeon--subject no. 48 complained of his being too quiet, whilst subject no. 34 found his quietness relaxing.

Public vs private patients. When frequency of support from surgeons was divided into whether it was given to public or private patients respectively (Table 7.7), the only significant difference was at 3 months post surgery when surgeons reportedly listened to and tried to understand private patients more frequently than public patients. Thus in most cases surgeons did not appear to make any distinction between their treatment of public and private patients respectively. However Table 7.8 indicates that public patients were more dissatisfied with surgeons' support than were private patients (although this difference was not significant). Because both groups of patients reported receiving similar amounts of support, the difference in satisfaction can presumably only be put down to it being more of a "norm" for public patients to complain and compare themselves with the treatment which they presume private patients would be receiving; whilst private patients, who have paid considerably more, and who may have carefully selected their surgeon, are more satisfied, if merely to justify their choice. Also, public patients are not always seen by the same surgeon, and so an equal amount of information coming from different sources may not generate the same satisfaction (Lieberman, 1986).

Hospital staff. Comments recorded in Appendix C-7 illustrate the importance of the role of nurses and social workers in the overall care of the patient. If such people are understanding, this may help take some of the load from the surgeon, as nurses and social workers are in the hospital all day and are therefore more available.

Hospital nurses were counted amongst the most helpful people by some subjects, who appreciated their availability and sensitivity (Appendix C-5, S. 57; Appendix C-7, Ss. 2 & 5), and the information which they made available (Appendix C-5, S. 8; Appendix C-7, S. 1). Some of the negative comments made about nurses are more of an indicator of a patient not receiving the message which the nurse tried to communicate, rather than a complaint about service. This is especially illustrated by subject no. 30 (Appendix C-7) when the nurses were checking that she was aware of what operation she was to have, but conveyed the impression that they didn't know what they were doing!

Appendix C-7 indicates that some hospital conditions were distressing. For example, one subject saw hospital as too clinical and unfeeling (S. 27); one was upset by another patient who found her prognosis hard to accept (S. 58); and another found that the worst thing about having chemotherapy was seeing other people who were worse off than herself (S. 9). The importance of careful selection of ward staff was illustrated when one hospital social worker upset three patients (Ss. 8, 19, & 22). Also, the chiropractor's remarks to subject no. 29, "You created your cancer by not having enough time for yourself. Doctors are butchers", illustrates the distress patients can feel when professional people have differing views.

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Comparison of support given by families, friends, and surgeons. At all three interviews, surgeons provided significantly less of both reassurance and empathic support than did family members (Table 7.3). This difference in support frequency was reported mainly in the area of giving patients less encouragement to talk about their emotional feelings than did families or friends (Appendix B-1). Dissatisfaction with this area of surgeons' support was high, rising to 26% at 1 month and 28% at 3 months post surgery (Appendix B-2). Surgeons gave patients more encouragement to talk about physical feelings than did family or friends, dissatisfaction with this support given by surgeons was also high (19% at 1 month and 25% at 3 months post surgery), indicating that patients needed to be able to say more at post surgical check-ups. At the time of surgery, patients believed that surgeons listened to and tried to understand them slightly more than did family and friends, but the frequency of this behaviour from all sources decreased over time, with the greatest decrease being from surgeons (Appendix B-1). This lack of being listened to and understood was reflected in patients' dissatisfaction ratings (Appendix B-2). Dissatisfaction with family support in this area was highest at the time of surgery (13%) but was overtaken by dissatisfaction with surgeons at 1 month (21%) and at 3 months post surgery (25%). Overall, the dissatisfaction rates for surgeons' empathic support were extremely high: 19% at the time of surgery; 34% at 1 month; and 30% at 3 months post surgery (Table 7.4). Perhaps the reason for this could be a different perception of the role of the surgeon as seen by surgeons and patients respectively. Surgeons may view themselves as experts in surgical techniques, whilst research has shown patients' satisfaction with surgeons is more related to their empathy than their skill (Dunkel-Schetter, 1984).

Surgeons reportedly gave significantly more informational support at all three interviews than did family members (Table 7.3). Yet there was much more dissatisfaction with this support than there was with that given by families (Table 7.4). The reason could be that, although the majority of subjects said that the surgeon didn't evade or refuse to answer questions, some admitted that they didn't ask many questions, giving reasons such as being afraid of the answers (Ss. 27, & 48); feeling stupid asking in front of the nurse (S. 14); or the surgeon being too busy (Ss. 28, 35, 51, & 8); patronizing (S. 32); or abrupt (S. 41). This may be the reason for the great increase in dissatisfaction at 1 month post surgery. In particular, the item "told you what to expect" had a dramatic rise in dissatisfaction from 5% in the first interview to 21% 1 month later (Appendix B-2). However, it is difficult to determine whether or not advice had been given, as many patients were in such a state of shock over what had happened that they took in very little information. There may also be a problem for surgeons in knowing how much to tell patients, and in determining how much those who don't ask want to know. Coupled with this is the fact that surgeons themselves feel a considerable amount of stress arising from the ambiguities of cancer, and from their relationship with, and responsibility for, their patients' emotional needs (Amir, 1987).

Table 7.4 indicates that families and friends are more likely than surgeons to be resented for giving too much "support". This demonstrates that for families in particular and to a lesser extent for friends, there seems to be a balance in satisfaction with support which is rather finely tuned. Thus a lot is expected of the probably untrained lay person who, by virtue of personal bonds with the sick person, is widely expected to fulfil a supportive function. Yet research has indicated that "natural" support givers are the most valuable source of empathic support (Winefield & Neuling, 1987). This may place a lot of stress on family members, who may not feel equal to the task. This would apply most particularly to husbands, as they were nominated by over 90% of married subjects as the most supportive family member.

It is interesting to compare answers given by subjects as to which type of support is most helpful from each source (Table 7.5). The three most often chosen from families were: first, "Helped with chores, transport or childcare"; second, "Told you they loved you or made you feel loved"; and third, "Listened carefully to what you said and tried to understand". The three most often chosen forms of support from friends were the same as those chosen from family members, except that they came in a different order. "Helped with chores, transport or childcare" was selected third instead of first. As this was more often a support given by families, it was not necessary for friends to fill this need. For surgeons the three most often chosen were: first, "Answered all your questions"; and second, "Told you what to expect" and "Listened carefully to what you said and tried to understand". Also, 16% of subjects said that their surgeon did nothing (apart from the surgery) that they considered to be particularly helpful! Understandably, the item selected as the most helpful support from surgeons was "Answered all your questions", yet this is interesting in view of the number of subjects who admitted not asking their surgeons many questions for the reasons given above. This table also further illustrates the fact that subjects appreciated surgeons giving advice on what to expect, but didn't want this from non-professional sources. This item was not selected at all from families, and only once from a friend, this friend being one who had had similar treatment.

Social support and adjustment

There were very few significant effects in the relationship between support frequency and adjustment. Those who received more support from friends at the time of surgery were significantly more anxious and depressed, and had lower self esteem, than those who received less support from friends; and those who received a greater amount of support from this source during the month after surgery were significantly more anxious and had more physical problems (Tables 7.9 & 7.10). This corresponds with Hyman's (1971) findings of a positive correlation between family support and disability amongst chronically ill patients. However it can not imply causality. It may be that, as Shinn, Lehmann, and Wong (1984) claimed, distress may elicit more support in the short term. However, it may be that a great amount of "support" resulted in subjects becoming temporarily less well adjusted, almost like a "learned helplessness" effect. In contrast to the above association, those receiving greater amounts of support from the surgeon at the time of surgery had a significantly higher measure of self esteem. This may reflect the differential effect of assistance from the surgeon and from friends on self esteem, or it may simply be that those who feel better about themselves are more able to elicit helpful amounts of support.

Psychological adjustment was significantly related to satisfaction with support from (a) family members at the time of surgery and at 3 months post surgery, and (b) surgeons at 1 and 3 months post surgery (Tables 7.11 & 7.12). Satisfaction with family support was of prime importance for psychological adjustment in the initial stages, whilst patients were accustoming themselves to the fact that they had cancer and were undergoing surgery. One month later, satisfaction with support from surgeons became more important whilst patients received biopsy results, and made decisions about, and if necessary began, adjuvant therapy. Then, at 3 months post surgery, satisfaction with support from both family members and surgeons was significantly associated with psychological adjustment. This indicates patients' continuing need for support from both of these sources. It may also indicate a misfit between patients' and surgeons' understanding of the surgeon's role, as there was considerable dissatisfaction with empathic and informational support from surgeons, even although they gave significantly more information than family members. Some surgeons were very busy and did not encourage questions, perhaps believing that their greatest usefulness in the giving of support was before and immediately after surgery. Also, a number of patients commented that for various reasons they felt unable to tell their surgeon things that were worrying them.

Past research has indicated that social support and adjustment influence each other (Winefield & Neuling, 1987; Wortman, 1984). Social support is associated with good adjustment, and conversely, those who are well adjusted find it easier to elicit social support. Because the direction of influence is two-way, there is difficulty in assigning causality. Table 7.13 indicated that in the first month after surgery there were only one pair of variables where an effect of greater cause was evident, i.e., anxiety levels at the time of surgery had a significantly greater effect on the amount of family support given 1 month later than family support at the time of surgery had on anxiety 1 month later. This could have been initiated by either party. Anxious patients may have confided more fully in their families and so elicited more support; or families of the more anxious patient may have sensed this anxiety and increased their support in order to allay the patient's fears. However, this effect of anxiety on family support should be interpreted cautiously, as it did not continue between the interviews held at 1 month and 3 months post surgery.

A comparison of cross-lagged correlations between psychological adjustment and satisfaction with support at the time of surgery and 1 month later indicated that the effect of depression on satisfaction with surgeons' support was significantly greater than the effect of satisfaction with surgeons' support on depression (Table 7.14). Again, this should be interpreted cautiously, as it did not continue between the interviews held at 1 and 3 months post surgery. It could mean either that depressed patients' unfavourable attitude towards their illness at the time of surgery reduced their appreciation of what the surgeon was trying to do for them in the following month; or it might have been that surgeons put a distance between themselves and their more depressed patients in the first month after surgery, perhaps finding them difficult to handle. The possibility of either of these views being correct may be given weight by the significant negative correlation between depression at the time of surgery and the amount of support given by the surgeon 1 month later (Table 7.13), although no causal relationship can be inferred here. Again, it appears either that patients who were depressed in hospital actually received less support from their surgeon at 1 month post surgery, or that their depressed outlook reduced their ability to see what their surgeon was doing for them.

Volunteer hospital visitors

The individuality of patients was demonstrated in this section. One who was visited 5 days after her surgery complained that this was too soon, whilst another who was visited 4 days post surgery complained that this was too late. This emphasizes that there is not one optimum time to visit all patients, but services should be tailored to fit patient needs where possible. This may be difficult, however, because of the number of people involved in organizing a visit. First the surgeon recommends the visit to the patient and, if she agrees, then the ward nurse informs the BCSS coordinator, who contacts a suitable visitor. Also, not all volunteers are able to visit at short notice.

The most valued service noted in the questionnaire was receiving advice about exercising the arm which had become somewhat immobile due to the effects of axillary node sampling. Twenty-five (50%) of the 50 subjects who answered this part of the questionnaire were grateful for this, as few had access to a physiotherapist and it is probable that no staff member had the specific responsibility of passing on this information. After this, the most valued service was receiving information about prostheses, and then advice on resuming social life. These are all areas where someone with specialized knowledge is most helpful. These volunteer visitors have had breast cancer, and have been trained in hospital visiting, and so are aware of patient needs.

However, from the comments made about the volunteer hospital visitor, it is obvious that the questionnaire did not tap the most valuable things about the visit. It was not the advice or information imparted that was most helpful, but the general attitude of the visitor, and the fact that she was a model of how breast cancer and its treatments can be successfully overcome. Social comparison theory states that people evaluate themselves and their abilities through comparison with similar others, and it appears that the greatest benefit from the hospital visitor program came from upward comparisons. The most often used phrase was, "She gave me confidence"--confidence in the ability to live a full life again and to look "normal".

Cancer support groups

According to the 45 subjects who answered the questionnaire on what an ideal cancer support group should spend time on (Table 7.16), most emphasis should be given to providing medical information and solving specific cancer related problems, whilst considerably less time should be devoted to the giving of warmth, love, and companionship, although most agreed that these aspects should also be a part of the group. A cancer support group with these emphases would supplement the information given by surgeons and health professionals. Patients need a lot of information, but as the comments section has demonstrated, many of them do not ask for this from their surgeons. It would be easier for people who felt hindered from asking the surgeon to get their information in a support group situation where the atmosphere may be more conducive to the welcome reception of questions, and where perhaps others may ask questions for all to hear the answers.

As the majority of subjects believed that at least a moderate amount of time should be given to all of the items listed in the questionniare, it would seem that they were aware of the possible benefits of a cancer support group. Yet at 6 months post surgery, when this questionnaire was being answered, only six (11%) of the 56 respondents had attended a cancer support group, although information regarding these groups had been provided to all patients. This unusually low number of support group attenders was first noticed when 34 subjects had answered the final questionnaire. Nineteen (56%) of the first 34 respondents stated that they would prefer meeting with a group of breast cancer patients to discuss cancer related problems, rather than talking privately with one similar patient, or not doing either, and yet only five (14%) had attended a cancer support group. For this reason it was hypothesized that the positioning of the question may have had an effect on the answers. Therefore the question on preferences for discussing cancer related problems was moved from its position immediately after the list of support group items to the previous page, immediately following the questions on why some people do not share their concerns with others. This repositioning resulted in a significant difference in responses, as only 1 of the remaining 20 subjects claimed she would prefer to meet with a group. This significant response difference due to the repositioning of the question necessarily rules out any comment with regard to preferences for the discussion of cancer-related problems. However, it certainly demands attention in raising the very real possibility that respondents can be channelled into a way of responding simply by the positioning of questions.

Some people did not discuss their cancer related concerns. Only 17 (31%) of the 55 subjects who answered the question on sharing of cancer related concerns said that they shared their problems fairly often, whilst 15 (27%) said that they don't need to talk. Looking at the high percentage who did talk to their husband, children, siblings, or close friends (Table 7.6), it seems that many talk sometimes but not often. Some of the comments also illustrate the fact that many people don't like to dwell on things but need to be able to talk occasionally. Therefore, the 27% who said that they don't need to talk about their worries may not be denying, but may be amongst those who talk sometimes but don't need to do so often. This also may depend on the personal meaning of the word "often". The 10 (18%) who said that they don't want to worry or upset anyone are amongst those who look after their relationships and protect them, as also are the 8 (15%) who don't want to appear self-centered, self-pitying, or complaining. But this projection of how others may receive their worries may be incorrect, and may inhibit a closeness which could benefit both the giver and the receiver.

Summary

This research used the sources and types of supportive behaviours first explored by Dunkel-Schetter (1984), and the results found by the MDSS supported and expanded her findings.

This indicates the generalizability of Dunkel-Schetter's findings, and also the usefulness of the MDSS. The internal reliability of the MDSS is high (Table 2), and its sensitivity has been demonstrated by the different results emerging for each type of support from each source. As this means of measuring support is both reliable and sensitive, and as it comprehensively taps the multidimensional nature of social support, it may well be a useful instrument for use with other populations.

Results indicated that significantly less support was given by all sources as time from surgery passed. Family members, and to a lesser extent friends, were appreciated for empathic and tangible support rather than advice or information. Although there was evidence that some patients were reluctant to worry others with their concerns, there was very little non-materialization of expected support from non-professional sources.

Psychological adjustment was significantly related to satisfaction with support from (a) family members at the time of surgery and at 3 months post surgery, and (b) surgeons at 1 and 3 months post surgery. This indicates patients' continuing need of support from both of these sources. Yet by far the most frequent complaints of too little empathic and informational support were directed at surgeons (Table 7.4). This may be partly due to a difference in the perceived role of surgeons by patients and surgeons respectively. Some surgeons may not see their role as providing empathic support, or, if they do, may not have the time or skills to fulfil these patient needs. Perhaps this need could be filled by someone who is part of the hospital team, and who is closely associated with the surgeons in their dealings with patients and knows the individual patient's prognosis. A study undertaken by Maguire et al. (1980) on the efficacy of counselling by a specialist nurse, found that, whilst such an intervention did not prevent psychiatric morbidity, it did enable the nurse to recognise and refer most patients who needed help, and thus reduced morbidity in the longer term. Maguire's study indicated patients' unwillingness to disclose their need for help--a fact that was also brought out in the present study. This points to the need for awareness on the part of professionals of the factors inhibiting patients from seeking help.

One important aspect of social support is support elicitation (Winefield, 1984), and the ability to deal with unsatisfactory social interactions. These are part of the coping construct. Studies have demonstrated that support is more readily available to those who are coping effectively (Bruhn & Philips, 1984). Conversely, Thoits (1986) defined social support as 'coping assistance', indicating that those who have adequate support are enabled to cope more satisfactorily. The effect of various coping strategies on the social support - adjustment process should be considered (Coyne & DeLongis, 1986; Shisana & Celentano, 1987). Therefore the next chapter will investigate the effects of different coping strategies on psychological, physical, and social adjustment, and also the relationship between coping and social support.

CHAPTER 8

Coping Strategies in the Prospective Study

As reviewed in Chapter 4, coping is "what one does about a perceived problem in order to bring about relief, reward, quiescence, or equilibrium" (Weisman & Worden, 1976, p. 3), and may be directed at changing the stressor itself or at regulating the emotions of the stressed person. The way people cope is influenced by their belief systems, problem solving skills, social skills, and the social and material resources available to them, together with the meaning of the particular stressor in their lives. Therefore, there is a specificity about coping which cannot be captured by a global study of general coping style. There is also a multidimensionality about coping, due to the changing person-environment relationship which is effected as a stressor is evaluated, acted upon, and re-evaluated. Responses which are not successful in alleviating the effects of the stressor may be changed, new responses may be sought, and a variety of responses may be utilized at any one time in order to alter the stressor itself or to lessen its impact. Hence it is important to capture the continuous movement between thoughts, actions, and the many responses which may be used. This can only be fully captured by the use of multiple measures in a longitudinal study.

It is important to investigate the inter-dependency between coping, social support and adjustment. "Social support can interface with almost every coping strategy mentioned in the stress literature" (Shumaker & Brownell, 1984, p. 25). Support may enable a person to cope more effectively (Billings & Moos, 1982) and hence enhance adjustment. Coping is often facilitated by reassurances of love or caring. Different aspects of support may influence coping in various ways: tangible support dissipates some aspects of a stressor; informational support assists in organizing appropriate coping responses; and empathic support mobilizes coping resources by increasing self esteem (Wilcox & Vernberg, 1985). However, this is not a one-way procedure. Seeking or receiving social support is, in itself, a form of coping. Further, the way a person copes may affect the support received (Broadhead et al., 1983). Well-integrated individuals generally receive more assistance than those who are coping less well (Bruhn & Philips, 1984). Yet, as Wortman (1984) stated, the relationship between social support and coping has been neglected. This research, therefore, will inspect the interrelationship between coping, social support, and adjustment.

Past research has attempted to classify coping responses into clusters either by factor analysis or theoretically, but as yet there is no agreement as to which set of groupings is most useful (Billings & Moos, 1984). In this study coping responses will be divided into active and passive responses, and the active responses will be further divided into cognitive and behavioural. These groupings were selected because they are well-defined and comprehensive, thus avoiding problems encountered with the use of factor-analysis derived groupings where a coping response may fit equally well into more than one category. In order that this study will not be biased in its consideration of adjustment, the three aspects of physical, social, and psychological adjustment will be considered, and causal relationships will be statistically investigated.

Hypotheses

1. The more coping strategies used, the less depressed and anxious the subject will be (Moos & Tsu, 1977; Pearlin & Schooler, 1978).

2. Rather than any one particular group of coping strategies being used more than others, subjects will either tend to use a wide range of strategies or else use few of any kind. This will lead to a high positive correlation between coping strategy groups (Aldwin & Revenson, 1987; Folkman & Lazarus, 1985).

3. There will be high positive correlations between coping and social support, indicating that these two variables are inter-related (Thoits, 1986).

Method

Measures

Coping with stress during the month preceding and the 3 months following surgery was assessed by a 25-item questionnaire adapted from Folkman and Lazarus's (1985) Ways of Coping checklist. After distribution of the questionnaires for feedback, the wording of one item was altered from "Looked for sympathy and understanding from someone" to "Looked for understanding from someone", as many objected to the word "sympathy" whilst agreeing that they would look for understanding. Subjects were asked how often in the past month they had used each of the listed coping strategies. This was rated on a 4-point scale ranging from "does not apply/never" to "very often". Folkman and Lazarus (1985) used a 4-point scale in their revised Ways of Coping checklist, and found it to be more satisfactory than the YES/NO response which had been used previously.

Statistical analyses

Coping items were grouped according to the strategy used, as shown in Table 8.1. These groupings were suggested by Billings and Moos (1981), and were found to be more logical than those generated by factor analyses, as discussed in Chapter 3.

Table 8.1

Groupings of Coping Strategies

Avoidance / Denial
- Felt time would make a difference--the only thing to do was wait
- Went along with fate; sometimes you just have bad luck
- Went on as if nothing were happening
- Tried to keep your feelings to yourself
- Tried to make yourself feel better by eating, drinking, or smoking
- Avoided being with people in general
- Kept others from knowing how bad things were
- Took it out on other people
- Refused to believe it would happen
- Tried to keep your feelings from interfering with other things too much
- Wished that the situation would go away or somehow be over with
- Had fantasies or wishes about how things might turn out

Active--Cognitive
- Criticized or lectured yourself
- Looked for the silver lining, so to speak, tried to look on the bright side of things
- Prayed
- Prepared yourself for the worst
- Went over in your mind what you would say or do
- Thought of how a person you admire would handle this situation, and used that as a model
- Reminded yourself how much worse things could be
- Treated the illness as a challenge or battle to be won

Active--Behavioural
- Talked to someone to find out more about the situation
- Asked a relative or friend you respect for advice
- Tried to find out as much as you could about cancer and your own case
- Looked for understanding
- Talked to someone about how you felt

Cronbach's Alpha was calculated using the SPSSx program "Reliability" (SPSS Incorporated, 1983), in order to examine the internal reliability of the strategy groups, and Pearson's correlations indicated the level of association between groupings of coping strategies at each interview. Student's *t*-tests determined whether there were any response differences which may be accounted for either by distance from hospital and surgeon or by the different methods of questionnaire presentation due to this distance factor (i.e., interview or postal).

Each subject's frequency ratings for each group of coping strategies were averaged, resulting in scores ranging from 0-3 for each group. These scores were then analysed by a repeated measures multivariate analysis of variance (MANOVA) with trend analyses to determine the overall pattern of change over the 3 months. This program took into account the variability in the time between interviews. Planned comparisons comparing avoidance/denial with both of the active strategies, and then comparing the two active strategies with each other, assessed any significant differences in the use of the three strategies at any one time. Newman-Keuls post hoc comparisons looked at any other differences between strategies which were not obvious from the use of the planned comparisons.

An analysis of variance (ANOVA) ascertained whether there was any relationship between any control variable and any of the coping strategies used. These relationships with control variables were examined as described in Chapter 6, in order to avoid confounding effects due to the interrelationships between them and the type of surgery given.

A division was made at the median for each coping group at each interview, and an analysis of variance determined whether adjustment at the time of each interview was related to coping strategies used. Cross-lagged correlations (Cook & Campbell, 1976) detected any association between (a) coping strategies used at the time of surgery, and psychological adjustment 1 month later; or (b) psychological adjustment at the time of surgery, and coping strategies used 1 month later. A _z_-test employing Fisher's logarithmic transformation of _r_ to _Z_ (Diem, 1962; Sheskin, 1984) then ascertained whether there was any significant difference between these pairs of cross-lagged correlations, as described in Chapter 7.

Pearson's Correlations investigated any associations between coping and social support. Cross-lagged correlations then detected any association between these variables across time, as described above, and _z_-tests ascertained whether there was any significant difference between the pairs of cross-lagged correlations.

Results

Student's _t_-tests computed as a check on response differences from postal questionnaires versus interviews demonstrated no significant differences in any coping strategy either at the time of surgery or at 1 or 3 months post surgery.

At 3 months post surgery, two subjects stated that they had no problem coping: one then left the coping questionnaire blank, whilst the other answered with all zeros. These two were omitted from the analysis. Table 8.2 shows the reliability coefficients for the three coping groups and the correlations between them.

Table 8.2

Reliability Coefficients for Coping Groups Averaged across the Three Interviews, and Correlations Between them at each Interview

Coping strategies	No. of items	Chronbach's Alpha	Pearson's correlations					
			In hospital		1 month post-op.		3 months post-op.	
			Cog.	Beh.	Cog.	Beh.	Cog.	Beh.
Avoidance/denial	12	.69	.22*	.18	.51+	.67+	.48+	.51+
Active--Cognitive	8	.71	--	.41+	--	.60+	--	.64+
Active--Behavioural	5	.81	--	--	--	--	--	--

* $p < .05$; + $p < .01$.

Use of coping strategies

There was no significant association between age, marital status, type of surgery, nodal cancer spread or adjuvant therapy on the use of any of the three coping strategy groups.

The mean use of each individual coping response at each interview can be seen in Table 8.3, together with the results of trend analyses.

Table 8.3

Frequency of Usage of Individual Coping Responses at each Interview

	In hospital (N = 58)	1 month post-op. (N = 57)	3 months post-op. (N = 53)
Avoidance / Denial			
Felt time would make a difference--the only thing to do was wait	1.05	1.44	1.30
Went along with fate	1.36	1.28	1.17
Went on as if nothing were happening ..	1.38	1.56	1.68
Tried to keep feelings to yourself	1.41	1.26	1.45
Tried to make yourself feel better by eating, drinking, or smoking	0.60	0.40	0.43
Avoided being with people	0.60	0.39	0.57
Kept others from knowing how bad things were	1.21	0.88	0.98 +
Took it out on other people	0.31	0.28	0.26
Refused to believe it would happen	0.57	0.46	0.60
Tried to keep your feelings from interfering with other things	1.71	1.42	1.50
Wished the situation would go away	1.90	1.51	1.42 *
Had fantasies or wishes about how things might turn out	0.95	0.60	0.77
Active--Cognitive			
Criticized or lectured yourself	0.71	0.88	0.93
Looked for the silver lining	2.02	2.07	2.07
Prayed	1.47	1.47	1.50
Prepared yourself for the worst	1.45	0.79	0.74 ++
Went over in your mind what you would say or do	1.02	0.74	0.59 **
Thought of how a person you admire would handle this situation, and used that as a model	0.57	0.63	0.50
Reminded yourself how much worse things could be	1.88	1.91	1.63
Treated the illness as a challenge or battle to be won	1.24	1.65	1.37 +
Active--Behavioural			
Talked to someone to find out more about the situation	0.85	0.77	0.59
Asked a relative or friend you respect for advice	0.64	0.56	0.41
Tried to find out what you could about cancer and your own case	0.93	1.28	1.02
Looked for understanding	1.14	1.16	0.93
Talked to someone about how you felt ..	1.36	1.23	0.93 **

Manova Trend Analysis: * $p < .05$ linear; ** $p < .01$ linear.
+ $p < .05$ quadratic; ++ $p < .01$ quadratic.

Note. Maximum score = 3.

It is acknowledged that there may be a problem in undertaking multiple tests of significance. In this case there were 25 items tested for linear and quadratic trends, i.e., 50 significance tests involved. For this reason it was necessary to check that the Type 1 error rate over the whole set of tests was below the acceptable 5% level. Sakoda, Cohen, and Beall (1954) provided figures which allow this assessment, and indicated that the chance of the Type 1 error rate, with six significant results out of 50 tests, is < .05 (Sakoda et al., 1954, p. 173, Fig. 1). Therefore we can be confident that the null hypothesis may be rejected on the six occasions where significant trends have been demonstrated.

Table 8.4 shows the mean frequency of the use of each group of coping strategies at each interview. Avoidance/denial and cognitive strategies were used fairly constantly during the 3-month period following surgery. Behavioural strategies, however, were used with the same frequency in hospital and at 1 month post surgery, but then less frequently at 3 months post surgery. The MANOVA program took into account the variability in time between interviews, and indicated that there was a significant linear trend in the use of behavioural strategies over the 3-month period, $\underline{F}(1, 104) = 9.23$, $\underline{p} < .01$. This resulted from the similar amount of use of this strategy over the first month and then a drop in use over the next 2 months.

Table 8.4

Frequency of Usage of Groups of Coping Strategies at each Interview

	In hospital (*N* = 58)	1 month post-op. (*N* = 57)	3 months post-op. (*N* = 53)
Avoidance/Denial	1.09	0.96	1.02
Active--Cognitive	1.29	1.27	1.19
Active--Behavioural	0.98	1.00	0.79 ‡

‡ $p < .05$ linear trend.

Note. Maximum score = 3.

Planned comparisons between the use of each strategy at each interview, demonstrated that on all three occasions cognitive strategies were used significantly more often than were behavioural strategies: in hospital $F(1, 171) = 7.57$, $p < .01$; 1 month post surgery $F(1, 168) = 4.21$, $p < .05$; 3 months post surgery $F(1, 156) = 10.49$, $p < .01$. There were no significant differences between avoidance/denial strategies and the two active strategies taken together. A Student-Newman Keuls post hoc comparison demonstrated that cognitive strategies were used significantly more often than avoidance/denial at 1 month post surgery.

Coping and adjustment

A division was made at the median frequency of use of each group of coping strategies in order to ascertain the psychological, social, and physical adjustment of subjects according to the use of each strategy group (Table 8.5). Table 8.6 gives the results from the analyses of variance performed on these adjustment variables to determine whether there was any relationship between them and the use of any group of coping strategies at the time of surgery or at 1 or 3 months post surgery respectively.

Table 8.5

Cell Numbers and Means on Psychological, Social, and Physical Adjustment According to Coping Strategies used at each Interview

		Anxiety	Depress.	Self esteem	Social activ.	Physical probs.
In hospital	n	M	M	M	M	M
All strategies						
low use	28	39.4	9.1	24.0	8.9	--
high use	30	46.3	13.3	23.4	9.3	--
Avoidance/Denial						
low use	28	37.4	7.9	25.1	10.2	--
high use	30	48.3	14.4	22.4	8.1	--
Active--Cognitive						
low use	33	44.2	11.3	22.3	8.6	--
high use	25	41.4	11.2	25.5	9.8	--
Active--Behavioural						
low use	30	40.1	9.9	23.7	8.1	--
high use	28	46.1	12.7	23.7	10.2	--
1 month post surgery						
All strategies						
low use	28	35.0	7.3	25.3	8.2	7.5
high use	29	43.6	13.0	22.9	10.4	14.3
Avoidance/Denial						
low use	28	32.9	6.4	25.9	9.2	8.2
high use	29	45.6	13.8	22.3	9.5	13.7
Active--Cognitive						
low use	29	38.2	8.6	24.2	8.2	9.0
high use	28	40.5	11.8	23.9	10.5	13.0
Active--Behavioural						
low use	28	36.1	7.8	24.8	8.1	7.4
high use	29	42.4	12.5	23.4	10.5	14.4
3 months post surgery						
All strategies						
low use	25	32.3	6.2	25.5	9.1	3.9
high use	28	40.6	10.4	22.8	11.4	5.0
Avoidance/Denial						
low use	26	30.3	5.3	26.6	10.7	2.7
high use	27	42.9	11.4	21.6	9.9	6.2
Active--Cognitive						
low use	26	35.1	7.5	25.2	9.4	3.2
high use	27	38.2	9.3	22.9	11.1	5.6
Active--Behavioural						
low use	26	33.7	6.8	24.8	8.9	4.1
high use	27	39.6	10.0	23.3	11.6	4.8

Note. The division between high and low use was made at the median.

Table 8.6

Analyses of Variance on Adjustment Variables by Coping Strategies

	In hospital		1 month post-op.		3 months post-op.	
	MS	*F*	*MS*	*F*	*MS*	*F*
Anxiety: Total coping	690.5	3.78	1041.8	7.86 +	907.1	7.47 +
Avoidance/denial	1929.0	12.17 +	1741.0	15.47 +	1646.1	16.48 +
Active--Cognitive	652.2	4.12 *	36.7	0.33	13.3	0.13
Active--Behavioural	817.5	5.16 *	29.8	0.26	1.1	0.01
Avoidance x Cognitive	4.9	0.03	17.4	0.15	20.1	0.20
Avoidance x Behavioural	17.8	0.11	367.4	3.26	64.0	0.64
Cognitive x Behavioural	17.6	0.11	0.7	0.01	259.4	2.60
Depression: Total coping	259.0	4.52 *	465.4	9.09 +	236.2	5.34 *
Avoidance/denial	653.2	12.94 +	488.8	11.54 +	359.1	8.83 +
Active--Cognitive	65.0	1.29	8.0	0.19	1.5	0.04
Active--Behavioural	137.9	2.73	20.4	0.48	2.1	0.05
Avoidance x Cognitive	54.3	1.08	7.0	0.17	38.3	0.94
Avoidance x Behavioural	90.5	1.79	257.8	6.09 *	54.7	1.35
Cognitive x Behavioural	0.1	0.00	50.3	1.19	31.5	0.77
Self esteem: Total coping	4.7	0.12	81.3	2.33	101.3	2.98
Avoidance/denial	143.2	4.13 *	165.8	4.88 *	290.0	9.34 +
Active--Cognitive	208.2	6.00 *	5.1	0.15	18.4	0.59
Active--Behavioural	23.0	0.67	0.0	0.00	22.7	0.73
Avoidance x Cognitive	29.2	0.84	3.4	0.10	0.0	0.00
Avoidance x Behavioural	1.2	0.04	61.1	1.80	0.1	0.00
Cognitive x Behavioural	9.5	0.27	34.6	1.02	40.7	1.31
Social activities: Total	3.3	0.15	73.4	3.98	68.5	3.62
Avoidance/denial	72.7	3.65	12.5	0.73	86.3	5.04 *
Active--Cognitive	8.5	0.43	29.9	1.76	9.6	0.56
Active--Behavioural	44.9	2.26	41.5	2.44	117.8	6.89 *
Avoidance x Cognitive	0.0	0.00	22.9	1.34	35.5	2.08
Avoidance x Behavioural	49.4	2.48	83.9	4.93 *	14.6	0.85
Cognitive x Behavioural	6.7	0.34	13.1	0.77	37.2	2.18
Physical probs: Total coping	--	--	674.4	16.82 +	15.5	0.49
Avoidance/denial	--	--	97.9	2.90	148.0	5.20 *
Active--Cognitive	--	--	4.7	0.14	47.1	1.65
Active--Behavioural	--	--	281.1	8.32 +	38.0	1.34
Avoidance x Cognitive	--	--	8.8	0.26	19.7	0.69
Avoidance x Behavioural	--	--	232.6	6.89 *	6.2	0.22
Cognitive x Behavioural	--	--	115.1	3.41	48.8	1.71

* *p* < .05; + *p* < .01.

Note. As there were no significant three-way interactions, the three-way interaction terms were pooled into the error (residual) sum of squares.

Table 8.7 gives cell information for significant interaction effects found in the analyses of variance.

Table 8.7

Cell Numbers and Means on Depression, Social Activities, and Physical Difficulties at 1 Month Post Surgery, where the use of Avoidance/Denial Coping Strategies Interacted Significantly with the use of Behavioural Strategies

	Avoidance strategies	Behavioural strategies			
		low use		high use	
		n	M	n	M
Depression					
	low use	20	4.50	8	11.13
	high use	8	15.88	21	13.00
Social activities					
	low use	20	8.95	8	9.75
	high use	8	6.00	21	10.81
Physical difficulties					
	low use	20	5.30	8	15.37
	high use	8	12.63	21	14.05

Anxiety. In hospital anxiety levels were significantly related to the use of all three groups of coping strategies (Table 8.6). The greater use of avoidance/denial or behavioural strategies was significantly associated with high levels of anxiety: avoidance $F(1, 51) = 12.17$, $p < .01$; behavioural $F(1, 51) = 5.16$, $p < .05$ (Table 8.5). In contrast with these effects, the greater use of cognitive strategies at the time of surgery was significantly associated with low levels of anxiety, $F(1, 51) = 4.12$, $p < .05$. At 1 month and 3 months post surgery, the greater total use of coping strategies of all kinds was associated with significantly greater anxiety levels: 1 month post surgery $F(1, 55) = 7.86$,

$p < .01$; 3 months post surgery $F(1, 51) = 7.47$, $p < .05$. However, the only single significant coping factor associated with anxiety at 1 and 3 months post surgery was that subjects with a high use of avoidance/denial strategies had higher levels of anxiety than those with a low use of this strategy group: 1 month post surgery $F(1, 50) = 15.47$, $p < .01$; 3 months post surgery $F(1, 46) = 16.48$, $p < .01$.

Depression. At all three interviews the greater total use of coping strategies of all kinds was associated with significantly greater depression levels: in hospital $F(1, 56) = 4.52$, $p < .05$; 1 month post surgery $F(1, 55) = 9.09$, $p < .01$; 3 months post surgery $F(1, 51) = 5.34$, $p < .05$ (Table 8.6). At all interviews, the greater use of avoidance/denial coping strategies was significantly associated with high levels of depression: in hospital $F(1, 51) = 12.94$, $p < .01$; 1 month post surgery $F(1, 50) = 11.54$, $p < .01$; 3 months post surgery $F(1, 46) = 8.83$, $p < .01$ (Table 8.5). At 1 month post surgery there was also a significant interaction effect between avoidance and behavioural coping strategies on depression, in that those who used few of both of these strategy groups had the lowest depression levels whilst those who used avoidance but not behavioural strategies had the highest depression levels (Table 8.7).

Self esteem. In hospital, the greater use of cognitive strategies was significantly associated with high self esteem, $F(1, 51) = 6.00$, $p < .05$. Also, at all interviews the greater use of avoidance/denial strategies was significantly associated with lower levels of self esteem: in hospital

$F(1, 51) = 4.13$, $p < .05$; 1 month post surgery $F(1, 50) = 4.88$, $p < .05$; 3 months post surgery $F(1, 46) = 9.34$, $p < .01$ (Tables 8.5 & 8.6).

Social activities. At the time of surgery there were no significant relationships between social activities and coping strategies. However, at 1 month post surgery social activities were significantly related to the interaction of avoidance and behavioural coping strategies, $F(1, 50) = 4.93$, $p < .05$, in that those who used avoidance but not behavioural strategies engaged in the least number of social activities whilst those who used both groups of strategies had the highest number (Table 8.7). At 3 months post surgery, the use of avoidance strategies was significantly associated with subjects engaging in few social activities, $F(1, 46) = 5.04$, $p < .05$, whilst the use of behavioural strategies was significantly associated with subjects engaging in many social activities, $F(1, 46) = 6.89$, $p < .05$.

Physical difficulties. The greater total use of coping strategies of all kinds at 1 month post surgery was significantly associated with having physical problems, $F(1, 55) = 16.82$, $p < .01$. At this time physical problems were significantly associated specifically with the use of behavioural strategies, $F(1, 50) = 8.32$, $p < .01$ (Tables 8.5 & 8.6), and the interaction of avoidance and behavioural strategies, $F(1, 50) = 6.89$, $p < .05$. Those who used few of both avoidance and behavioural coping strategies had the fewest physical problems whilst those tending to use behavioural and not avoidance strategies had the most physical problems (Table 8.7). At 3 months post surgery, subjects who used avoidance strategies had significantly more physical problems than those not using these strategies, $F(1, 46) = 5.20$, $p < .05$ (Table 8.6).

Direction of causality between coping and adjustment

Table 8.8 shows the correlations between (a) the frequency with which coping strategies were used at the time of surgery and psychological variables 1 month later; and (b) psychological variables at the time of surgery and the use of coping strategies 1 month later.

Table 8.8

Cross-lagged Correlations Between Anxiety and Depression and Frequency of use of Coping Strategies at the Time of Surgery and at 1 Month Post Surgery, and z-tests on these Pairs of Correlations.

Variable at time of surgery	Variable at 1 month post-op.	Pearson's correlation ($N = 57$)	Fisher's Z transformation	z
Anxiety	Avoidance/denial	.41 +	.44)	0.45
Avoidance/denial	Anxiety	.48 +	.52)	
Depression	Avoidance/denial	.35 +	.37)	0.60
Avoidance/denial	Depression	.45 +	.48)	
Anxiety	Cognitive	.18	.18)	1.47
Cognitive	Anxiety	-.10	-.10)	
Depression	Cognitive	.23 *	.24)	1.49
Cognitive	Depression	-.05	-.05)	
Anxiety	Behavioural	.23 *	.24)	0.99
Behavioural	Anxiety	.05	.05)	
Depression	Behavioural	.16	.16)	0.28
Behavioural	Depression	.11	.11)	

* $p < .05$; + $p < .01$; Pearson's correlation.
None of the z-tests was significant

A significant association was found between anxiety and depression at the time of surgery and the use of avoidance/ denial 1 month later: anxiety $r = .41$, $p < .01$; depression $r = .35$, $p < .01$; anxiety at the time of surgery and behavioural strategies 1 month later, $r = .23$, $p < .05$; depression at the time of surgery and cognitive strategies 1 month later, $r = .23$, $p < .05$; and avoidance at the time of surgery and anxiety and depression levels 1 month later: anxiety $r = .48$, $p < .01$; depression $r = .45$, $p < .01$. However, the z-test demonstrated no significant difference between the pairs of cross-lagged correlations, and hence no causal relationship can be inferred.

Coping and Social Support

Table 8.9 shows the interrelatedness between the coping strategies used by subjects and the frequency with which they received support from their families, friends, and surgeon, and their satisfaction with this frequency.

Table 8.9

Pearson's Correlations between Coping Strategies and the Frequency of, and Satisfaction with, Social Support received from each Source at each Interview

	Frequency			Satisfaction		
In hospital	Family	Friends	Surgeon	Family	Friends	Surgeon
Avoidance/Denial	.20	.19	.14	-.13	-.18	.01
Active--Cognitive	.39 +	.42 +	.23 *	.02	-.02	-.17
Active--Behavioural	.34 +	.43 +	.32 +	.24 *	-.14	-.10
1 month post surgery						
Avoidance/Denial	.34 +	.55 +	.28 *	-.19	-.20	-.05
Active--Cognitive	.38 +	.47 +	.21	-.24 *	-.37 +	-.13
Active--Behavioural	.40 +	.62 +	.40 +	-.15	-.22	.01
3 months post surgery						
Avoidance/Denial	.39 +	.44 +	.05	-.17	-.11	-.05
Active--Cognitive	.51 +	.58 +	-.01	-.07	-.11	-.13
Active--Behavioural	.60 +	.59 +	-.04	-.01	-.07	-.21

* $p < .05$; + $p < .01$.

Coping and support frequency. At the time of surgery the frequency of support received from all sources was significantly correlated with the use of cognitive and behavioural coping strategies: family support with cognitive $r = .39$, $p < .01$, and behavioural $r = .34$, $p < .01$; friends' support with cognitive $r = .42$, $p < .01$, and behavioural $r = .43$, $p < .01$; and surgeons' support with cognitive $r = .23$, $p < .05$, and behavioural $r = .32$, $p < .01$.

At 1 month post surgery frequency of support from all sources was again highly positively correlated with the use of most of the coping strategy groups: family support with avoidance/denial $r = .34$, $p < .01$, cognitive $r = .38$, $p < .01$, and behavioural $r = .40$, $p < .01$; friends' support with avoidance/denial $r = .55$, $p < .01$, cognitive $r = .47$, $p < .01$, and behavioural $r = .62$, $p < .01$; and surgeons' support with avoidance/denial $r = .28$, $p < .05$, and behavioural $r = .40$, $p < .01$.

At 3 months post surgery frequency of support from family and friends was correlated with the use of all coping strategy groups, $p < .01$: family support with avoidance/denial $r = .39$, cognitive $r = .51$, and behavioural $r = .60$; and friends' support with avoidance/denial $r = .44$, cognitive $r = .58$, and behavioural $r = .59$.

Coping and satisfaction with support. There were very few significant correlations between coping and satisfaction with support. At the time of surgery, there was a significant positive correlation between behavioural coping and satisfaction with support received from family members, $r = .24$, $p < .05$; and at 1 month post surgery there were significant negative correlations between cognitive coping and satisfaction with support from family members, $r = .24$, $p < .05$, and friends, $r = .37$, $p < .01$. There were no significant correlations between coping and satisfaction with social support at 3 months post surgery.

Direction of causality between coping and social support

Coping and support frequency. In order to determine which had the greater causal effect--coping on social support, or social support on coping--cross-lagged correlations were computed between these variables across time. Table 8.10 shows the correlations between (a) coping strategies used at the time of surgery and the amount of support received from families, friends, and the surgeon 1 month later; and (b) social support received at the time of surgery and the use of coping strategies 1 month later.

Table 8.10

Cross-lagged Correlations Between Frequency of Support from each Source and the use of Coping Strategies at the Time of Surgery and at 1 Month Post Surgery, and z-tests on these Pairs of Correlations.

Variable at time of surgery	Variable at 1 month post-op.	*N*	Pearson's correlation	Fisher's *Z* transformation	*z*
Family support	Avoidance/denial	54	.00	.00)	2.08+
Avoidance/denial	Family support	54	.39 **	.42)	
Friend support	Avoidance/denial	55	.29 *	.30)	0.12
Avoidance/denial	Friend support	52	.31 *	.33)	
Surgeon support	Avoidance/denial	57	.22	.22)	1.37
Avoidance/denial	Surgeon support	47	-.06	-.06)	
Family support	Cognitive	54	.30 *	.31)	0.63
Cognitive	Family support	54	.18	-.18)	
Friend support	Cognitive	55	.44 **	.48)	0.14
Cognitive	Friend support	52	.47 **	-.50)	
Surgeon support	Cognitive	57	.19	.19)	0.34
Cognitive	Surgeon support	47	.12	.12)	
Family support	Behavioural	54	.18	.18)	0.10
Behavioural	Family support	54	.20	.20)	
Friend support	Behavioural	55	.46 **	.50)	0.48
Behavioural	Friend support	52	.38 **	.40)	
Surgeon support	Behavioural	57	.24 *	.24)	1.53
Behavioural	Surgeon support	47	-.07	-.07)	

* *p* < .05; ** *p* < .01; Pearson's correlation.
\+ *p* < .05, *z*-test.

Significant positive associations were found between the amount of support received from <u>families</u> at the time of surgery and cognitive strategies used 1 month later, $r = .30$, $p < .05$, and between avoidance/denial at the time of surgery and support received from families 1 month later, $r = .39$, $p < .01$. Support received from <u>friends</u> at the time of surgery was significantly associated with all three coping strategies 1 month later: avoidance/denial $r = .29$, $p < .05$; cognitive $r = .44$, $p < .01$; and behavioural $r = .46$, $p < .01$; whilst all three groups of coping strategies used at the time of surgery were also significantly associated with support received from friends 1 month later: avoidance/denial $r = .31$, $p < .05$; cognitive $r = .47$, $p < .01$; and behavioural $r = .38$, $p < .01$. The only significant association with <u>surgeons'</u> support was between this support at the time of surgery and the use of behavioural coping strategies 1 month later, $r = .24$, $p < .05$.

The z-test demonstrated that the only significant difference between the above pairs of cross-lagged correlations was that the use of avoidance/denial at the time of surgery had a greater causal effect on the amount of support received from family members 1 month later than the amount of support from family members at the time of surgery had on the use of avoidance/denial 1 month later, $z = 2.08$, $p < .05$. In order to determine whether this trend between the use of avoidance/denial and family support continued after 1 month post surgery, correlations were calculated between avoidance/denial at 1 month and family support at 3 months post surgery, $r = .18$, $n = 52$, and between family support at 1 month and avoidance/denial at 3 months post surgery, $r = .41$, *n* = 50. There was no significant difference between these correlations, *z* = 1.22.

Coping and satisfaction with support. Table 8.10 shows the correlations between (a) the frequency with which coping strategies were used at the time of surgery and the frequency at which subjects received support from each source 1 month later; and (b) social support at the time of surgery and the use of coping strategies 1 month later.

Table 8.11

Cross-lagged Correlations Between Satisfaction with Support from each Source and the use of Coping Strategies at the Time of Surgery and at 1 Month Post Surgery, and z-tests on these Pairs of Correlations.

Variable at time of surgery	Variable at 1 month post-op.	*N*	Pearson's correlation	Fisher's *Z* transformation	*z*
Family support	Avoidance/denial	54	-.15	-.15)	0.10
Avoidance/denial	Family support	54	-.17	-.17)	
Friend support	Avoidance/denial	55	-.04	-.04)	0.25
Avoidance/denial	Friend support	52	.01	.01)	
Surgeon support	Avoidance/denial	57	-.13	-.14)	0.28
Avoidance/denial	Surgeon support	47	-.19	-.19)	
Family support	Cognitive	54	.02	.02)	0.54
Cognitive	Family support	54	-.08	-.08)	
Friend support	Cognitive	55	-.13	-.14)	0.59
Cognitive	Friend support	52	-.25 *	-.25)	
Surgeon support	Cognitive	57	-.24 *	-.25)	0.97
Cognitive	Surgeon support	47	-.05	-.05)	
Family support	Behavioural	54	-.09	-.09)	0.53
Behavioural	Family support	54	-.19	-.19)	
Friend support	Behavioural	55	-.05	-.05)	0.10
Behavioural	Friend support	52	-.03	-.03)	
Surgeon support	Behavioural	57	-.23 *	-.24)	0.16
Behavioural	Surgeon support	47	-.26 *	-.27)	

* $p < .05$, Pearson's correlation.
None of the *z*-tests was significant

Significant negative associations were found between the use of cognitive strategies at the time of surgery and satisfaction with support received from _friends_ 1 month later, $r = -.25$, $p < .05$; and between behavioural coping strategies at the time of surgery and satisfaction with _surgeons'_ support 1 month later, $r = .26$, $p < .05$. There was also a significant negative association between satisfaction with support received from surgeons and the use of both cognitive and behavioural strategies 1 month later: cognitive $r = -.24$, $p < .05$; behavioural $r = -.23$, $p < .05$. However, the z-test demonstrated that there was no significant difference between the pairs of cross-lagged correlations, and hence no causal relationship can be inferred.

Discussion.

The internal reliability of the three groups of coping strategies is high, as also are the correlations between them (Table 8.2). This supports the findings of Folkman and Lazarus (1985), and also those of Aldwin and Revenson (1987) who found significant correlations between seven out of their eight groups of coping items. High correlations between reliable scales imply that, rather than specifically using one type of strategy to the exclusion of the others, some subjects are active in the use of all types of coping strategies whilst others use few of any type.

Table 8.4 indicates that at each interview subjects reported using cognitive strategies most often. These strategies were used significantly more than behavioural strategies throughout the 3-month period following breast surgery, and were also used significantly more than avoidance/denial at 1 month post surgery. When this is related to the fact that the greatest worry of cancer patients in this study was fear and uncertainty about the future (Chapter 6), it appears that these findings support Molleman et al. (1984) who found cognitive strategies to be most widely used against uncertainty or anxiety.

Table 8.3 indicates the frequency of use of individual coping items, and the most striking aspect of this table is the variation between the use of these items. The most frequently used coping behaviour throughout the 3-month period was "Looked for the silver lining, so to speak, tried to look on the bright side of things", and the least frequent behaviour reported was "Took it out on other people". It is possible that the questionnaire may have been open to response bias, as socially acceptable ways of dealing with problems have reportedly been used most often whilst those least socially acceptable have reportedly been used least.

Coping behaviours which were used more at the time of surgery than at any other time were "Wished that the situation would go away or somehow be over with" (avoidance/denial), "Went over in your mind what you would say or do" (cognitive), and "Talked to someone about how you felt" (behavioural), which had significant linear trends; and "Kept others from knowing how bad things were" (avoidance/denial), and "Prepared yourself for the worst" (cognitive), which had significant quadratic trends (Table 8.3). These are all ways of coping with the anxiety and uncertainty of cancer and its treatments, especially in the early stages when biopsy results were unknown. These strategies would have been less useful once subjects knew more about their prognosis and began adjuvant therapy where necessary, and therefore knew what to expect. For example, subject no. 17 reported at the time of surgery that she would rather die than have chemotherapy, indicating that she feared the worst, but once she began treatment she found it not to be as bad as imagined.

The fact the the two items "Kept others from knowing how bad things were" and "Talked to someone about how you felt" are included together in the group of coping behaviours used most at the time of surgery, emphasizes the difference between talking to people generally and confiding in a special person. Whilst many subjects confided in a close friend or relative at the time of surgery, they may not have talked to a wide group of others due to the uncertainty of the extent of the illness or the treatment they would undergo. Also, many may have been unsure of their own feelings about having breast cancer, and this would no doubt have prevented them from discussing things. The slight increase in "Kept others from knowing how bad things were" at 3 months post surgery, may have been due to subjects being reluctant to talk of their fears of recurrence once treatment had been completed. For example, the comments from subject no. 48 (Chapter 6) indicate that she confided in her husband about her situation early in her treatment, but didn't want to worry him at 3 months post surgery. It is easier to talk about what is happening whilst undergoing treatment, but once treatment has been completed others are more inclined to treat the patient as "cured", thus making it more difficult for her to talk about the situation.

The cognitive item "Reminded yourself how much worse things could be" was used consistently often throughout the 3-month period (Table 8.3). Taylor (1983) and Wood et al. (1985) gave examples of women with breast cancer who compared themselves favourably either with people they knew or with hypothetical others who were less well adjusted than themselves. Also, patients with limited surgery compared themselves favourably with those who had a mastectomy; older patients considered themselves to be better off than younger patients; and married patients wondered how they would cope if they were not married. It appears that most people could find someone worse off than themselves (Jenkins & Pargament, 1988), or at least imagine a worse situation than the one they were in, and use this in order to make their own situation appear more bearable.

"Treated the illness as a challenge or battle to be won" was utilized more at 1 month post surgery than at any other time (Table 8.3), presumably in order to cope with the inconvenience and/or pain of adjuvant therapy. Another item which was utilized more at 1 month post surgery than at any other time was "Tried to find out as much as you could about cancer and your own case". The use of this strategy increased from the time of surgery, when more energy was being put into "Prepared yourself for the worst" and "Wished that the situation would go away or somehow be over with". It appears from the significant decrease over time in these latter two items and the increase in information seeking, that as early as 1 month post surgery subjects were beginning to take some reponsibility for their cure. This finding agrees with that of Gotay (1984) whose early cancer patients coped mostly by taking firm action and seeking information. The increase in information seeking from the time of surgery also supports Cohen and Lazarus (1979), whose results led them to believe that information seeking was maladaptive when there was little one could do about the situation, such as when in hospital.

Overall, the use of coping strategies indicates that at 1 month post surgery subjects were taking more control of the situation, and at 3 months post surgery they were getting on with their lives and treating the cancer as something in the past. This was further illustrated by the fact that by 3 months post surgery 75% of those previously working had returned to work, and 60% of all subjects reported feeling little or no stress (Chapter 6). For this reason a measure of coping strategies was not taken after this time.

Coping and adjustment

The results of this study do not support those reported by Moos and Tsu (1977) or Pearlin and Schooler (1978), who claimed that the more coping strategies used, the less depressed and anxious the subject will be. In fact, the findings of Aldwin and Revenson (1987), who also used the Ways of Coping Scale, more closely resemble the rather paradoxical findings of the present study that the greater use of coping strategies was associated with increased anxiety and depression and a lowering of self esteem (Table 8.5). In this respect, Aldwin and Revenson suggested that as "checklists of coping implicitly assume that 'more coping is better coping'" (p. 345), possible reasons for this unusual finding could be either that (a) important coping strategies have been omitted, or (b) a change may be needed in the measurement used for adjustment. However, it may be that subjects attempted a variety of different coping strategies when the ones that they had already tried did not reduce their stress. This would account for those with higher stress levels also registering a greater use of coping strategies. It may have been helpful in this respect to have asked subjects how successful they felt each coping effort was (Aldwin & Revenson, 1987; Worden, 1983).

Anxiety. Subjects who used avoidance/denial or behavioural strategies at the time of surgery, had significantly higher levels of anxiety than those not using these strategies, whilst lower anxiety at this time was significantly related to the use of cognitive strategies (Tables 8.5 & 8.6). This may indicate either that using cognitive strategies results in more peace of mind, or that those with lower levels of anxiety are more capable of using these positive cognitive strategies. The significant relationship between the use of avoidance/denial strategies and greater anxiety at the time of surgery was continued at 1 and 3 months post surgery. This pattern does not indicate any benefit in the use of this strategy on the early stages of illness, although the reason for this may be that the coping items used did not adequately cover avoidance or denial. Higher anxiety levels at 1 and 3 months post surgery were also significantly related to the greater total use of coping strategies, and this has been commented upon in the previous paragraph.

Depression. High depression levels were significantly related to the use of all coping strategies at all three interviews (Tables 8.5 & 8.6). As the Wakefield Depression Scale measured feelings of depression rather than depressive illness, possibly those who felt depressed were motivated to attempt a range of coping strategies as a means of relieving their dampened spirits. However, the depressed feelings may have resulted from unsuccessful attempts at various coping strategies. It would have been helpful in this respect to have asked subjects how successful they felt their coping attempts were.

Subjects making more use of avoidance/denial coping strategies at all three interviews had significantly greater depression levels. As this was also the case with anxiety, it could be that the use of avoidance/denial strategies is not conducive to psychological adjustment even in the early stages of cancer. However, it may equally well be that coping in this manner may be the only option of those who are highly anxious and depressed. At 1 month post surgery there was also a significant association between subjects with high depression levels and those who used denial/avoidance strategies whilst not using behavioural strategies (i.e., they kept mostly to themselves); and between subjects with low depression levels and those who used few of both behavioural and denial strategies (Table 8.7). This perhaps points to the value for some patients in being able to find that half-way mark between keeping things to themselves and seeking support from others until they know more about what is happening and how they want to deal with it.

Self esteem. In hospital high self esteem was significantly related to the increased use of cognitive strategies. This could indicate that those who actively thought things through felt better about themselves in the early stages; but conversely it may also mean that only those with high self esteem were capable of this sort of cognitive activity. At all interviews the higher use of avoidance/denial strategies was significantly associated with lower levels of self esteem (Tables 8.5 & 8.6). This again seems to demonstrate the negative value of the continued use of avoidance/denial strategies; or, on the other hand, perhaps only those with high anxiety or depression, or low self esteem continued to resort to these strategies.

Social activities. At 1 month post surgery, there was a significant association between subjects using avoidance but not behavioural strategies and those engaged in few social activities (Tables 8.6 & 8.7). Again at 3 months post surgery, although there was no significant interaction effect, there were significant main effects which indicated that fewer social activities were associated with a lesser use of behavioural strategies and a greater use of avoidance strategies. A glance at the items comprising these strategy groups demonstrates the logic of this finding. One would need to be relatively socially active in order to use behavioural strategies, whilst avoidance strategies entail a lessening of social activity. In fact it may be that this result illustrates the artefact of content overlap between coping activities and adjustment. Some of the items used in the Ways of Coping Scale are also measures of social activity. For example, subjects using methods such as "avoided being with people", and "took it out on other people", may well have lower social activity levels than those using behavioural methods, such as seeking advice or understanding from others. The coping strategy itself determines, or is determined by, the level of social activity. One cannot avoid others without having a low social activity level, just as one cannot go to others for advice or understanding without acting socially. Therefore these coping strategies which may be useful when considering an external factor, such as depression, do not give any helpful information in the study of social activity levels.

Physical difficulties. At 1 month post surgery it was found that those using behavioural strategies reported encountering significantly more physical problems, especially if they were not using avoidance/denial strategies (Tables 8.5, 8.6, & 8.7). Behavioural strategies entail admitting problems and seeking help to find out more about the situation, and this may have resulted in a heightened awareness of physical difficulties and hence more reporting of them. At 3 months post surgery there was a significant association of physical problems with the use of avoidance/denial strategies. As the use of avoidance/denial at 3 months post surgery was significantly associated with less favourable scores on all five measurements of adjustment, this seems to indicate that the continued use of avoidance/denial may not be useful.

Direction of causality. Correlations indicated a significant association between (a) anxiety at the time of surgery and the use of avoidance and behavioural coping strategies 1 month later; (b) depression at the time of surgery and the use of avoidance and cognitive coping strategies 1 month later; and (c) the use of avoidance at the time of surgery and both anxiety and depression levels 1 month later (Table 8.8). However, as there was no significant difference between the pairs of cross-lagged correlations, no causal relationship can be inferred.

Coping and Social Support

The relationships between coping and adjustment shown in this chapter, and between social support and adjustment (Chapter 7), are not independent of each other, as demonstrated by the strong correlations between coping and social support, particularly with respect to support frequency (Table 8.9). This supports Shumaker and Brownell (1984), who claimed that "social support can interface with almost every coping strategy mentioned in the stress literature" (p. 25), and is evidence for the coping theorist's perspective that social support can be an important element in the appraisals of stressors and available coping resources.

It is of interest to note here that the greater use of cognitive strategies at 1 month post surgery was significantly correlated with increased frequency of support from family and friends and with decreased satisfaction with support from these sources (Table 8.9). As subjects using cognitive coping strategies were dealing with their situation in a way which is often not obvious to others, it is possible that this may have elicited greater amounts of support from family and friends, but generated less satisfaction because the support given may not have been what was required. This would not have occurred to the same extent with the other groups of coping strategies as they are more overt. Likewise, it would not have occurred to the same extent at other times because (a) when one is in (or about to enter) hospital, support is often very directed, and (b) at 3 months post surgery one is more in control and hence more able to communicate needs than just after surgery.

A comparison of cross-lagged correlations between coping and social support frequency at the time of surgery and 1 month later indicated that the effect of the use of avoidance/denial on family support frequency was significantly greater than the effect of family support frequency on the use of avoidance/denial (Table 8.10). However, this finding should be interpreted cautiously, as the significant relationship did not continue between the interviews held at 1 and 3 months post surgery. It appears that subjects using avoidance/denial strategies at the time of surgery elicited a greater amount of support from family members 1 month later, but this was not continued after this time. There were no significant differences in the pairs of cross-lagged correlations between coping and satisfaction with social support.

Summary

It was hoped that the study of coping strategies would indicate some useful ways by which breast cancer patients could be assisted to adjust to their illness and treatment. However, this did not eventuate, as no group of coping strategies was consistently associated with decreased anxiety and depression. The only factor associated in any way with a lessening of distress was the use of cognitive strategies at the time of surgery. The two most commonly used items within this group of strategies were "Looked for the silver lining, so to speak; tried to look on the bright side" and "Reminded yourself how much worse things could be". There were no other associations between the use of specific coping strategy groups and increased adjustment. Therefore it appears that "positive thinking" at the time of breast cancer diagnosis and surgery is associated with psychological adjustment.

The greater use of avoidance/denial was significantly associated with higher anxiety and depression and lower self esteem at all three interviews, and this would appear to indicate that the use of this strategy is not conducive to psychological adjustment even in the early states of cancer. Research has assumed that initial temporary denial provides time to ward off anxiety (Achte et al., 1986) and so protects until other forms of coping can be mustered (Ray & Baum, 1985), but the present study does not confirm that assumption. In fact, not only was denial unhelpful, but the mustering of other forms of coping after the initial stage was also not associated with a lessening of anxiety.

In this study the greater use of coping strategies was significantly associated with increased anxiety and depression. Aldwin and Revenson (1987), who had similar findings, noted the necessity to "identify adaptive coping strategies, delineate their contextual appropriateness, and understand how qualitative factors, such as level of effort and skill in using strategies, may affect the complex relation between coping and mental health" (p. 346). Two possibilities are raised: (a) the Ways of Coping Scale used in this study and also by Aldwin and Revenson appears to be such as to invite response bias. This is indicated by the high response to more socially acceptable items such as "Tried to look on the bright side of things", and the low response to less socially acceptable items such as "Took it out on other people"; or (b) subjects may have different criteria regarding their interpretation of the rating scale. For example, it is difficult to quantify how often in the past month one "went on as if nothing were happening".

CHAPTER 9

Summary of Study 1

There were very few, if any, continuing psychosocial problems amongst the sample of breast cancer patients in this study. The initial stress generated by the diagnosis and treatment of breast cancer did not remain, as was evident by the fact that at 3 months post surgery (a) the mean anxiety level had returned to that which the test manual gave for normal populations and the mean depression level was also approaching the test manual norms; (b) 60% of subjects claimed to be, at most, only slightly stressed by cancer related problems; and (c) 60%-75% of those who were working before their surgery had returned to their employment. These findings support those of Gottesman and Lewis (1982) and Silberfarb et al. (1980).

There were only five subjects whose post-surgical measures of anxiety and depression increased to more than two standard deviations above the mean (Chap. 6). One of these subjects was unhappy both in her work and home situation; one had a husband with a serious illness or injury; and one had a brother who died of cancer during the 6 months duration of the study. This left only two with problems related to breast cancer: one was adversely affected by radiotherapy and improved in adjustment once this treatment had finished; and the other had an abcess on her other breast. Therefore this research supported the findings of Penman et al., (1987) and Silberfarb et al. (1980) that there was no prominence of psychosocial problems amongst cancer patients.

Hypotheses

The results are summarised below, with reference to the hypotheses listed in Chapter 5.

Hypothesis 1. There will be a positive relationship between anxiety and depression, and a negative relationship between self esteem and both anxiety and depression (Greer & Burgess, 1987).

These relationships were found, as hypothesized (Table 6.2), and were significant to $p < .01$ at each of the four interviews.

Hypothesis 2. There will be a lessening of anxiety and depression as time from surgery passes (Cella & Tross, 1986), and also a lessening in the number of cancer related physical difficulties experienced. At the same time there will be an increase in self esteem and social activity levels.

Table 6.1 and the associated planned comparisons demonstrated a significant decrease in anxiety, depression, and physical difficulties, and a significant increase in social activities as time from surgery passed. However, there was no significant difference in measurements of self esteem. The results from this study were similar to those of Gottesman and Lewis (1982) and point to the possibility that the Rosenberg Self-Esteem scale is measuring a personality trait rather than a state.

Hypothesis 3. Uncertainty generates stress (Morris et al., 1985; Pruyn et al., 1986). Therefore patients who have less tolerance for ambiguity will be less able to cope with the "unknowns" of cancer and its treatment, and hence will become more stressed. This should lead to a positive correlation between both anxiety and depression and scores on the Intolerance of Ambiguity Scale.

The Intolerance of Ambiguity scale proved unreliable, and therefore individual differences in ability to cope with uncertainty could not be quantified. However, the fact that uncertainty generated stress was illustrated in other ways. Most of the breast cancer patients in the present study selected "fear and uncertainty about the future due to cancer" as their most difficult problem (Table 6.7), and those selecting this problem had high anxiety and depression levels (Table 6.8). In fact at 3 months post surgery the mean anxiety level for this group was significantly higher than that of those who selected other problems as their most difficult. Stress resulting from the fear of recurrence, which is generated from the uncertainties of cancer and its treatment, was also illustrated in many comments made by patients.

Sub.	
9	I am nervous about having chemotherapy...but more worried about getting rid of cancer.
12	I will probably live in fear of it recurring for the rest of my life.
14	I worry about symptoms, but I know this is irrational.
24	I'm scared. Every small pain worries me.
51	I will commit suicide if the cancer spreads.
55	I believe cancer can't be cured.
57	If I have to go back with more cancer that's when I'll break.

Whilst there were a variety of responses to breast cancer, fear of recurrence had become a major factor for most subjects. These findings support Peters-Golden (1982) and Worden and Weisman (1977) in that worry from having had cancer predominates over body image problems.

Hypothesis 4. Subjects whose support needs are met will have higher levels of psychological adjustment (Peters-Golden, 1982; Zemore & Shepel, 1989) and less physical illness (Schaefer et al., 1981) than those who lack this support.

Defining "Subjects whose support needs are met" as those who were totally satisfied with the support received, an association was found between this group and those who had high levels of adjustment. There was a significant relationship between high levels of psychological adjustment and satisfaction with the support received from family members at the time of surgery; from the surgeon at 1 month; and from the family and surgeon at 3 months post surgery (Tables 7.11 & 7.12). There was also a significant relationship between satisfaction with support received from friends and a low number of physical difficulties experienced at 3 months post surgery.

Hypothesis 5. The subject's perceived quality of support received will have a stronger association with health outcomes than will frequency of support received (Billings & Moos, 1982; Winefield & Neuling, 1987).

The subject's perceived quality of support had a stronger association with health outcomes than did frequency. This study demonstrated the importance of particular kinds of support from family members and surgeons (Chap. 6). Friends gave the same kinds of support as families, but in lesser quantities. Therefore a demonstration of support efficacy would presumably come from the most important sources of support, i.e., families and surgeons. Table 7.12 gives the results of the analysis of variance performed on adjustment by patients' *satisfaction* with support received. Most of these results were highly significant ($p < .01$) and demonstrate the importance of support from families and surgeons to psychological and social adjustment. In contrast, Table 7.10 gives the results of the analyses of variance performed on adjustment by *frequency* of support received. Here the significant results mainly related to support given by friends, and the significance levels are generally lower than those found in Table 7.12. Therefore this hypothesis is accepted because the most important sources of support (i.e., family and surgeons) were found to have a stronger association with health outcomes when patient satisfaction was considered rather than frequency.

Hypothesis 6. As the source of support is more important than the amount of help provided (Lieberman, 1986), patients will require informational support from their surgeons, but may resent this from non-professional sources (Dunkel-Schetter, 1984). This will be shown by subjects (a) being satisfied with significantly less information from family and friends than from surgeons, or (b) stating that they would have appreciated more information from surgeons and less from family and friends.

The source of support was more important than the amount of help provided. Patients required informational support from their surgeons, but often resented this from non-professional sources. This was illustrated by subjects being satisfied with significantly less information from family and friends than from surgeons (Tables 7.3 & 7.4). Over the 3 months, the amount of information provided by family members was only 27% of that provided by surgeons, and friends provided only 18% of the amount provided by surgeons. This difference between the support given by surgeons and that given by other sources was highly significant ($\underline{p} < .01$ at each interview). However, the average percent of respondents requiring more information was 3 from families, 1 from friends, and 22 from surgeons. This indicates that although surgeons were already the greatest providers of information, patients required even more from this source, whilst they were mainly satisfied with that which families and friends provided. Many comments also supported this hypothesis. For example, comments on support from friends indicated that they gave unwanted information: "Everyone's got a medical opinion and that just craps me off" (S. 14); whilst comments on surgeons' support, such as those from subjects no. 4, 8, and 41 (Appendix C-5), indicated that they didn't give enough information.

Hypothesis 7. The husband's reactions to his wife's breast cancer may be crucial to her adjustment (Wortman, 1984). Therefore patients will require more empathic support from husbands and family members than from other sources. This will be shown by subjects either (a) receiving more empathic support from family members than from other sources, or (b) stating that they would have appreciated more empathy from their families.

At all three interviews patients were receiving significantly more empathic support from family members than from surgeons ($p < .01$ on each occasion), and they required more of this type of support from both sources (Tables 7.3 & 7.4). Other evidence from this study which supported Wortman's claim is that 68% of married subjects confided in their husbands when they became worried about cancer related problems, and over 90% nominated them as their most supportive family member. It was also found that 42% of married subjects claimed a marked improvement in their marriages during the first 6 months after breast cancer surgery, whilst many others stated that their partners were very supportive before the onset of cancer. This, together with the need for more empathic support shown in Table 7.4, indicates that a great deal of empathic support was required from husbands.

Hypothesis 8. As indicated above, specific kinds of support are required from the surgeon and family. Further, if help is not received from the source from which it is required, other sources may not be useful (Neuling & Winefield, 1988). Therefore, patients will be satisfied with less support from friends than from family members and surgeons.

This hypothesis was supported, as at all three interviews friends provided significantly less overall support than did the other two sources ($p < .01$ on each occasion), and yet patients were more satisfied with the support they received from their friends than that which they received from either family members or surgeons (Tables 7.3 & 7.4).

Hypothesis 9. There will be some non-materialization of expected support, as people have a fear of identifying with cancer patients (Peters-Golden, 1982). This will be noticed mainly amongst friends, as it is easier for them to avoid contact with the patient than it is for families.

There was some non-materialization of expected support, although subjects mainly received the support they required (Table 7.4). Comments showing that some subjects had problems with non-support included those from subjects no. 4 and 8 (Appendix C-4).

Hypothesis 10. Some patients, not wanting to worry people or to appear complaining, will impose barriers to communication with friends, relatives (Lichtman & Taylor, 1986), and doctors (Eidinger & Shapira, 1984; Maguire, 1985c). As a result, they will not receive the support they require. This will be indicated by a lack of satisfaction with support from these sources, together with comments as to why there was lack of communication.

Some patients did not receive support because of self-imposed barriers to communication. This fact was borne out, for example, in the comments made regarding husbands by subjects no. 12, 48, and 57; on friends by subjects no. 30 and 35; and on surgeons by subjects no. 8, 51, and 58 (Appendices C-3, C-4, & C-5 respectively).

Hypothesis 11. The more coping strategies used, the less depressed and anxious the subject will be (Pearlin & Schooler, 1978; Moos & Tsu, 1977).

This finding of Pearlin and Schooler (1978) and Moos and Tsu (1977) was not supported. In fact the results of the present study were directly opposed to this, but supported the findings of Aldwin and Revenson (1987).

Hypothesis 12. Rather than any one particular group of coping strategies being used more than others, subjects will either tend to use a wide range of strategies or else use few of any kind. This will lead to a high positive correlation between coping strategy groups (Aldwin & Revenson, 1987; Folkman & Lazarus, 1985).

This hypothesis was supported, as high correlations between groups of different coping strategies were found at all interviews (Table 8.2).

Hypothesis 13. There will be high positive correlations between coping and social support, indicating that these two variables are inter-related (Thoits, 1986).

This hypothesis was supported, as 20 of the 27 correlations between coping and support frequency were significant (Table 8.9).

Theoretical perspectives

Attribution Theory emphasizes the importance of recipient views on (a) the intention of support-givers and (b) oneself as support-receiver, and the effects of these views on help-giving, help-receiving, and help-seeking. Although role-prescribed behaviours do not usually give rise to attributions about the intent of the support-giver, these attributions were often made when behaviours either exceeded, or did not measure up to, that which was role-prescribed. For example, Chapter 7 cites patients who attributed to their surgeon qualities of being caring or understanding, or on the other hand patronizing or evasive, and attributed to themselves lack of knowledge or stupidity. The effect of negative self-evaluations was generally that patients making these attributions refrained from seeking assistance from their surgeon. Attribution theory also indicates the importance of congruence between the support models held by the giver and receiver respectively, and this is relevant for cancer patients in that health behaviour depends not only on the individual's adjustment but also that of the family and/or closest friends. This study noted (Chapter 6) that the relationship between husbands and wives improved in 42% of cases and remained consistently close for many others. It therefore appears that when couples were faced with the wife's cancer the attributions that they made in order to understand and take some control over what was happening were congruent with each other. Thus many relationships were strengthened rather than weakened.

Coping Theory emphasizes the influence of support on recipient veiws of stressors (primary appraisal) and available resources (secondary appraisal). Such support may assist in reappraising the effect of a potential stressor and may change behaviour accordingly. Evidences of the application of this theory were found in the selective way that informational support was received. From the correlations between support satisfaction and frequency (Table 7.2) and recipient ratings of satisfaction with support (Table 7.4), it appeared that many patients could not get enough information from surgeons, but received too much from families and, to a lesser extent, friends. This is an indication that patients wished to make a reasonable assessment of the stressor, cancer, through information provided by professional sources rather than through lay opinion. Coping theory also includes the use of support as "socially mediated coping", and many instances of this can be seen in this study. Chapter 7 contains many uses made of social support as a coping resource as patients received empathic, informational, tangible, and reassurance support from families, friends, and health professionals. In as much as this help was viewed as "supportive" by patients it would have assisted them to view their situation more positively and so reappraise the stressor and/or the resources available to combat it.

Equity (Social Exchange) Theory emphasizes the notion of reciprocity and its effects on giving and receiving support. An ideal way to investigate the applicability of this theory would have been through the use of self-help groups where, by mutual support and encouragement, participants can be both giver and receiver. However, as so few patients in this study attended support groups, this investigation was not possible. Equity theory also emphasizes the feelings of indebtedness that may result from inequity or lack of reciprocity in a relationship, especially where the relationship is not an intimate one or one of professional/client. However, although this study investigated support given from three sources: surgeons, friends, and families, there were no reported cases of patients feeling indebted to those who were supportive to them. This was no doubt because in the case of surgeons, a professional relationship, equity is restored by payment of an account, whilst in the case of friends and family, the most supportive person from each source was nominated, i.e., the closest or most intimate, and "equity accounting" is not strictly kept in such relationships. The only indication of subjects' feeling indebted to a help-giver was given when they were asked for their main reason for taking part in the research. Forty-two percent said that they saw it as a way of showing their appreciation for the care received from their doctors. This demonstrates the use of a third party in reciprocation, as described by Fisher et al. (1983). Patients who had received extra support from their doctors were not able to return this directly, but were able to help others in a similar situation by taking part in research.

Social Comparison Theory emphasizes the costs and benefits of comparing oneself with similar others. An example of the applicability of this theory was found when patients made "upward" comparisons with the volunteer hospital visitor and commented on their gaining confidence in their ability to successfully overcome the diagnosis and treatment of breast cancer. In this way, social comparison theory can be linked to coping theory as patients used social means to effect a reappraisal of the potentially harmful effects of the stressor (primary appraisal) and their ability to muster resources to deal with this (secondary appraisal). This use of "upward" comparisons is most commonly used in situations dealing with uncertainty (Dunkel-Schetter & Wortman, 1982).

Conclusions

A patient need which became obvious from this study was that empathy and information were required from the surgeon for at least 3 months after their surgery, yet patients often did not ask for this. This finding replicates those of Eidinger and Shapira (1984) and Maguire (1985c), and indicates one of the greatest unmet needs of cancer patients. In South Australia, the Anti-Cancer Foundation provides support to new breast cancer patients through the Breast Cancer Support Service. Through this service, a previous breast cancer patient visits a new patient in hospital with the aim of showing her that one can lead a full life after breast cancer and can also look 'normal'. This study looked briefly at the role of the volunteer hospital visitor but did not tap her essential usefulness as a "model". It seems that the volunteer visitor is someone who could fill an important place in the support needs of cancer patients. If she were introduced by the surgeon or hospital staff, as many of these visitors were, she would have some medical credence in the eyes of the patient, and yet she would have more time available than a lot of the medical staff. Also, having had similar surgery, she would be able to relate to the fears of the patient. If such a person received adequate training in communication, she could be an invaluable help. For this reason the next study will look more fully at the support that these visitors can give.

Cancer not only affects the patient, but also the family (Kerson & Kerson, 1985). Yet the family is expected to be the main source of support for the cancer patient, and its members may not feel equal to the task. This study found that 42% of married subjects stated that their marriage had shown a marked improvement during the first 6 months after breast cancer surgery, and so supports the claims of Dean (1988), Lichtman and Taylor (1986), and Morris et al. (1977). This study also found that 68% of married subjects confided in their husbands when they became worried about cancer related problems, and over 90% nominated their husband as their most supportive family member. As the husband is obviously the most important person in the life of most breast cancer patients, and his reactions may be crucial to the patient's adjustment (Wortman, 1984), another study was carried out to consider the needs and problems of these non-professional sources of support, in order to determine how they can be helped to handle this situation (see Chapter 11).

SECTION III

STUDY 2

A REVIEW OF THE HELPFULNESS OF THE BREAST CANCER SUPPORT SERVICE

CHAPTER 10

Using Peers as Hospital Visitors

Having noted in Chapter 7 the need for information and empathic support from medical professionals, and the possibility that some of these needs may be met by peers, this chapter investigates the help that the BCSS volunteer hospital visiting program offers and also the effect that giving this help has on the volunteers.

"The rationale for patient visitor programs is that role incumbents in control of their lives and reactions to their cancer can coach new patients about transcending the sick role. Dialogue with these role models may permit patients to achieve cognitive mastery over events that otherwise might prove to be distressing or ambiguous" (Mantell, 1983, p. 50).

The psychological theory discussed in Chapter 3 which pertains to the use of peers as hospital visitors is that of social comparison. This theory is concerned with people's tendency to evaluate their abilities and feelings through comparison with similar others. Upward comparisons (comparisons with those who are considered to be adjusting better than oneself) provide a role model for coping, whilst downward comparisons (comparisons with those adjusting less well than oneself) enhance self esteem. Bandura (1977) noted that seeing others coping with a situation similar to the one the observer faces, can generate expectations of personal improvement. He also pointed out that the effectiveness of role-modelling is dependent to some degree on the similarities between the observer and the role-model, and that greater hopefulness is generated when the role-model is seen as one who has worked to achieve rather than one who appears impervious to threats. The applicability of social comparison theory will be investigated in this study.

The Australian Breast Cancer Support Service (BCSS)

The use of peers as volunteer hospital visitors began in Australia in 1975, and was based on the American "Reach to Recovery" programme (Rogers, et al., 1985). Each of the Australian states has its own cancer organisation which runs the BCSS for that state; whilst the cohesion of the service is maintained by the Australian Cancer Society, with a National BCSS seminar being held bi-annually.

In South Australia, the first training session for volunteer hospital visitors was held in June 1975. The College of Surgeons nominated two medical advisors to the service, to participate in the training of volunteers and to be responsible for updating the medical information given at inservice sessions. As at April 1988 there were 62 visitors currently in the Service, 15 of whom work in country areas and 6 of whom are bilingual--a necessity in a multi-cultural society. The languages covered include Dutch, French, German, Greek, Italian, Polish, Russian, Spanish, and Ukranian.

It is important that volunteer hospital visitors be carefully selected in order to identify those who have warmth and compassion for others and are able to cope with stressful situations, as distinct from those who may be using the volunteer programme as a way of conteracting their own worries about the future (Mantell, 1983). "Objectivity sufficient to help another [with a serious health problem] does not come naturally or easily" (Kahn, 1978, p. 15). Training is also essential in the development of a visitor who will be patient-centered yet not promote patient-dependency, and who will refrain from giving quasi-medical advice (Maguire, 1985a).

In South Australia, initial training is comprised of 2 days' information from the Anti-Cancer Foundation social worker who is the co-ordinator of the BCSS, and includes input from current volunteer hospital visitors and a surgeon advisor. It may also include a session from a physiotherapist or an oncology nurse. Inservice training, known as "refresher training", and which all volunteer visitors are encouraged to attend, is a 1-day session which is held two or three times per annum. These normally include up-dating and exchanging information and discussing any areas of concern, and are especially beneficial as an opportunity to meet other hospital visitors and learn from their experience. This is of particular benefit to new volunteers and to those who live in the country and may feel somewhat isolated. Sessions from professionals in the field, such as a surgeon, plastic surgeon, or physiotherapist, may also be included, as the group requires. Hospital visitors are also encouraged to attend the Educational Support Groups run by the BCSS for new breast cancer patients, so that they can gain more insight into the problems faced by these patients.

Referrals for visits are made to the BCSS co-ordinator, usually by the ward sister, and always with the consent of the attendant surgeon. The co-ordinator then selects the appropriate visitor by matching her, where possible, with the age of the patient and the type of surgery she has had. The purpose of the visit is for the patient to see a healthy, well-adjusted previous breast cancer patient and to be able to discuss any concerns that she may be unable, for various reasons, to raise with her surgeon or the ward staff. The volunteer also carries samples of breast prostheses for the patient to view, if interested. The patient is given a soft lambswool temporary breast form which she can use immediately on her new scar. This enables her to look "normal" until she feels able to procure her permanent prosthesis. The patient is also given information leaflets, and the visitor's name and telephone number are left with her. The BCSS is not intended to usurp the role of health professionals, but adds another dimension which is hoped will be of psychological and practical benefit to the patient. Other services are provided by the BCSS, such as the establishment of an advisory centre where women can view a complete range of prostheses, and educational support groups for breast cancer patients. However, this study is concerned primarily with the direct assistance given to the patient at a time of great stress when she may be uncertain of the future and unsure of her own feelings and ability to adjust.

The role of the volunteer hospital visitor

"Partly they take the place of other concerned lay persons, friends or families who may not be available or able to function in that role. Partly these volunteers have moved into the role of the professional, who... has not met the need either" (Kahn, 1978, p. 15). Patient visitors are particularly well-suited to the advocacy role, indicating to both professionals and the patient's family what it is like to live with cancer (Mantell, 1983).

Volunteer hospital visitors may give the four kinds of support elucidated in Chapters 3 and 7. Informational support is mainly comprised of knowledge of the availability and prices of prostheses, but may also include indicators of when to resume work or social activities of various kinds; exercises to improve arm movement; and help with talking to family members, friends, or medical staff, if the patient is experiencing trouble in these areas. Indirect or vicarious informational support is received as the patient observes the volunteer as living proof that a full life can be led after breast cancer. The most effective helping model is one who is overcoming difficulties by determined effort rather than one who is proficient and requires little effort (Bandura, 1977). Tangible support includes the provision of a temporary breast prosthesis and may also be concerned with how to get help in paying for a permanent prosthesis. Emotional support and reassurance are an integral part of the service. "Associating with similar others can help victims to realize that much of what they are experiencing is a normal consequence of the life crises with which they are faced and is not the result of their own inadequacies" (Wortman & Dintzer, 1978, p. 88). This gives support and encouragement (Cox, 1986), and the reassurance that others who have been through the same experience are now coping effectively offers patients hope for their future (Ray & Baum, 1985). "Immediately post operatively...the patient is troubled,... shocked...and frightened; also, she may be angry and is almost certainly depressed to some degree. She is concerned about her prognosis, her ability to use her arm, and her appearance. The well adjusted mastectomy volunteer could provide many of the answers" (Markel, 1971, p. 1676). Patients may be more able to disclose their feelings to someone who has had a similar experience, and this may reduce their sense of isolation (Maguire, 1985a).

However, not all agree as to how much help is given by volunteer hospital visitors. Magarey (1988) stated that "apart from the provision of advice about external breast-forms and clothing, this contact is unlikely to influence significantly the underlying psychological problems" (p. 241). Although there is no scientific data on the short- or long-term psychological effects of using volunteer hospital visitors (Maguire, 1985c), it does appear that most patients wish to talk with similar others, and derive some benefit from this (Pruyn, Rijckman, van Brunschot, & van den Borne, 1985; Wortman & Dunkel-Schetter, 1979). "Because the issues are so complex, we need to examine the characteristics and perspectives of both the recipient and the provider of support" (Dunkel-Schetter, 1984, p. 93). Behaviours intended to be helpful are sometimes not received as such (Wortman, 1984). Therefore, if volunteers are to be effective support-givers, their perceptions of what is helpful must be as close as possible to those of the patient. This study, therefore, will compare the perspectives of volunteers with those of patients.

Another reason for considering the perspective of the volunteer hospital visitor is that she is a previous breast cancer patient. It should be of some value in understanding new breast cancer patients if research were also aware of the strengths and weaknesses of those who had lived for some years after this crisis. However, volunteer hospital visitors may be a somewhat biased sample, as they are presumably people who have come to terms with their diagnosis and treatment.

A further issue is that the giver of support is often, in some way, a receiver. Assisting others who now face crises that the helper faced a few years ago, makes the helper aware of her own progress. The theory of social comparison is applicable here, as the volunteer hospital visitor makes a "downward" comparison, thus enhancing her self esteem. The fact that the helper also receives a benefit was noted by Meagher, Gregor, and Stewart (1987), when they found that most volunteer hospital visitors remained in the service for a number of years. However, being a volunteer hospital visitor may also be a drain on time and on emotional resources.

This research

This research will examine, from the point of view of both the patient and the volunteer, the needs of the patient and the benefits and drawbacks of the service.

Hypotheses

1. Social comparison theory states that people in ambiguous situations tend to elicit information and to evaluate themselves through comparison with similar others. Therefore it was hypothesized that, because of the BCSS volunteer's special position as a previous breast cancer patient, she

would help fill patients' needs for information and empathic understanding. She would also be a role-model for patients' "upward" comparison and emulation of coping strategies.

2. Different age groups, types of surgery, and treatments present their own unique problems, which would be best understood by those who have faced similar situations. Also, social comparison theory states that people compare themselves with similar others. Therefore it was hypothesized that patients would consider it important that their hospital visitor matched them in age, type of surgery, and treatment.

3. Social comparison theory states that "downward" comparisons enhance self esteem. Therefore it was hypothesized that Volunteers would receive benefit from the service they provided as it would help them gain a sense of competence in coming to terms with their own breast cancer. The satisfaction received from using their cancer experience to help others would in some way vindicate the fact of their illness.

4. The focus of the BCSS is on positive living. Volunteer hospital visitors are well-adjusted breast cancer patients, who lead full and satisfying lives. Therefore it was hypothesized that the most negative aspect of being a BCSS volunteer would be encountered when a fellow volunteer died of cancer, because this would bring to mind the volunteer's own vulnerability as a cancer patient.

5. The BCSS aims to show patients that it is possible to lead a full life and to look "normal" after breast surgery. Therefore it was hypothesized that hospital visitors would consider that looking fit and well was the most important characteristic of a BCSS visitor.

6. All BCSS hospital volunteers are previous breast cancer patients who would therefore have some insight into many of the problems facing the patient. Further, all BCSS volunteers are trained, in order that they may be aware of difficulties which may upset others but which they themselves may not have faced. Therefore it was hypothesized that there would be no significant differences between the views of patients and volunteers on (a) the most difficult problems for mastectomy patients, and (b) the strengths and weaknesses of the BCSS.

Method

Subjects

BCSS hospital visitors. Questionnaires were posted to all volunteers who had made a hospital visit between 1985 and 1987. Forty-six questionnaires were sent, and 42 (91.3%) were returned.

Breast cancer patients. A short, 2-page questionnaire was posted to all English speaking patients visited by the BCSS in the months of May, June, and July, 1987, irrespective of whether they were in a private or public hospital. Of the

74 questionnaires posted to breast cancer patients, 68 (91.9%) were returned. However, it was found that all except one of these patients had had a mastectomy, and so it was decided to exclude this one in order to have a more homogenous group. The reason for the lack of patients who had undergone a less intensive surgical procedure was that many surgeons referred only mastectomy patients to the BCSS, because until a few years ago these were the only patients seen by this Service.

Measures

BCSS hospital visitors. In order to investigate volunteers' insights into the value and focus of the BCSS, and it's meaning to them as volunteers, the questionnaire included volunteers' opinions on what was the most important characteristic of a volunteer, together with the benefits and costs derived from hospital visiting. Subjects rated, in order of importance, the characteristics of a BCSS visitor. These included having empathy; looking fit and well; being a good listener; being friendly; and being able to give information. They also rated, in order of importance, the most positive and negative aspects of being a BCSS volunteer. Positive selections included getting a sense of fulfilment or satisfaction; gaining some status or recognition in the hospitals or the Anti-Cancer Foundation; and working with a group of friends in the BCSS. A reason of their own could be added if necessary. Listed amongst the costs or negative aspects were: feeling emotionally drained or depressed after a visit or if a fellow volunteer died of cancer; being constantly reminded of having had cancer; worrying about family reactions to the time spent on visits; and feeling guilty when unable to visit.

Researchers have indicated the importance of adequate training of volunteer hospital visitors (Maguire, 1985a), and so a section was devoted to this aspect. Space was available for comments under headings concerned with initial training and inservice "refresher" training sessions. Subjects rated the sufficiency of their training on a 4-point scale, ranging from "excellent preparation" to "totally unprepared".

Support for the support-givers is important and often lacking (Kahn, 1978). Therefore a section was included on this area. Subjects rated, on a 4- point scale ranging from "never" to "often", how often they discussed their hospital visits with each of a list of possible supportive people. This list included a friend, husband, other BCSS volunteers, and Anti-Cancer Foundation staff. Volunteers then rated, on a 4-point scale ranging from "not at all guilty" to "very guilty", how they would feel about asking for a holiday from visiting, or to leave the Service.

In order to determine the similarity, or otherwise, of volunteers' and patients' views on the problems associated with breast cancer and the strengths (and weaknesses) of the BCSS, three questions were asked of both groups. The first was, "What do you consider to be the most difficult or troubling problem for patients who have just had a mastectomy?" The problems listed were the same as those listed for patients in Study 1. Following this, the helpfulness of different areas of information and advice given by the BCSS was rated on a 4-point scale ranging from "not applicable" to "very helpful". This was also the same as that used in Study 1. Finally, subjects rated, on a 3-point scale ranging from "not true" to "very true", a list of 10 possible strengths and weakness of the BCSS hospital volunteer system (Rogers et al., 1985).

Breast cancer patients. Patient-visitor matching was investigated by asking patients whether their visitors were approximately the same age as themselves and underwent the same type of surgery and adjuvant therapy. Patients then evaluated on a 3-point scale ranging from "not very important" to "very important" the importance to them of each type of matching.

Following this were two questions that had also been asked of the volunteers: (a) the helpfulness of different areas of information and advice; and (b) possible strengths and weaknesses of the BCSS visit. Finally, subjects were asked whether they would recommend that other breast cancer patients have a visit from the BCSS, and space was left for any comments they would like to make.

Procedure

Before beginning the study, the volunteers' and patients' questionnaires were given to three Anti-Cancer Foundation social workers and one Anti-Cancer Foundation board member who was previously a BCSS visitor. These people provided feedback on the suitability and clarity of the questions asked, and the questionnaire was accordingly adjusted before being sent out.

BCSS hospital visitors. Volunteer visitors were told of the research aims at a "refresher" meeting, and their cooperation was sought. A week later questionnaires were posted to all who had made a hospital visit within the last 2 years. A copy of this questionnaire may be found in Appendix A-9, and the explanatory letter sent with it may be found in Appendix A-7. This was followed by a reminder letter after 3 weeks, thanking those who had replied and asking those who had not replied to please do so as soon as possible. This reminder letter can be found in Appendix A-11. Forty-six questionnaires were sent and 42 (91.3%) were returned.

Breast cancer patients. Questionnaires were posted to recently visited patients by the BCSS, as considerations of confidentiality did not permit them to pass on names and addresses. A copy of the questionnaire may be found in Appendix A-10. A covering letter from the BCSS was enclosed, explaining why the questionnaire was being sent and setting out the aims of the research. This can be seen in Appendix A-8. The completed questionnaire was returned to the investigator, thus respecting patient confidentiality whilst also keeping replies confidential from the BCSS so that patients would feel more free to answer honestly.

Questionnaires were posted when the patient was 11-18 days post surgery. It was decided not to post them earlier than this out of consideration for patients who had just been through a traumatic experience. However, the time chosen was considered close enough to the visit for patients to remember its impact. In the first week of the study, questionnaires were posted to four patients, and 1 week later a further two were sent. However, by the end of the following week none of these six had been returned, and so a reminder letter was sent to these six patients. This can be seen in Appendix A-12. The format of the covering letter was then changed for further postings so that it began "Dear..." instead of "Survey of Mastectomy Patients", in case the original format may have upset some patients (Dillman, 1978). Reminder letters were sent to all subjects 1 week after the questionnaire had been posted. Of the 74 questionnaires posted, 68 (91.9%) were returned.

Conversations with patients in Study 1 indicated that many of them did not understand medical terms to the extent that they did not know whether they had had a mastectomy or a less intensive surgical procedure. Therefore it was decided to head the questionnaire differently for each type of patient rather than to ask them for this information. Questionnaires and covering letters sent to mastectomy patients were headed "Survey of mastectomy patients", whilst those sent to patients who had less intensive surgery were headed "Survey of breast cancer patients". However, when it appeared that this heading might have upset some patients, it was removed from the covering letter but remained on the questionnaire form for identification purposes.

Statistical analyses

Chi-squared tests determined any significant differences between patients' and volunteers' responses, but as there were too many cells with an expected frequency of less than five, some response categories were collapsed as follows:

(a) responses to the question relating to the helpfulness of information and advice were collapsed from "not applicable", "not very helpful", "quite helpful", and "very helpful" into "not helpful" and "helpful" by combining the first and last two responses respectively; (b) responses to the question relating to possible strengths and weaknesses of the BCSS visit were collapsed from "not true", "somewhat true", and "very true" into "not true" and "true" by dividing the middle column evenly between the other two. Kendall's coefficient of concordance (*W*) ascertained whether there was agreement in the answers given by BCSS volunteers and patients respectively.

Missing data. As no standardized scales were used, and each question was treated as a separate entity, any question left unanswered was removed from the analysis for that subject.

Results

BCSS hospital visitors

Forty subjects answered the questions on how they joined the BCSS, and their length of service. Thirty-two (80%) had been working as hospital visitors for 3 years or more, and 36 (90%) had made 10 or more hospital visits. Twenty-nine (73%) volunteered for the service, whilst the others were asked to do so by the Anti-Cancer Foundation or by their surgeon. Of this latter group, one admitted feeling some obligation to do hospital visiting as a result of being asked.

All 42 subjects answered the question on the possible benefits of being a BCSS volunteer. Table 10.1 lists their answers.

Table 10.1

The Number of BCSS Volunteers Selecting Each Item as the Most Important Benefit to her in being a Hospital Visitor

	Choices		
	1st	2nd	3rd
Getting a sense of fulfilment in giving to someone in need and being valued by them	16	13	4
Gaining some status or recognition in the hospitals I visit, as being a person of competence	0	0	1
Gaining some status or recognition in the Anti-Cancer Foundation, as being a person of competence	0	1	1
Finding an excellent group of friends amongst the other BCSS volunteers	0	2	3
Feeling I was doing the right thing	3	5	15
Getting satisfaction from doing something positive with my cancer experience	20	14	4
Getting satisfaction from knowing that I was, in some way, repaying the services given to me	3	7	10
Other	0	0	1

The other reason given was: "It keeps you from being blase about having cancer--you realize it can recur at any time".

Table 10.2 lists possible emotional costs to the BCSS volunteer in being a hospital visitor, together with the number of subjects choosing each one as her most important. There were 38 subjects who answered this section--two said there were no negative aspects, and two just left it unanswered.

Table 10.2

The Number of BCSS Volunteers Selecting Each Item as the Most Negative Aspect of being a Hospital Visitor

	Choices		
	1st	2nd	3rd
Feeling emotionally drained after a visit	8	2	5
Feeling upset because I've had a visit which didn't go well	4	3	6
Feeling depressed when I have identified too closely with a lady I visited	1	1	4
Feeling upset when a fellow BCSS visitor dies of cancer	15	7	4
Feeling depressed because visits are a constant reminder of the fact that I have had cancer	1	2	1
Feeling depressed when I hear information about breast cancer that I'd rather not know	1	8	3
Worrying that my family feel I spend too much time with the BCSS	0	0	2
Feeling guilty when I'm asked to do a visit but am unable to because of prior commitments	7	6	4
Feeling guilty when I'm asked to do a visit but am unable to because of illness	1	4	2

Table 10.3 lists characteristics which may be seen as required by a successful BCSS hospital visitor, together with the number of subjects who considered each to be one of the three most important. All 42 subjects answered this section.

Table 10.3

The Number of BCSS Volunteers Selecting Each Item as the Most Important Characteristic of a Hospital Visitor

	Choices		
	1st	2nd	3rd
To have empathy..	16	1	7
To have sympathy.......................................	0	2	0
To be a good listener..................................	14	18	6
To be able to give information about treatment..........	0	0	0
To be able to give information about prostheses.........	2	1	11
To be able to explain what happened to you..............	0	0	0
To look fit and well, and to wear appropriate clothing..	7	15	7
To be able to relate to people different from yourself (e.g. in background or education)......................	0	2	3
To be friendly...	2	2	7
To have a sense of humour...............................	1	1	1

The next section was devoted to training of BCSS volunteers. Thirteen (31%) of the 42 felt that the initial training given by the BCSS was excellent, whilst a further 26 (62%) felt it was adequate. This left only 3 (7%) who believed it to be inadequate. "Refreshers", or inservice training days which are held 3-4 times a year, were considered sufficient by 27 (77%) of 35 BCSS volunteers.

Comments made by volunteers with respect to training included the need for all volunteers to keep up to date with the latest information of interest to mastectomy patients, and to attend refresher sessions whenever possible; the need for volunteers who have had a mastectomy to learn more about the less intrusive operations which are now more commonly being done, and for all volunteers to know more about breast reconstructions; and the need to spend more time on giving new volunteers an insight into how different situations may be handled, in order to give them confidence. Three volunteers commented that they would have liked more personal talks with the BCSS coordinator in order to reassure them that they were performing up to standard.

The availability of support for volunteers after making a hospital visit was investigated by subjects rating how often they received support from each of the listed sources. There were 41 subjects who answered this section, and their responses are given in Table 10.4.

Table 10.4

The Frequency with which BCSS Volunteers Discussed their Hospital Visits with each of the Listed People

	Often	Some-times	Hardly ever	Never
A friend....................................	0	4	6	31
Your husband................................	7	12	5	17
Another BCSS volunteer......................	0	13	10	18
The BCSS co-ordinator.......................	7	19	10	5
Other Anti-Cancer Foundation staff..........	1	8	5	27
Any other person............................	1	2	0	38

Those listed under "any other person" included ward sisters, social workers, and nurses.

Thirty-seven (90%) volunteers had never been in the position of wanting to talk to someone but finding no-one available; 3 had hardly ever been in this position; but 1 said she sometimes found herself with no support.

The final question in this section asked BCSS volunteers whether they would feel guilty if they wished to (a) have a "holiday" from visiting or (b) leave the service. Twenty-three (56%) of the 41 who answered this question said that they would not feel guilty, whilst, of the others, 12 (29%) would feel a little guilty; 4 (10%) would feel quite guilty and would postpone their decision for a while; and 2 (5%) would feel very guilty, in fact that they would really like a break but have not been able to ask for it.

Breast cancer patients

Fifty-three patients (79%) had a BCSS visitor approximately the same age as themselves, and 57 (85%) reported having the same type of surgery as their visitor (5 had different surgery and the remaining 5 didn't know what surgery their visitor had). All patients who considered it very important that their visitor was approximately the same age as themselves or had the same type of surgery were, in fact, adequately matched in those respects. Matching of adjuvant therapy was more difficult, however, as 36 patients (54%) didn't know at the time of the visit if they were to have adjuvant therapy. Even when this was known it was not always possible to match visitors with patients, and 12 had the same adjuvant therapy as their visitor whilst 19 had different adjuvant therapy. Patients rated the importance of these matchings, as set out in Table 10.5.

Table 10.5

Patient views on the Importance of Matching Age, Type of Surgery, and Adjuvant Therapy of the Patient with her BCSS Visitor

	Very Important	A little Important	Not very Important
Matching of age	29 (43%)	14 (21%)	24 (36%)
Matching of type of surgery	39 (58%)	14 (21%)	14 (21%)
Matching of adjuvant therapy	19 (28%)	10 (15%)	38 (57%)

Sixty-four (96%) patients indicated that they would recommend a BCSS visit to other breast cancer patients. Of the other three, two said that it depended on whether the patient wanted it or not, and one did not answer this question.

Patients were invited to comment on the BCSS visit, and these comments are included in Appendix C-8.

BCSS hospital visitors and breast cancer patients

BCSS volunteers were asked three questions which had also been asked of patients, in order to see how closely volunteers' perceptions matched those of the patients, and to determine where any discrepancies lay. The first of these questions was "What is the most difficult problem for patients who have just had a mastectomy?" This question had been asked of patients in Study 1. The Chi-squared test found no significant differences in the answers given by BCSS volunteers and patients respectively, and a comparison of answers given appears in Table 10.6. Only patients who had had a mastectomy were used in this comparison, as the BCSS visit very few patients who have less intensive surgery.

Table 10.6

A Comparison of the Percentages of Breast Cancer Patients and BCSS Volunteers who Selected certain Cancer-related Problems as the Most Difficult or Troubling for Patients who have just had a Mastectomy

	BCSS (N = 42)	Patients (N = 35)
Fear and uncertainty about the future due to cancer.	83%	77%
Limitations in physical abilities or lifestyle.	0	11%
Difference in appearance due to cancer.	14%	3%
Pain, symptoms, or discomfort from illness or treatment.	2%	6%
Problems with family or friends related to cancer.	0	3%

A total of 83 patients, 16 from Study 1 who were visited by the BCSS, and 67 from the present Study, rated the helpfulness of the BCSS on different areas of information given. However, one patient in the present Study answered by circling "very helpful" for each item in this question, and "very true" for each item in the next question on possible strengths and weaknesses of the BCSS. This patient's answers were omitted from the analysis because (a) it was unlikely that all areas on information and advice would have been applicable to her situation, let alone very helpful, and (b) the strengths and weaknesses section began with a positive statement and then alternated with negative statements and it was again unlikely that she found them all to be very true. A comparison of patients' views with those of BCSS volunteers is given in Table 10.7. Kendall's coefficient of concordance showed that there were no significant differences within each group in the answers given on this question: BCSS $\underline{W} = .42$, Chi-squared approximation (9, $\underline{N} = 41$) = 154.28, $\underline{p} < .01$; patients $\underline{W} = .44$, Chi-squared approximation (9, $\underline{N} = 82$) = 324.42, $\underline{p} < .01$. However, Chi-squared comparisons between the two groups showed a significant difference on 6 of the 10 items: communicating with the doctor Chi-squared (1) = 32.29, $\underline{p} < .01$; communicating with the family Chi-squared (1) = 11.12, $\underline{p} < .01$; financial matters Chi-squared (1) = 8.19, $\underline{p} < .01$; resuming work Chi-squared (1) = 18.91, $\underline{p} < .01$; resuming sport Chi-squared (1) = 11.66, $\underline{p} < .01$; resuming social life Chi-squared (1) = 9.84, $\underline{p} < .01$.

Table 10.7

A Comparison of the Percentages of Breast Cancer Patients and BCSS Volunteers who found certain Areas of Advice given by the BCSS to be Helpful

	BCSS ($N = 41$)	Patients ($N = 82$)
Advice on communicating with the doctor.	71%	17% *
Advice on communicating with the family.	54%	22% *
Advice on what treatment should be given.	12%	7%
Advice on the side effects of treatments.	32%	20%
Advice on exercising of arm.	66%	60%
Advice on prostheses.	98%	92%
Advice on financial matters.	34%	11% *
Advice on resuming work.	54%	15% *
Advice on resuming sport.	46%	16% *
Advice on resuming social life.	76%	44% *

* $p < .01$

Table 10.8 shows the results of the comparison between what BCSS visitors and breast cancer patients respectively considered to be the strengths and weaknesses of the hospital visit. Kendall's coefficient of concordance showed that there were no significant differences within each group in the answers given on this question: BCSS $W = .85$, Chi-squared approximation (9, $N = 40$) = 305.96, $p < .01$; patients $W = .56$, Chi-squared approximation (9, $N = 64$) = 322.37, $p < .01$. However, Chi-squared comparisons between the two groups showed a significant difference on 7 of the 10 items: "Just seeing someone who had recovered helped me feel I could too" Chi-squared (1) = 14.60, $p < .01$; "She could understand my worries because she could remember feeling the same way" Chi-squared (1) = 14.33, $p < .01$; "Talking to her made me feel less isolated and alone" Chi-squared (1) = 14.71, $p < .01$; "I asked her questions I couldn't ask anyone else" Chi-squared (1) =

35.83, $p < .01$; "I already knew everything she told me" Chi-squared (1) = 4.44, $p < .01$; "She was too cheerful and I wasn't in the mood for that" Chi-squared (1) = 13.57, $p < .01$; "She was too different from me; I couldn't talk to her" Chi-squared (1) = 5.38, $p < .01$.

Table 10.8

A Comparison of the Percentages of Breast Cancer Patients and BCSS Volunteers who Considered certain Statements about the Strengths and Weaknesses of the BCSS to be True.

Positive comments	BCSS (N = 41)	Patients (N = 64)
Just seeing someone who had recovered helped me feel I could too.	99%	80% +
She could understand my worries because she could remember feeling the same way.	93%	70% +
Talking to her made me feel less isolated and alone.	93%	70% +
She lifted my spirits.	83%	71%
I asked her questions I couldn't ask anyone else.	83%	39% +
Negative comments		
Her visit came too soon after my operation.	18%	11%
She talked too much about herself.	10%	5%
I already knew everything she told me.	11%	23% *
She was too cheerful and I wasn't in the mood for that.	16%	2% +
She was too different from me; I couldn't talk to her.	12%	3% *

* $p < .05$; + $p < .01$

It was intended to divide these answers according to whether patients were satisfactorily matched with their BCSS visitor or not, but this proved impossible, as all who considered age and type of surgery matching to be very important were, in fact, adequately matched.

Discussion

BCSS hospital visitors

Meagher et al. (1987), in their study of diadic social support for cardiac surgery patients, noted that "the helper-therapy principle is evident by the continued commitment of the volunteer group" (p. 835). This was also evident in the present study, as 80% of the BCSS hospital visitors had been giving volunteer service for 3 years or more. Volunteers saw the main benefit to themselves in hospital visiting as being, almost overwhelmingly, the satisfaction they received from (a) doing something positive with their cancer experience and (b) giving to someone in need and being valued by them (Table 10.1). These benefits represent the hospital visitors' getting some sense of mastery over what has happened to them by being able to give support to others who are now in a similar position as they themselves were a few years earlier. The benefits to hospital visitors also represent the enhanced self esteem experienced as they were able to make "downward" comparisons (as per social comparison theory) with those who were less well adjusted than themselves.

Being a BCSS volunteer has its negative aspects, and the greatest of these was coping with the death of a fellow volunteer (Table 10.2). This not only represents the loss of a friend, but also alerts the volunteer to the possibility that this could happen to her, as she has also had cancer. This illustrates a negative aspect of social comparison theory which may cause a volunteer to reappraise the power of the stressor, cancer, and may well shake the confidence of one who is a role-model of a fit and well-adjusted ex-cancer patient. Other negative aspects of being a BCSS volunteer hospital visitor were feeling emotionally drained after a visit and feeling guilty when prior commitments clashed with hospital visiting. This last aspect is interesting expecially when considered together with the fact that 44% of volunteers said that they would feel some degree of guilt if they asked to have a holiday or leave the service. The help that BCSS volunteers can give patients is unique in that the volunteer is living proof of life after breast cancer. Perhaps the knowledge of the uniqueness of the service brings with it a sense of responsibility, no doubt reinforced by the gratitude of patients, and this may cause a sense of guilt when unable to visit.

BCSS volunteers listed the most important characteristic of a hospital visitor as being a good listener, having empathy, and looking fit and well (Table 10.3). The last of these refers to being a role model, whilst the others refer to the esteem-enhancing function of support rather than problem-solving. It is surprising that "being a good listener" was selected most often (91% selected this characteristic), as it is not specific to those who have been through the same experience as the person to whom they are listening. However, the patient may give more credibility to one who had "been there". Also, giving precedence to this characteristic underlines the focus of the visit as being on the experiences of the patient rather than those of the visitor. It is obvious from the comments made by breast cancer patients that they also considered these three aspects of listening, empathy, and looking fit and well to be of utmost importance.

Examples of this are those from subjects no. 7 and 35, who were impressed by their volunteer's appearance, subject no. 7 also remarking on her volunteer's positive attitude to her prosthesis, and subjects no. 14, 19, and 51, who found their visitors very understanding and empathic (Appendix C-8). The reason why the characteristic of being able to relate to others different from oneself was not rated as of paramount importance by BCSS volunteers was no doubt because the BCSS had a number of ethnic volunteers who covered any important cultural differences.

Many volunteers commented on the importance of adequate training. Although BCSS volunteers do not give any medical advice, it is still helpful if they are conversant with any major changes taking place. Many volunteers realised the need to keep up with the latest breast cancer treatments, as some had had their surgery many years ago. It is also important that BCSS hospital visitors be aware of the avenues of support available for patients, so that they can refer them where necessary. For these reasons, and also to update knowledge on the types of prostheses available, and to offer support to other BCSS workers, it is important that they attend as many inservice training sessions as possible.

Support for the support-givers was found to be adequate in most cases, with 90% claiming that there was always someone available to talk over the visit when required. There was a range of support-givers to whom the BCSS volunteer could turn, with most using the BCSS co-ordinator (63%) and/or their husbands (43%). Volunteers were required to submit a written report to the co-ordinator after each visit, and many may have found that writing this had a therapeutic or "deprogramming" effect. The fact that few discussed their visits with friends is probably due to the importance placed on confidentiality within the service. In this respect it is of interest to note the number who confided in their husbands. This rather high percentage in view of the code of confidentiality may be a further indication of the close bond between marriage partners after a cancer experience, as found in Study 1, such that the husband may be seen as an extension of the self. If this were the case, to discuss visits with him would not be regarded as a breach of confidentiality. However, although most volunteers claimed that their support needs were met, the unanswered question was whether the volunteers readily sought support when they needed it. A suspicion that they may have denied their needs seems reasonable in view of the fact that 15% admitted not being able to ask for a holiday from the service when they needed it.

Breast cancer patients

The comments made by patients who had been visited by the BCSS (Appendix C-8), together with the high response rate to this questionnaire (91.9%), indicate that the BCSS volunteer hospital visitor filled a need. Many patients feel the need to talk to someone who has undertaken the treatment that they are about to embark on (Pruyn et al., 1985). This will enable them to make "upward" comparisons with the role-model, as per social comparison theory, and so reappraise the threats of cancer and their ability to meet these threats. Thus patients will know more of what to expect, so reducing the element of uncertainty and its attendant fears. Patients may also feel more confident of coping, knowing that others have done so before them. Breast cancer patients need to know that it is possible for them to lead a full life, doing all that they were used to doing, and looking just as attractive as they did before their surgery. The BCSS hospital visitor, as one who has accomplished this, is one of the few people who can validly impart this hope.

From the answers given, it appears that most BCSS volunteers were well matched with the patients they visited, as far as age and type of surgery were concerned. However, matching of adjuvant therapy was not possible because at the time of the visit many patients did not know what adjuvant therapy (if any) they would require. This matching would not present any ultimate problems, however, even for those who considered it to be very important, because a session could readily be arranged with another volunteer who had undergone any treatment that the patient was about to begin.

BCSS hospital visitors and breast cancer patients

It would be expected that BCSS volunteers had a reasonable understanding of the position of breast cancer patients, because they had been in a similar situation. In order to determine whether in fact they did have this good understanding, three questions were asked of both the volunteers and recent breast cancer patients for comparison purposes.

There were no significant differences in the answers given by the two groups as to what was the most difficult problem of the recent mastectomy patient (Table 10.6). BCSS volunteers were well aware that by far the most troubling problem was fear and uncertainty about the future. This awareness would not only have come from their own experience with cancer, but also from the conversations with patients they have visited. It was interesting to note the (non-significant) difference in the selections made by hospital visitors and patients respectively in the item referring to appearance. Study 1 indicated that the number of patients most worried about their appearance rose from 3% to 16% over the first 3 months post surgery. As patients became more secure that their cancer had been cured by surgery, they focussed on their "mutilation". It was hypothesised that this may result from a hierarchy of fears which changed as time from surgery passed. BCSS volunteers are obviously aware that body image is a problem to many patients, as well as fear of recurrence, and 14% thought this would be the greatest worry of recent patients. This may indicate that BCSS volunteers were unaware of this shift in emphasis over time.

There was no significant difference within the group of BCSS volunteers or the group of patients in their answers to the questions on the usefulness of information given by them or their ratings of the services provided. However, significant differences were found when the answers provided by each of these groups were compared with each other (Tables 10.7 & 10.8). This indicates that both the BCSS and patients respectively hold fairly unified views on what aspects of the BCSS services are most beneficial, yet in some respects the views of these two groups differ from each other, and so these differences need to be investigated.

BCSS volunteers rated the usefulness of advice on financial matters; communicating with the doctor and family; and resuming work, sport, and social life significantly more highly than did patients (Table 10.7). However, if the question had asked for the items to be ranked in order of usefulness, the agreement between patients and volunteers would be more obvious, as the three items which both groups considered most useful were: advice on prostheses; exercising of arm; and resumption of social life. These were also the same most valued items of information found in Study 1 (Table 7.15). Advice on what treatment should be given was found helpful by fewer patients than was any other item, and this was expected by the BCSS volunteers as they generally do not see patients′ case records and are not permitted to give medical information. If patients asked for an opinion on medical matters, they were referred to their surgeon.

In many cases BCSS volunteers rated their services more highly than did patients (Table 10.8). There was a significant difference in agreement with the positive comments of "Just seeing someone who had recovered helped me feel I could too", "She could understand my worries because she could remember feeling the same way", and "Talking to her made me feel less isolated and alone". At least 70% of patients agreed with these comments, demonstrating that these were indeed valued aspects of the visit, but over 90% of hospital visitors thought that patients would agree with those items, and this was a significant over-estimation in each case. Another positive comment, "I asked her questions I couldn′t ask anyone else", was agreed with by only 39% of the patients, whilst 83% of the hospital visitors thought this was true.

It appears that many patients do, in fact, ask questions of people other than the BCSS volunteer, and it seems that many volunteers under-estimated the number of patients who would feel able to ask questions of their surgeon and/or others. This was also evident in the reaction to the statement, "I already knew everything she told me", as 23% of the patients agreed with this, whilst only 11% of the hospital visitors thought that this would be the case.

The other difference in this section was that BCSS volunteers considered some visitors may have been too cheerful for patients, or too different from them, whilst patients were not aware of this. There was, in fact, only one complaint of a hospital visitor being too cheerful, and this was made by subject no. 55 in Study 1 (Appendix C-6). On the other hand, many patients praised the attitude of their visitor, saying that she generated confidence.

Summary

With reference to the six hypotheses stated earlier, this research demonstrated the following:

Hypothesis 1. Social comparison theory states that people in ambiguous situations tend to elicit information and to evaluate themselves through comparison with similar others. Therefore it was hypothesized that, because of the BCSS volunteer's special position as a previous breast cancer patient, she would help fill patients' needs for information and empathic understanding. She would also be a role-model for patients' "upward" comparison and emulation of coping strategies.

This hypothesis was supported. Many patients stated that the BCSS volunteer was helpful with information on prostheses and arm mobilization. They also stated that the volunteer understood them, helped them to feel less isolated, and instilled in them a confidence in their recovery.

Hypothesis 2. Different age groups, types of surgery, and treatments present their own unique problems, which would be best understood by those who have faced similar situations. Also, social comparison theory states that people compare themselves with similar others. Therefore it was hypothesized that patients would consider it important that their hospital visitor matched them in age, type of surgery, and treatment.

This hypothesis was not supported. Only 43% considered age matching to be very important whilst 36% considered it to be unimportant; 58% considered matching of surgery type to be very important whilst 21% considered it unimportant; and only 28% considered treatment matching to be very important whilst 57% considered it unimportant (Table 10.5).

Hypothesis 3. Social comparison theory states that "downward" comparisons enhance self esteem. Therefore it was hypothesized that volunteers would receive benefit from the service they provided as it would help them gain a sense of competence in coming to terms with their own breast cancer. The satisfaction received from using their cancer experience to help others would in some way vindicate the fact of their illness.

This hypothesis was supported. Eighty percent of the volunteers had been with the BCSS for at least 3 years, thus indicating that there were benefits received by them from being in the Service. The two benefits listed most often by volunteers as being the most important to them were "getting satisfaction from doing something positive with my cancer experience", and "getting a sense of fulfilment in giving to someone in need and being valued by them".

Hypothesis 4. The focus of the BCSS is on positive living. Volunteer hospital visitors are well-adjusted breast cancer patients, who lead full and satisfying lives. Therefore it was hypothesized that the most negative aspect of being a BCSS volunteer would be encountered when a fellow volunteer died of cancer, because this would bring to mind the volunteer's own vulnerability as a cancer patient.

This hypothesis was supported. Table 10.2 indicated that a fellow volunteer dying of cancer was by far the most upsetting experience resulting from being a volunteer.

Hypothesis 5. The BCSS aims to show patients that it is possible to lead a full life and to look "normal" after breast surgery. Therefore it was hypothesized that hospital visitors would consider that looking fit and well was the most important characteristic of a BCSS visitor.

This hypothesis was not supported. The two most important characteristics were given as being a good listener and having empathy. However, to look fit and well and to wear appropriate clothing was considered the third most important characteristic of a volunteer visitor, and so it was given some prominence in the minds of the visitor.

Hypothesis 6. All BCSS hospital volunteers are previous breast cancer patients who would therefore have some insight into many of the problems facing the patient. Further, all BCSS volunteers are trained, in order that they may be aware of difficulties which may upset others but which they themselves may not have faced. Therefore it was hypothesized that there would be no significant differences between the views of patients and volunteers on (a) the most difficult problems for mastectomy patients, and (b) the strengths and weaknesses of the BCSS.

The first part of this hypothesis was supported. There were no significant differences in what was seen by BCSS volunteers and patients respectively to be the most difficult problem of the recent mastectomy patient (Table 10.6). However, the second part of the hypothesis was not supported, as there were many differences in the views of volunteers and patients on the strengths and weaknesses of the hospital visitor service (Table 10.8). Although there were plenty of indications that patients were very appreciative of the services of the BCSS, volunteers were inclined to rate their services more highly than were patients.

Conclusions

It appears from the responses and comments made by patients who had been visited by the BCSS (Appendix C-8) that the volunteer hospital visitor was well received in most cases, and filled a need. Another indication of the value of the visit may be assumed from the high response rate of 92% to this questionnaire. Breast cancer patients need confidence, not only that they will survive the cancer, but also that they will look "normal" after their surgery, and this kind of hope cannot be given easily. The BCSS hospital visitor is able to impart this confidence merely by the way she looks. She is a model of one who has survived and who looks as attractive as she did before surgery. She is also aware of many of the problems which the new breast cancer patient may face, and so is able to present these in a positive framework. It is obvious how helpful this must also be to the hospital visitor, who only a few years ago was a patient wondering how--or even if--she would survive. This ex-patient is now being admired by others who aspire to look as healthy and sound as positive as she does. This service is surely one which benefits both the giver and the receiver.

Study 1 indicated that patients required more support from surgeons in the first 3 months after surgery than many surgeons were able to give. One of the aims of this study was to ascertain whether this need could be met by the BCSS hospital visitor. However, although the BCSS does meet valid patient needs, it is unlikely that it meets the specific need for which the patient requires support from her surgeon. The BCSS volunteers are not medically trained and do not have access to patients' files. It would appear that there is a type of support which can only be given by someone who is conversant with the explicit knowledge of each patient's case. There can be nothing quite as comforting as being reassured by someone who knows the case particulars and can give more than percentages and probabilities. Of course, surgeons themselves can often only answer in generalities, as they do not know as much about the disease of cancer as they would like to. So, whilst the dilemma still remains, it seems that the BCSS, although helpful in certain areas, is not able to give the same kind of reassurance as someone with full medical training as well as knowledge of the patient's case.

SECTION IV

STUDY 3

PSYCHOSOCIAL NEEDS AND RESPONSES OF HUSBANDS OF BREAST CANCER PATIENTS

CHAPTER 11

Coping with Cancer: Husbands of Patients

Having noted the role of husbands as sources of support in Chapter 7, and given their lack of formal training in providing it, this chapter investigates the support needs of husbands.

The psychological theories discussed in Chapter 3 which pertain to husbands supporting wives are Attribution Theory and Equity (Social Exchange) Theory. Attribution theory notes the importance of recipient views on the intentions of the support giver, and emphasizes the need for congruence between the support models of the giver and receiver of support. Equity theory describes social support as an exchange of resources, and emphasizes the notion of reciprocity. The applicability of these theories will be investigated.

"A life-threatening illness is an event which forces the patient to rely more on family resources, and therefore it afflicts the family as well as the patient." (Spiegel, Bloom, & Gottheil, 1983, p. 33). A diagnosis of cancer is devastating to all family members (Goldberg, Wool, et al., 1984; Kerson & Kerson, 1985; Rosser, 1981). It is a time of bewilderment and anxiety, as complex and formidable problems have to be faced (Bard & Sutherland, 1955).

It has been shown that breast cancer patients rely heavily on family members for empathic support and reassurance. This helps restore morale (Goldberg, Stolzman, Goldberg, 1984). Most mastectomy patients are particularly concerned about the reactions of their husbands, and many studies have found husbands to be the most important and convincing source of support to patients (Peters-Golden 1982; Pruyn et al., 1986; Smith et al., 1985).

The present study, however, found marital status alone to have no significant effect on adjustment to breast cancer. This supported Bloom (1982b), and it has been suggested that the important factor was not the mere existence of a husband, but the confiding nature of the relationship (Ray & Baum, 1985). Shinn, Lehmann, and Wong (1984) cited studies indicating that an intimate relationship with a spouse protected women from depression following serious life events, where support from other confidants was less effective.

It is important that cancer patients involve significant others in attempting to deal with their fears (Goldberg, Stolzman, & Goldberg, 1984), and the most helpful way of doing this is by open communication (Kerson & Kerson, 1985). However, this is often difficult in a crisis. Husbands also may have many concerns which they feel they can not share with their wives (Lichtman & Taylor 1986). Being fearful for his wife's situation, uncertain of what lies ahead, and unsure of how to cope, the husband may withdraw, leaving his wife feeling rejected (Goldberg, Stolzman, & Goldberg, 1984). Communication problems may also be initiated by the wife, who, in attempting to protect both herself and her husband may hide her scar or never mention the fact of her changed appearance (Ray & Baum, 1985). This lack of communication often also manifests itself in the sexual relationship, where the husband may refrain from making advances for fear of hurting his wife, who again may interpret this as rejection (Bard & Sutherland

1955). Sometimes the patient might not feel ready to resume sexual activity, yet still yearn for warmth and intimacy (Kerson & Kerson, 1985).

In their study of the effects of childhood leukemia on the family, Fife, Norton, and Groom (1987) noted that stable and supportive relationships held together in spite of acute stress, whilst previously poor relationships had more difficulty. However, Lichtman and Taylor (1986) claimed that when women have cancer, one of the most striking aspects was that most marriage relationships at least stayed the same, and some improved. This improvement in many marriages as a direct result of the cancer experience was evident in Study 1 of this present research. Hence it appears that many couples unite with each other against a common threat.

Rosser (1981) noted that the literature often assumed that the married breast cancer patient's greatest fear was for her husband's continued love, whilst the husband's greatest fear was for his wife's life. A study by Lichtman and Taylor (1986) demonstrated that husbands were significantly more concerned about their wives' cancer recurrence than were patients themselves. Husbands also worried about their wives' emotional reactions to having cancer.

Wellisch, Jamison, and Pasnau (1978) noted that all husbands in their study were obviously emotionally involved in their wives' mastectomy. Being the main source of support places a heavy burden on husbands, who are themselves stressed and therefore may be vulnerable to a variety of physical and emotional difficulties (Klein, Dean, & Bogdonoff, 1967; Wellisch, Mosher, & van Scoy, 1978). Many may not know how to provide support to a person with a life threatening illness.

On the one hand, they are not able to give medical advice, and on the other hand, efforts at distracting their wives from expressing fear or sadness by being relentlessly cheerful are often the cause of further distress (Dunkel-Schetter, 1984). Thus the task of husbands supporting breast cancer patients is an extremely difficult, although important one. Therefore determining the support needs of husbands and providing help where required must be as important as providing these needs for the patient (Battersby 1981).

It appears that breast cancer not only raises concerns for husbands, but may also deprive them of their usual confidants. Lichtman and Taylor (1986) stated that most husbands of breast cancer patients do not discuss their fears with their wives, although the wife would be the first person to whom they would turn under other circumstances. It also seems that others do not offer help to men as readily as they may to women (Chesler & Barbarin, 1984). Perhaps an offer of help may indicate that the man is seen as weak or needy, and so others are not willing to break with traditional roles. However, men have sometimes indicated a need for understanding or advice (Gale, 1981). Husbands of mastectomy patients should have the opportunity of talking about their fears and feelings with the surgeon (Bard & Sutherland 1955). This will give them a more realistic view of the situation, and also may enable them to communicate more freely with their wives. It has been reported that few surgeons include husbands in counselling sessions (Battersby, Armstrong, & Abrahams, 1978). If husbands and other family members were involved in professional consultations, this could well have the double benefit of alerting them to the issues facing patients and also helping them to cope with their own emotional stress (Meyerowitz 1980). Gale's (1981) study indicated that husbands of mastectomy patients who required advice or support preferred to have this from surgeons or professional staff, rather than relatives or other patients etc. Another reason for consultation with the surgeon is that many husbands wish to take part in the decision-making process of their wives' surgery. Wellisch, Jamison, and Pasnau (1978) found that 57% of their 31 respondents were involved in this process, and "a large majority of the sample wished in retrospect that they had had more involvement" (p. 546). However, it should be noted that this "large majority" was actually 23.3% of 31 (p. 544), i.e. 7 respondents!

The traditional role expectation of men is that of decision-maker and provider (O'Reilly & Thomas, 1989), resulting in the projection of images of strength and independence. This may lead to gender-based differences in coping styles, especially if, as Cohen and Wills (1985) state, women derive more benefit than men do from talking about feelings and problems with close confidants. If admitting a need for help is seen as a sign of weakness or dependency, this will conflict with male traditional role expectations. Therefore men may be reluctant to disclose emotional needs (Chesler & Barbarin, 1984), thus denying their feelings or dealing covertly with them. Some may take refuge outside the family, or in alcohol (Kerson & Kerson, 1985). Wellisch, Mosher, and van Scoy (1978) claimed that a significant subgroup of mastectomy patients' husbands denied any problem and were unable to cope with their wives' difficulties. Another study demonstrated that whilst there was a small group who could not cope, the majority either coped well or denied feeling stressed (Wellisch, Jamison, & Pasnau, 1978). It was no doubt difficult for these researchers to separate those making satisfactory adjustments from those denying their problems, especially when respondents were recalling feelings of up to 5 years ago. Also, as the 31 respondents represented only 15% of the total to whom the questionnaire was sent, it may be that many who were stressed preferred not to reply. Folkman and Lazarus (1980) found that, although men traditionally used problem-focused coping and women emotion-focused coping, this was not the case in health-related stress situations studied by them. There were no differences in the amounts of emotion-focused coping used by both sexes, although men used significantly more problem-focused coping in situations which had to be accepted or when information was required.

This research

Results from Study 1 indicated that there was a fine balance required of families in giving support to breast cancer patients. It was not as clear-cut as was support from surgeons and other professionals, in that patients were either satisfied with the amount of support they received, or else they required more. With respect to family support, some patients were satisfied and some required more, but there were also a number who preferred less of some types of support. Therefore it appeared that one of the greatest problems for family members may have been in knowing how much support to give. This would be particularly troublesome for husbands, as the main support givers, because of their own emotional involvement and stress in the situation. For this reason, this study will be devoted to the issue of stress and coping in husbands of breast cancer patients, in order to determine (a) how they feel they can best help their wives; (b) whether they feel restrained from helping either by their wives' attitudes or their own; (c) what their main area of stress is; (d) how they cope with this; and (e) whether they would like assistance of any kind.

Hypotheses

1. The majority of husbands will desire to take part in the decision-making process of their wives' surgery, but some will be inhibited from taking as full a part as they would wish (Wellisch, Jamison, & Pasnau, 1978).

2. Husbands may not receive all the support they require because many will not feel able to speak to their wives about their concerns for fear of upsetting them. Thus the one person to whom they would normally go for support, i.e. their wives, will not be available to them (Lichtman & Taylor, 1986).

3. Husbands will require more support from surgeons than they are getting (Battersby et al., 1978). Their need for support from this source will be increased if they are unable to speak with their wives. Also, Study 1 indicated that surgeons were generally too busy to give as much support as patients required, and so it is expected that this will hold

at least to the same degree for the husbands of patients.

4. The greatest fear of husbands of breast cancer patients will be that the cancer may recur (Lichtman & Taylor, 1986). This will be a more troubling problem for them than the fact of their wives' altered body.

5. There will be gender-based differences in coping style, which originate from traditional gender-based differences in role expectations. Men traditionally appear strong and able to cope, and consider seeking help as a sign of weakness (Chessler & Barbarin, 1984), whereas women derive satisfaction from discussing problems and feelings (Cohen & Wills, 1985). Therefore husbands will tend to use avoidance/denial coping strategies such as keeping their feelings to themselves (Wellisch, Mosher, & van Scoy, 1978), rather than active--behavioural strategies relating to seeking empathic understanding.

Method

Subjects

Subjects were husbands of all the English-speaking breast cancer patients referred to the Anti-Cancer Foundation Breast Cancer Support Service from January to June, 1988, inclusive. Eighty-six of the 106 questionnaires sent out were returned (81%).

The 86 husbands ranged in age from 27 to 76 (median age = 60), and their wives' ages ranged from 25 to 76 (median age = 58). Seventy-five patients had a mastectomy, whilst the other 11 had less extensive surgery. At the time of answering the questionnaire, adjuvant therapy was being given to 28 patients: 10 were having chemotherapy and 18 radiotherapy. Seven of this latter group were also to have chemotherapy.

Measures

As no previous study had been found where husbands gave their opinions to the extent that this research required, all questions were original to this research, with the exception of the Most Difficult Cancer-related Problem (Taylor et al., 1986), Ways of Coping (adapted from Folkman & Lazarus, 1985), and Wakefield Self-Assessment Depression Inventory (Snaith et al., 1971), which were the same as those used in Study 1, and the Spielberger State-Trait Anxiety (Spielberger, 1985), which was similar to the one used in Study 1.

Wellisch, Jamison, and Pasnau (1978) indicated that the majority of their respondents were involved in the decision-making process leading to their wives' surgery. Subjects in the present research indicated their part in this process by selecting their answer from: "I went with her to the surgeon, and we all discussed it together" and "I didn't go with her to the surgeon, but we discussed it at home"; and those who didn't take part in this process selected their answer from: "I went with her to the surgeon, but we left the decision to him" and "I believe it should be her decision". Subjects then noted whether they would have liked to have had a greater part in this decision-making process, and those answering "yes" selected their reason for not being able to do so from: "My wife preferred to do it her way" and "The surgeon didn't give me any opportunity".

The frequency with which husbands received empathic, informational, and tangible support, the source from which it was received, and satisfaction with this frequency was investigated. Peer support was also investigated by subjects indicating whether they had, or would like to have had, the opportunity to talk to (a) a woman with similar surgery to his wife or (b) a husband of such a person.

Subjects' satisfaction with the amount of empathic, informational, and tangible support they were able to give their wives was then investigated. Those who would like to have given more support indicated whether they were hindered by their wife's attitude or their own inability, whilst those who considered that they had given enough support indicated why they considered the amount they had given to be sufficient.

Demographic data (age of subject and his wife, adjuvant therapy being undertaken by wife, and number of weeks since wife's surgery) was inserted in the middle of the questionnaire, as a way of determining how long it was after the wife's surgery that the husband answered the questionnaire. This was important to know, in order to compare husbands' coping strategies and psychological adjustment with those of wives at the same time. It was considered that if demographic data was requested on the first page, subjects may answer this and tackle the remainder of the questionnaire later, thus rendering it impossible to make comparisons.

Husbands selected what they considered to be the most troubling cancer-related problem for their wives, from the list used in Study 1. They then rated their wives' stress level. It was emphasized here that husbands should give their own opinion and not ask their wives for these answers. This was so that these answers could be compared with (a) patients' answers in Study 1, and (b) husbands' stress levels and the most troubling problem for them, which was the next section for husbands to answer.

Following this came the Ways of Coping Questionnaire (adapted from Folkman & Lazarus, 1985) and the Wakefield Self-Assessment Depression Inventory (Snaith et al., 1971), which were the same as those used in Study 1. There was a change in the Spielberger State-Trait Anxiety questionnaire in that Form Y was used in place of Form X. This consisted of six changes, i.e. "I am strained" instead of "I am regretful"; "I feel satisfied" instead of "I feel rested"; "frightened" instead of "anxious"; "indecisive" instead of "high strung"; "confused" instead of "over-excited and 'rattled'"; and "steady" instead of "joyful". These changes had been found to improve the psychometric properties for the Scale (Spielberger, 1983). As Form X was highly correlated with Form Y (Spielberger, 1983), and as "for most clinical and research applications the two forms may be considered essentially equivalent for the assessment of anxiety" (p. 10), results from this study were able to be compared with those from Study 1.

Procedure

Before beginning the study, the questionnaires were given to the husbands of 10 breast cancer patients from Study 1, three Anti-Cancer Foundation social workers, and a pastoral care worker who was previously working with the Peter McCallum Cancer Institute in Melbourne. The 10 husbands answered the questionnaire by post, and included comments on the clarity of the instructions, the test format, and the content of the individual items. The social workers and pastoral care worker were interviewed after having inspected the questionnaire, for comments on the suitability and clarity of the questions, and the questionnaire was accordingly adjusted before being posted to subjects.

The questionnaires were posted by the BCSS, as in Study 2, because considerations of confidentiality did not permit them to pass on the names and addresses of those whom they had visited. Also, as the BCSS considered it would be a breach of confidentiality to write directly to patients' husbands, questionnaires were posted to patients, together with a letter indicating the aims of the study and requesting them to pass the questionnaire on to their husbands. A copy of this letter can be found in Appendix A-13. A letter from the investigator to the husbands was also enclosed, setting out the aims of the research, and this can be found in Appendix A-14, whilst Appendix A-15 contains the questionnaire.

Questionnaires were posted when the patient was 15-22 days post surgery. It was decided not to post them earlier than this out of consideration for patients and their husbands who had just been through a traumatic experience. However, as

Study 1 indicated that patients' psychological trauma abated within a short time after surgery, it was considered advisable to send questionnaires as early as reasonably practicable. This was followed by a reminder letter from the BCSS to patients 1 week later (Dillman, 1978), and this can be found in Appendix A-16.

As it had been found in Study 1 that many patients did not understand medical terms to the extent that they did not know whether they had had a mastectomy or a less intensive surgical procedure, it was decided that, rather than ask husbands for this information, the BCSS would underline the word "one" on the first paragraph of the questionnaire for all patients who had less than a mastectomy. This enabled the researcher to differentiate between these two surgery groups.

Statistical analyses

As the mean number of weeks taken by husbands to reply to the questionnaire was 4, any comparisons made between results of this Study and Study 1 were made with measurements taken at 1 month post surgery.

An analysis of variance ascertained whether there was any relationship between the control variables (husband's age, type of surgery for wife, and adjuvant therapy) and anxiety, depression, or coping strategies used. An analysis of variance also indicated any relationships between adjustment and the use of any particular group of coping strategies.

Chi-squared tests determined any significant differences between husbands' opinions of the most difficult cancer-related problem for (a) themselves and (b) their wives; and also between (a) husbands' opinions of the most difficult problem for their wives and (b) the answers to this question given by subjects in Study 1. Student's t-tests indicated any significant differences between stress ratings on the most difficult cancer-related problem, with comparisons as above.

Student's t-tests compared husbands' use of coping strategies, and also their levels of anxiety and depression, with those of patients in Study 1 at 1 month post surgery.

Missing data. If there was only one missing item in either of the anxiety or depression questionnaires these scores were averaged, otherwise if there were more items missing no score was calculated on that scale for that subject. All other missing data were omitted from the analysis for that subject.

Results

The time between wives' surgery and husbands' answering the questionnaire ranged from 3-9 weeks, with a median of 4 weeks.

Taking part in decision-making

Fifty-six (65%) of the 86 subjects went with their wives to the surgeon. Thirty-eight of these discussed the situation together, feeling that they made a joint decision with the surgeon, whilst 17 left the decision to the surgeon, and 1 left it to his wife. Of the remaining 30 husbands:

14 discussed the situation with their wives and 13 felt that they made a joint decision whilst 1 left this to his wife; 15 left the decision entirely to their wives without any discussion; and 1 was away from home at the time. Thirteen subjects would like to have had more part in the decision of their wives' surgery, but nine had wives who preferred to do it their way and four claimed that the surgeon did not give them the opportunity. Of this latter four, none went with their wives to the surgeon; two discussed the situation at home and two left the decision to their wives.

Support for husbands

Empathic support was received often by 49 subjects, whilst a further 32 subjects received this support sometimes. This made a total of 81 (94%) who had the opportunity to talk about their own concerns regarding their wives' cancer. Mostly these concerns were shared with wives (70%), whilst 43% spoke to relatives, 42% to the surgeon, 30% to a friend, and 25% to health professionals. Seventy-five (89%) were satisfied that they had received the empathic support they required, and of the nine remaining, all spoke about their cancer-related concerns at least sometimes. Those who required more empathic support were asked from whom they wished to receive this, and some selected more than one person: two wished to speak more often with the surgeon, three with other health professionals, six with their wives, three with relatives, and two with friends.

Informational support on how subjects could help their wives was received often by 24 subjects, whilst a further 26 received this advice sometimes. This left 34 (41%) of the 84 respondents who were never given any such advice. Mostly this advice was provided by wives (60%), whilst 42% were told by their wives' surgeon, 40% by other relatives, 32% by friends, and 30% by a health professional other than the surgeon. Twenty-four subjects (29%) said that they would like to have had more information in this regard, and of these 15 had been given no advice. Those who required more information were asked from whom they wished to receive this, and some selected more than one person: 12 wanted information from the surgeon, two from other health professionals, five from their wives, three from relatives, and four from friends.

Tangible support was received often by 38 subjects, whilst a further 23 received help sometimes. This left 23 (27%) of the 84 who answered this question who were given no help with practical chores since their wives' surgery. However, only 11 subjects indicated that they would have liked help more often, and only three of these had received no help.

Peer support was received by 17 (20%) of the 85 subjects who answered this question, in that they were able to speak with a man whose wife had had similar surgery to his wife, and a further 20 (24%) wished to have this opportunity. Forty-four (52%) had the opportunity to speak with a woman whose surgery was similar to their wives', and a further 13 (15%) wished to have it. There were 25 (29%) who did not wish to speak with either a man or woman in a similar position.

Support given by husbands

Of the 85 subjects who answered the question on giving empathic support to their wives, only five (6%) wanted to talk more often with their wives about their (the wives') feelings. Three of these were prevented from talking more often because they felt uncomfortable with the topic, and the other two believed that their wives wouldn't like it. This left 78 (92%) who were satisfied that they discussed things as often as they both wanted to, and two who believed that although their wives would like to talk more often it was not good for them to dwell on these things.

Informational support was evaluated by asking subjects whether they would like to give their wives more advice regarding (a) their treatment or (b) how they could help themselves. Twenty-four (29%) of the 84 subjects who answered this question would like to have given their wives more information, but four believed that their wives wouldn't appreciate this, whilst the other 20 felt that they lacked knowledge. This left 60 (71%) who were satisfied with the amount of advice they had given their wives. Twenty-one of these believed that it was the doctor's job to give information, whilst the other 39 stated that their wives did not require any more advice.

Eighty-five subjects answered the question on tangible support, with 14 (16%) stating that they would like to have helped their wives more often with practical household chores.

Reasons preventing them from doing this were that they did not have time (9%), or that their wives would not like it (7%). This left 71 (84%) who were satisfied with the amount of tangible support they were giving their wives. Three of these believed that although their wives would like more help it's better for them to get back to routine as soon as possible, whilst the other 68 claimed that they and their wives were both happy with the way things were.

The most difficult cancer-related problem

Table 11.1 lists cancer-related problems together with the number of subjects choosing each one as the most difficult for (a) themselves, and (b) their wives. Chi-squared comparisons indicated that husbands considered themselves significantly less troubled by their wives' change in appearance due to cancer than their wives were, Chi(1) = 7.84, $p < .01$, and significantly more troubled by their wives' pain, symptoms, or discomfort from illness or treatment than their wives were, Chi(1) = 13.20, $p < .01$. Table 11.1 also lists the most difficult problem as listed by patients in Study 1 at 1 month post surgery. Chi-squared comparisons between the most difficult problem for husbands and that for patients revealed that patients were significantly less troubled by pain, symptoms, or discomfort than husbands were about pain or discomfort in their wives, Chi(1) = 11.76, $p < .01$.

Table 11.1

The Number of Subjects Selecting certain Cancer-Related Problems as the Most Difficult or Troubling for Themselves or their Wives since they knew of the Cancer, and Comparing this with Patients from Study 1 at 1 month post surgery.

	Husbands' Problems	Husbands' View of Wives' Problems	Patients' Problems (Study 1)
	(N = 86)	(N = 86)	(N = 57)
Fear and uncertainty about the future, due to cancer	41 (49%)	47 (55%)	38 (67%)
Limitations in physical abilities or lifestyle due to cancer	6 (7%)	9 (11%)	7 (12%)
Change in appearance due to cancer	4 (5%)	17 (20%) ‡	5 (9%)
Pain, symptoms, or discomfort from illness or treatment	34 (41%)	12 (14%) ‡	7 (12%) ‡
Problems with children or friends related to cancer	1 (1%)	1 (1%)	0 --

‡ $p < .01$, Chi-squared comparison with husbands' selection of main problem.

Psychological adjustment

The analysis of variance indicated that there was no relationship between husbands' psychological adjustment and any control variable, i.e., his age, his wife's surgery, or adjuvant therapy.

Students' t-tests indicated that stress levels reported by husbands (M = 1.90, N = 84) were not significantly different from husbands' estimation of wives' stress (M = 2.04, N = 86), but were significantly higher than those reported by patients from Study 1 at 1 month post surgery (M = 1.61, N = 57), $F(1, 139) = 5.20$, $p < .05$.

Table 11.2 compares the psychological adjustment of husbands with that of patients in Study 1 at 1 month post surgery. Students' *t*-tests indicated that patients' depression levels were signficantly higher than those of husbands, *F*(1, 136) = 4.62, *p* < .05. The mean depression scores given in the test manual is 6.75 for females and 5.38 for males, which the authors demonstrated by analysis of variance to be not significant (Snaith et al., 1971).

Table 11.2

Mean Anxiety and Depression Levels of Husbands compared with those of Patients in Study 1 at 1 month post surgery.

	Husbands	*N*	Patients	*N*
Mean anxiety	37.85	(78)	39.35	(57)
Mean depression	7.56	(81)	10.16 *	(57)

* *p* < .05.

Coping

The analysis of variance indicated that there was no relationship between husbands' use of any particular group of coping strategies and any control variable.

Table 11.3 compares the coping strategies used by husbands with those used by patients in Study 1 at 1 month post surgery. Students' t-tests revealed no significant differences in the use of these strategies by husbands and patients respectively.

Table 11.3

Coping Strategies used by Husbands compared with those used by Patients in Study 1 at 1 month post surgery.

	Husbands	N	Patients	N
Avoidance / Denial	0.87	(78)	0.96	(57)
Cognitive	1.18	(78)	1.27	(57)
Behavioural	0.80	(80)	1.00	(57)

The mean use of each individual coping response can be seen in Table 11.4, together with the mean use found amongst patients in Study 1 at 1 month post surgery. Students' t-tests comparing these two means indicated that husbands of breast cancer patients used only one coping strategy significantly more often than did patients, i.e. "Tried to keep your feelings to yourself", $F(139) = 4.16$, $p < .05$. However, patients used the following strategies significantly more often than did husbands: "Criticized or lectured yourself", $F(138) = 9.92$, $p < .01$; "Went along with fate; sometimes you just have bad luck", $F(138) = 5.95$, $p < .05$; "Went on as if nothing were happening", $F(139) = 19.45$, $p < .01$; "Looked for understanding from someone", $F(138) = 6.10$, $p < .05$; "Talked to someone about how you felt", $F(139) = 7.18$, $p < .01$; and "Thought of how a person you admire would handle this situation, and used that as a model", $F(138) = 11.63$, $p < .01$.

Table 11.4

Frequency of Usage of Individual Coping Responses by Husbands, and by Patients in Study 1 at 1 month post surgery.

Avoidance / Denial	Husbands	*N*	Patients	*N*
Felt time would make a difference--the only thing to do was wait	1.43	(82)	1.44	(57)
Went along with fate	0.86	(83)	1.28 *	(57)
Went on as if nothing were happening	0.77	(84)	1.56 +	(57)
Tried to keep your feelings to yourself	1.66	(84)	1.26 *	(57)
Tried to make yourself feel better by eating, drinking, or smoking	0.45	(85)	0.40	(57)
Avoided being with people in general	0.35	(85)	0.39	(57)
Kept others from knowing how bad things were.	0.71	(85)	0.88	(57)
Took it out on other people	0.17	(84)	0.28	(57)
Refused to believe it would happen	0.41	(85)	0.46	(57)
Tried to keep your feelings from interfering with other things too much	1.55	(83)	1.42	(57)
Wished the situation would go away	1.22	(83)	1.51	(57)
Had fantasies or wishes about how things might turn out	0.72	(83)	0.60	(57)
Active--Cognitive				
Criticized or lectured yourself	0.40	(83)	0.88 +	(57)
Tried to look on the bright side of things ..	2.13	(84)	2.07	(57)
Prayed	1.24	(84)	1.47	(57)
Prepared yourself for the worst	1.00	(84)	0.79	(57)
Went over in your mind what you would do	0.91	(81)	0.74	(57)
Thought of how a person you admire would handle this situation, and used that as a model	0.18	(83)	0.63 +	(57)
Thought how much worse things could be	1.76	(83)	1.91	(57)
Treated the illness as a challenge to be won .	1.86	(84)	1.65	(57)
Active--Behavioural				
Talked to someone to find out more about the situation	0.81	(84)	0.77	(57)
Asked a relative or friend for advice	0.46	(85)	0.56	(57)
Tried to find out what you could about cancer and your own (wife's) case	1.15	(84)	1.28	(57)
Looked for understanding from someone	0.75	(83)	1.16 *	(57)
Talked to someone about how you felt	0.80	(84)	1.23 +	(57)

* *p* < .05; + *p* < .01.

Note. Maximum score = 3.

Coping and adjustment

A division was made at the median frequency of use of each group of coping strategies in order to ascertain the psychological adjustment of subjects according to their use of each group (Table 11.5). Table 11.6 gives the results from the analyses of variance performed on anxiety and depression to determine whether there were any relationships between them and the use of any group of coping strategies.

Table 11.5

Cell Numbers and Means on Anxiety and Depression According to Coping Strategies used

	Anxiety		Depression	
	n	*M*	*n*	*M*
Avoidance/Denial				
low use	41	33.4	44	5.3
high use	33	43.2	32	10.2
Active--Cognitive				
low use	41	36.8	41	6.3
high use	31	38.9	34	8.7
Active--Behavioural				
low use	39	37.4	42	7.5
high use	35	38.1	35	7.3

Note. The division between high and low use was made at the median

Table 11.6

Analyses of Variance on Adjustment Variables by Coping Strategies

	Anxiety		Depression	
	MS	*F*	*MS*	*F*
Avoidance/Denial	1559.3	15.14 +	309.4	8.10 +
Cognitive	18.0	0.18	14.1	0.37
Behavioural	41.5	0.40	50.9	1.33
Avoidance x Cognitive	415.0	4.03 *	32.0	0.84
Avoidance x Behavioural	426.2	4.14 *	114.5	3.00
Cognitive x Behavioural	859.2	8.34 +	104.6	2.74

* $p < .05$; + $p < .01$.

Note. There were no significant three-way interactions, therefore three-way interaction terms were pooled into the error (residual) sum of squares.

Table 11.7 shows the cell information for significant interaction effects found in the analyses of variance.

Table 11.7

Cell Numbers and Means on Anxiety, where the use of two Groups of Coping Strategies Interacted Significantly with each other

	Behavioural strategies				Cognitive strategies			
	low use		high use		low use		high use	
	n	*M*	*n*	*M*	*n*	*M*	*n*	*M*
Avoidance strategies								
low use	23	32.6	17	33.6	29	31.9	10	37.2
high use	15	45.8	17	41.5	10	50.4	21	39.7
Cognitive strategies								
low use	24	38.4	16	33.5				
high use	14	35.8	16	42.0				

Both anxiety and depression were significantly associated with the use of avoidance/denial strategies: anxiety $F(1, 59) = 15.14$, $p < .01$; depression $F(1, 59) = 8.10$, $p < .01$. There were also significant interaction effects on anxiety in that high anxiety levels were registered by those who (a) used avoidance but not cognitive strategies; (b) used avoidance but not behavioural strategies; or (c) used both active strategy groups together.

Discussion

The response rate in this study was very high, especially considering that the questionnaire went through two "filters" before being answered, as it was posted to the patient, who was asked to pass it on to her husband. Therefore the patient first had the opportunity to refuse to pass it on, and then the husband had the opportunity to refuse to take part. Morris and Ingham (1988) found that 4 out of 30 wives refused to allow their husbands to be interviewed. Wellisch, Jamison, and Pasnau (1978) achieved a response rate of 15% when their questionnaires were given to women attending a self-help mastectomy recovery group and to other mastectomy patients who had indicated that their husbands would be willing to take part. Gale (1981) used diagnostic records for her sample, and posted two questionnaires to mastectomy patients, one each for themselves and their husbands. She achieved a response rate of 22% for husbands. A reason for the high response rate in the present study may have been the personal approach by letter to patients who had recently been visited by the Breast Cancer Support Service, as opposed to Gale's use of diagnostic records. However, it appears that Wellisch et al. not only used this same personal approach, but also asked many of the women whether their husbands would take part, only sending questionnaires to those indicating possible agreement, and thus increasing the likelihood of a high return rate. Perhaps the high response rate in the present study was a reflection of the appreciation felt by patients to the Breast Cancer Support Service, who sent out the questionnaire. Perhaps it resulted from the type of questions asked, as other studies included sexual relationship problems whilst the present one did not. Perhaps it was because the questionnaire was sent soon after the women's surgery, whereas the other two studies were sent to women who had undergone mastectomy up to 5 years ago. If this is the case, this may simply be that questionnaires on more recent events get better response rates because these events are uppermost in respondents' minds. However, it may also be an indication that taking part has a therapeutic value in that subjects are able to focus on and express aspects which are concerning them. If so, this study adds support to the findings of Study 1 in this respect. It may be, however, that the high response rate was due to the wording of the introductory letters sent by the Breast Cancer Support Service and the researcher to patients and husbands respectively, together with the routine follow-up letter.

Taking part in decision-making

Most husbands took some active part in decision-making, either by accompanying their wives to the surgeon or by discussing the situation with them at home. However 19% (16 of 86 respondents) took no active part at all, and although some said that they desired to have had more part in the decision-making process, only five were from this group. This means that 13% of the husbands in this study wanted no part in the decision-making process of their wives' surgery, and indicates that there are are a significant minority of husbands who communicate very little with their wives. This may well reflect the situation in the community at large.

Support for husbands

The vast majority of husbands (89%) felt that they received sufficient empathic support in that they were able to talk about their cancer-related concerns when they needed to. This included the 6% who never spoke about such concerns, thus indicating that they have no such need. This may be an indication of denial of emotional needs, as spoken of by Chesler and Barbarin (1984). It is interesting to note that, contrary to the findings of Lichtman and Taylor (1986), most husbands discussed their cancer-related concerns with their wives. Thus it appears that, as predicted by equity theory, both partners in the marriage received benefit through mutual emotional support. More husbands, in fact, discussed their worries with their wives than with any other person. However, of the nine who wished they could speak more often about these concerns, six would have liked to do this more often with their wives. This indicates that some husbands do have difficulty in broaching this subject with their wives.

Informational support as to how husbands could best help their wives was given mainly by wives. This would be expected, as they would be most aware of their needs. However, perhaps the next question should have been whether husbands would have liked less of this type of information, as it is possible that some might have seen it as an annoyance rather than supportive. In this respect, it was interesting that only 15 of the 34 receiving no such information wished they could have had it. An indication of the willingness of surgeons to spend time with husbands discussing how they can best assist their wives was given when 42% of husbands said that they received this information from this source. It appears that more surgeons included husbands in discussions than was found by Battersby et al. (1978). However, 12 of the 24 husbands who said that they would like more of this information also stated that they required it from the surgeon. This indicates an unmet need in this area, as it represents 14% of the 84 respondents.

Tangible help in the form of assistance with practical chores was received by most husbands, and the great majority were satisfied with the amount of help given. There were some, however, who would have liked more assistance with chores such as housework, transport, or shopping whilst their wives were incapacitated. Of those who claimed that they had received no help at all, only three indicated that they would have liked some assistance. This left 24% claiming that they required no assistance at this time. This may be a further indication of men projecting an image of strength and independence, perhaps feeling that it is a sign of weakness to admit a need for help.

Two types of peer support were investigated by this study. Slightly more than half of the husbands had the opportunity to speak to a woman whose surgery was similar to their wives'. This was no doubt provided for them when the Breast Cancer Support Service visited their wives in hospital. Almost one third of those who missed out said that they would like to have had this opportunity. Thus there was a total of 57 (67%) who either spoke to, or wished to speak to a woman with similar surgery. One fifth of the men had the opportunity to speak to a man whose wife had had surgery similar to their wives', and a further 24% wished to do this. This gave a total of 37 (44%) who either spoke to, or wished to speak to a similar man. However, 29% had neither the opportunity nor the desire to receive peer support from either a man or woman in a similar situation. In Gale's (1981) study, 60% of the husbands indicated that if they required advice and support they would prefer to have it from medical professionals, whilst the other 40% wanted no such support from any source. Not one husband chose another mastectomy patient for support. This was no doubt because subjects had to select only one from those listed, and the men who admitted that they may require support preferred to receive it from professional sources. Fourteen percent of the women, however, preferred support from another mastectomy patient. As predicted by social comparison theory, "upward" comparisons to role-models gave confidence to those struggling to adjust. It also indicates that women have a need to be understood, and may feel that another patient may be able to do this more readily than, say, a professional. However, men may be more reluctant to admit their need for understanding.

Support given by husbands

Most husbands were happy with the support that they were able to give their wives. Empathic support was mainly given as often as the husband felt necessary, with only three husbands admitting that they felt uncomfortable talking about their wives' cancer-related problems, and two stating their belief that, although they would like more discussion, this would upset their wives. However, as this question did not ask how often the wives' problems were discussed, it may be that no discussion at all may have been seen as sufficient by the husbands, as was the case with the 6% who had no need to discuss their own concerns.

Informational support was not so forthcoming, with almost half of the husbands stating that their wives required more advice and either regretting that they could not give it, or declaring that it was the responsibility of the doctor. There appears to be a great need in this area, which points to the benefits of being able to speak to the surgeon, or his team, more freely.

Tangible support was given by most husbands as often as they saw necessary, with eight stating that they would like to be more available but didn't have the time, and three believing that they would be doing their wives a disservice by helping her as much as she would like, as it was better for her to get back to routine as soon as possible.

The most difficult cancer-related problem

Almost half of the husbands stated that their most troubling problem relating to their wives' cancer was fear and uncertainty about the future (Table 11.1). This was also seen by most husbands to be their wives' greatest worry, and in this they were probably correct, as indicated in Study 1 (Table 6.7). Husbands were least worried about problems with children or friends relating to their wives' cancer, and also claimed that this was the case with their wives. And it was, in fact, the case with patients in Study 1. However, some of the other problems selected indicated some significant differences either in the concerns of breast cancer patients and their husbands respectively, or in the different assumptions made by men and women.

Only 5% of husbands claimed that their wives' change in appearance was their greatest concern. This should allay the fears of breast cancer patients that their husbands may not be able to cope with their altered body and may not continue to love them. However, 20% of the husbands believed that change in appearance was their wives' most difficult problem. Yet Study 1 demonstrated that at 1 month post surgery this was the chief worry of only 9% of patients (Table 6.7). Thus it appears that husbands over-estimated the importance of change in appearance to their wives, just as patients over-estimated the effect that this problem may have on their husbands. The difference between the husbands in this study and the patients in Study 1 who listed change in appearance as their most difficult problem was not significant, but there was a significant difference between the husbands' view of this problem and their conception of their wives' view.

Table 11.1 also indicated that husbands were significantly more worried than their wives about the pain, symptoms, or discomfort that their wives suffered as a result of the cancer or its treatment. This table also demonstrated that husbands were aware that their wives were not as concerned about this aspect as they were. The 14% of husbands who believed that this was the main concern of their wives was very close to the 12% of patients who reported this as their main worry in Study 1.

Psychological adjustment

Husbands' ratings of their stress levels were significantly higher than those of patients in Study 1. This was most probably because husbands were asked to rate their stress levels since they knew their wives had cancer, whereas patients in Study 1 had already answered a questionnaire in hospital, and were subsequently asked to rate their stress levels from the time of the last interview. Many patients would have been aware that their level of stress was not as great as it was initially, and so would have adjusted their rating accordingly.

There was no significant difference in anxiety measures between husbands and patients, and husbands' depression levels were significantly lower than those of patients (Table 11.2). These measurements required that subjects indicate the way they feel at the time of answering the questionnaire, and therefore would be a more accurate comparison of the psychological adjustment of patients and husbands respectively than was the stress rating. It is interesting to note in this respect that husbands rated their wives' stress level as being higher than their own. Indications are that this would have been the case, as anxiety levels were similar, whilst depression levels were higher in patients than in husbands.

The similarity in anxiety levels for patients and husands demonstrates extreme stress felt by husbands at the time of their wives' trauma--it is equal to that of the patient herself. This supports Kerson and Kerson (1985) and Rosser (1981), who claimed that a diagnosis of cancer is devastating to all family members. It also indicates the difficulty that some may experience in trying to support another family member whilst themselves feeling an equal amount of anxiety. The significant difference in depression levels between patients and husbands of patients could be an indication of an added dimension of helplessness or hopelessness felt by patients, whilst their husbands may be forced to overlook this aspect in order to fulfil the role of supporter to their wives.

Coping

There were no significant differences found in the three main coping strategy groups when husbands' use was compared with that of patients from Study 1 (Table 11.3). However, when use of individual coping items was compared, some differences emerged (Table 11.4). Husbands kept their feelings to themselves significantly more often than did patients. This again points to their projecting an image of strength and ability to handle things. Patients, on the other hand, talked about their feelings and looked for understanding significantly more often than did husbands. This illustrates the gender differences in support seeking resulting from the differences in traditional role expectations of men and women respectively.

A somewhat surprising finding was that patients, significantly more than husbands, resigned themselves to fate and their "bad luck" and claimed that they went on as if nothing had happened. This is unusual because it probably would have been easier for men to continue as if nothing had happened, as employment would have provided some diversion for most of them. Perhaps this finding related to the feeling of hopelessness felt by patients as they, more than husbands, were relegated to a passive role of "bystander in the medical setting" (Fobair & Mages, 1981, p. 286). Alternatively, it might have been a way of patients "tuning out". Relating this to the findings in Study 1, it appears that patients may have used more of these two denial strategies than did husbands because they were more depressed, or conversely, the greater use of these coping strategies may have caused the higher depression levels in patients. Study 1 demonstrated a significant association between subjects with high depression levels and those using denial/avoidance strategies.

Patients were also significantly more susceptible to self-criticism than were husbands, and this may be understood from two points of view. Some might have blamed themselves for their cancer, thus leading to self-criticism. Alternatively, others might have criticised themselves if they were not able to put their problems behind them and carry out routine household duties.

Another coping strategy which patients used significantly more often than husbands was that of making useful "upward" comparisons to role-models in order to learn more about appropriate responses for handling the situation. This is also evident in patients being more ready to speak with previous breast cancer patients than were husbands.

Coping and adjustment

The results of this study support those of Study 1, in that the greater use of avoidance/denial coping strategies was significantly associated with increased anxiety and depression (Table 11.5). As with patients in Study 1, either the use of avoidance/denial was the best way that those with high anxiety and depression levels could cope with the situation, or on the other hand, low psychological adjustment levels resulted from the use of this group of strategies as measured in this research. However, as pointed out in Chapter 8, it is possible that avoidance/denial was not adequately covered by the coping items used.

Husbands registered the highest anxiety levels when they used avoidance/denial whilst using neither group of active strategies (Table 11.7). Avoiding or denying and, at the same time, not using cognitive strategies, resulted in the highest anxiety levels. This was closely followed by avoiding or denying whilst not using behavioural strategies. Husbands also registered significantly high anxiety levels when they used both of the active strategies together. This perhaps points to the value in being able to balance the use of different strategies, e.g., find moderation between keeping things to themselves and seeking support from others.

Summary

With reference to the five hypotheses stated earlier, this study found the following:

Hypothesis 1. The majority of husbands will desire to take part in the decision-making process of their wives' surgery, but some will be inhibited from taking as full a part as they would wish (Wellisch, Jamison, & Pasnau, 1978).

This hypothesis was supported. The desire of most husbands to take part in the decision-making process was evident by the 87% who either accompanied their wives to the surgeon, discussed the situation at home, or wished that they could have had the opportunity to do so. There were 11% who were inhibited by their wives from taking as full a part as they would have wished, and a further 5% who stated that the surgeon didn't give them any opportunity.

Hypothesis 2. Husbands may not receive all the support they require because many will not feel able to speak to their wives about their concerns for fear of upsetting them. Thus the one person to whom they would normally go for support, i.e. their wives, will not be available to them (Lichtman & Taylor, 1986).

This hypothesis was not supported. Whilst there were a minority who were inhibited from talking more often with their wives, by far the greatest percentage of both empathic and informational support received by husbands was given by wives.

Hypothesis 3. Husbands will require more support from surgeons than they are getting (Battersby et al., 1978). Their need for support from this source will be increased if they are unable to speak with their wives. Also, Study 1 indicated that surgeons were generally too busy to give as much support as patients required, and so it is expected that this will hold at least to the same degree for the husbands of patients.

This hypothesis was not supported. Many husbands were able to talk to surgeons about their cancer-related concerns and also received advice from them on how they could best help their wives. As only two husbands stated that they wished to talk about their concerns more often with the surgeon, it appears that most were satisfied. Also only 14% of the husbands wished to have more advice from surgeons, and this was considerably fewer than the 26% of patients requiring additional advice from this source at 1 month post surgery in Study 1.

Hypothesis 4. The greatest fear of husbands of breast cancer patients will be that the cancer may recur (Lichtman & Taylor, 1986). This will be a more troubling problem for them than the fact of their wives' altered body.

This hypothesis was supported, as 49% stated that fear of the future was their most troubling problem and only 5% were more worried about their wives' change in appearance (Table 11.1). However, 41% were most concerned about the pain and discomfort that their wives were suffering, and this is almost as many as those most worried about the future.

Hypothesis 5. There will be gender-based differences in coping style, which originate from traditional gender-based differences in role expectations. Men traditionally appear strong and able to cope, and consider seeking help as a sign of weakness (Chessler & Barbarin, 1984), whereas women derive satisfaction from discussing problems and feelings (Cohen & Wills, 1985). Therefore husbands will tend to use avoidance/denial coping strategies such as keeping their feelings to themselves (Wellisch, Mosher, & van Scoy, 1978), rather than active--behavioural strategies relating to seeking empathic understanding.

This hypothesis was supported. Significantly more husbands than patients kept their feelings to themselves, whilst patients looked for understanding from others and talked to someone about how they felt significantly more often than did husbands of patients (Table 11.4).

Conclusions

Most husbands were more concerned about possible cancer spread or recurrence than about any other aspect of the illness. This was the same major concern as patients were shown to have in Study 1. Fear and uncertainty about the future is a real problem with cancer, as its course is unpredictable and its treatments, which are often unpleasant, offer no guarantee of success (Molleman et al., 1984). These ambiguities can cause extreme stress, and for husbands this occurs at a time when they are required to be the main source of support for their wives. An additional problem for husbands at this time is often one of how best to help their wives. Most will not have had any previous experience in dealing with a person facing such an extreme crisis. Study 1 indicated that patients require a rather exacting amount of support from their husbands. They do not wish to be over-protected and treated as invalids, incapable of doing anything for themselves, yet they do need to be shown that they are loved and cared for. Husbands under stress are faced with this need.

Attribution theory points out the importance of congruence between the support models of the giver and receiver of support. Sometimes, as shown above, the models of these two parties did not coincide. However, this study indicated that there was congruence between the views of most husbands and wives. The majority of husbands joined with their wives from the beginning, in the fight against cancer. They accompanied them to the surgeon and/or discussed the situation with them, so assisting them in the decision-making process. This would have benefitted the wives as they would have felt supported, and also the husbands as they had some element of control in the situation.

Most husbands received all the empathic, informational, and tangible support they required, and most also felt that they were able to give all of these types of support that their wives required. This supports the indications from Study 1 that most marriages remained secure throughout the cancer experience, and many husband-wife relationships improved. There was very little indication of lack of communication between husbands and wives.

The anxiety of husbands was not significantly different from that of patients at 1 month post surgery. This indicates the extreme stress felt by husbands of breast cancer patients. They were in a similar position to patients themselves in that recurrence was the greatest fear of most, and the anxiety caused by this situation was equal to that of patients. Depression levels, however, were significantly higher for patients than for husbands of patients. This may signify a greater feeling of helplessness or hopelessness in patients, as compared with husbands, who were significantly less inclined to resign themselves to fate or bad luck.

Overall, this study has shown that most husbands are able to muster the help they need in order to support their wives effectively. It appears that surgeons are more willing to discuss the situation with husbands as well as patients than some of the literature indicates. Possibly there have been improvements made in this area as the need for family involvement has been made known. Also, there is very little evidence that husbands are unwilling to discuss their fears with their wives. Most of the evidence in this study points to husbands and wives mutually supporting each other, with the result that marriage relationships are strengthened. This study gives ample reason to applaud the work done by previous research in making needs known, and also the ground work done by professionals who have obviously made some effort to improve communication.

However, in order to avoid complacency, it must be pointed out that there still exists a group of husbands who did not feel the need to discuss any of their cancer-related concerns. This group was not dissatisfied with the support that they received or gave, purely because they did not recognise any need. Table 11.4 showed the significantly greater number of husbands than patients who coped by trying to keep their feelings to themselves, and the significantly fewer number who looked for understanding from someone or talked about how they felt. Thus it appears that many men do have to project the "strong image", which may be an effective coping strategy. Perhaps in the future, research may determine whether helping men to break free of the stereotype and to recognise and come to terms with their needs would result in less psychosocial stress for them and/or enable them to be more supportive to their wives.

This research began with a prospective study of breast cancer patients, and as a result of findings from this initial study it was decided to investigate the needs and responses of husbands, as main supporters of these patients. In order to compare levels of distress etc., at 1 month post surgery with those of patients in Study 1, a decision had to be made as to whether to send questionnaires to husbands of (a) patients in Study 1, who would answer them retrospectively, or (b) recent breast cancer patients. In order to avoid the possible unreliability of event recall after a period of 18 months (Jenkins et al., 1979), it was decided to use husbands of recent breast cancer patients. However, the disadvantage of this choice was that the husbands were not married to the patients with whom they were being compared. A further disadvantage was that when most husbands in Study 3 claimed that they supported their wives as often as necessary, it was not possible to ascertain the patients' view on this. Future research could follow up these suggestions, or perhaps include a group of, say, bereaved husbands for comparison purposes.

SECTION V

SUMMARY AND CONCLUSIONS

CHAPTER 12

Summary and Conclusions

Summary

A study of the literature revealed that breast cancer affects one in eleven women (Holland & Jacobs, 1986), and is the most common malignancy amongst women in the western world. It is not only a physical trauma but also a psychological one, and those affected have to cope with all the uncertainties of a life-threatening illness as well as possible surgical disfiguration. There was little agreement in the literature as to which of these problems was foremost in the minds of breast cancer patients. Some found a preoccupation with physical appearance (Maguire, 1985a), whilst others considered that issues of life and death were more prominent (Sanger & Reznikoff, 1981). Likewise, there was little agreement as to whether there was any significant psychological morbidity following breast cancer treatment. Although many researchers claimed to have found this (Maguire, 1985c; Rosser, 1981), others did not (Silberfarb et al., 1980), whilst still others claimed that any such morbidity was merely a form of normal grief (Holland & Jacobs, 1986). In any case, there was general agreement with the principal that it seemed contradictory to save a life by surgery and, perhaps adjuvant therapies, if the person so treated was to be condemned to a state of reduced self-acceptance together with an overwhelming fear of impending death.

The purpose of this research was therefore to determine how much (if any) psychological morbidity existed amongst breast cancer patients in Adelaide, and to consider ways of alleviating this, such as through social support or through encouraging patients in the use of more productive coping strategies.

Social support, defined as "personal contacts through which the individual maintains his social identity and receives emotional support, material aids and services, information, and new social contacts" (Walker et al., 1977, p. 35), has been shown in the literature to have some protective or buffering effect against illness (Falke & Taylor, 1983). Recent research has attempted to tap into the multidimensionality of the social support construct, but the lack of valid and reliable measures of social support makes it difficult to compare research across studies (Neuling & Winefield, 1988).

Coping, defined as "what one does about a perceived problem in order to bring about relief, reward, quiescence, or equilibrium" (Weisman & Worden, 1976, p. 3), also comprises a multidimensionality, partly because people use a variety of strategies at any one time, and partly because of the changing nature of events. Some strategies are used in order to influence the stressor itself, whilst some are used to regulate the emotions of the person facing the stressor (Lazarus & Folkman, 1984). As coping strategies have their effect, they may need to be replaced. However, research has yet to follow a group for an extended period of time in order to capture the essential multidimensional characteristic of coping.

Study 1

The aim of this study was to determine the physical, social, and psychological adjustment of recent breast cancer patients who had not had any previous life-threatening disease, and to evaluate their coping strategies and the support they (a) received and (b) required. The purpose was to determine the amount of psychosocial morbidity existing amongst breast cancer patients and to consider ways of alleviating this, such as through social support or the use of more productive coping strategies. In order to get accurate assessments, this took the form of a prospective study, where breast cancer patients were interviewed in hospital within a few days of surgery and were then interviewed or sent postal questionnaires at 1, 3, and 6 months post surgery. As there was currently a lack of valid and reliable measures of social support, this study developed one which encompassed the essential multidimensionality of the construct.

This study uncovered a variety of responses to breast cancer, ranging from those who returned to work within a very short time and were keen to put the whole episode behind them, to those with an over-riding fear of recurrence which lasted for the duration of the research. Many expressed an initial sense of unfairness and anger, but with most subjects this soon subsided.

Although anxiety and depression levels were high at the time of surgery, there were very few, if any, continuing psychosocial problems. Therefore the findings of this study supported those of Gottesman and Lewis (1982) and Silberfarb et al. (1980). By 3 months post surgery (a) mean anxiety was similar to that of normal populations and mean depression was approaching this level; (b) 60% claimed to be only slightly, or not at all, stressed by having had cancer; (c) subjects were taking part in significiantly more social activities and had significantly fewer cancer-related physical difficulties than 2 months previously; and (d) 60%-75% had returned to their previous employment. This return to work rate was at least comparable with studies done by Morris et al (1977) and those reported by Dean (1988).

The element of uncertainty in cancer generated considerable stress, as was indicated by the high anxiety levels in those awaiting results. These were similar to the levels of those who had recently been told that their cancer had spread.

Fear of recurrence was by far the most worrying problem, and those most concerned about this problem registered the highest anxiety levels. This supports Peters-Golden (1982) and Worden and Weisman (1977), rather than Polivy (1977), who claimed that the central problem of mastectomy patients was the threat to femininity. A further indication of concern with recurrence was that patients having less extensive surgery registered slightly higher anxiety and depression levels than mastectomees. This supports Fallowfield et al. (1986), who claimed that lumpectomy patients sometimes became concerned that all the cancer had not been removed. However, the first 3 months post surgery saw an increase to 28% in the number of mastectomy patients most worried about body image.

This may indicate a hierarchy of fears, such that as one lessens it makes way for another, initially less pressing, to emerge.

Adjuvant therapy presented no significant adverse psychological effects, although many expressed concern before undergoing treatment, and approximately half of the chemotherapy patients selected pain, symptoms, or discomfort from illness or treatment as their most difficult problem.

Marriage has been claimed to have a stress-reducing effect on mastectomy patients (Smith et al., 1985). However, whilst the present study found no significant effects of marital status on adjustment, cancer appeared to have a uniting effect on most family relationships. Over two-thirds of the married patients confided in their husbands, and over 90% nominated them as the most supportive family member. Many comments also indicated the closer bond between husbands and wives resulting from the cancer experience, including the 42% who claimed that their relationship had shown a marked improvement since they had known they had cancer. This supports the findings reported by Dean, 1988; Lichtman and Taylor, 1986; and Morris et al., 1977.

The Multi-Dimensional Support Scale (Neuling & Winefield, 1988), designed to comprehensively tap the multidimensional nature of social support, proved to be reliable and sensitive. Families, friends, and surgeons all gave significantly less support as time from surgery passed. Results indicated the importance of empathic support, especially from families, and thus supported Wortman (1984). Dunkel-Schetter's (1984) findings were also supported, in that cancer patients did not seek advice or information from non-professional sources.

In fact there was a rather finely tuned balance in support needs from families, in that they were more likely than other sources to be resented for giving too much "support". Most husbands, however, seemed to find a good mixture of helpfulness without creating a dependency, although there was a minority with family communication problems. Patients sometimes felt unable to express themselves for fear of upsetting those close to them.

Surgeons provided significantly less reassurance and empathic support than did family members, and this was reflected in patients' dissatisfaction ratings, thus supporting Dunkel-Schetter (1984) in that patient satisfaction is more related to surgeons' empathy than their skill. Surgeons, however, gave significantly more information than family members, yet there was still considerable dissatisfaction in this respect. There were also indications of patients not asking questions for fear of taking up too much of the surgeon's time, as was noted by Eidinger and Shapira (1984), for fear of the surgeon's reactions, or for fear of the answers.

Psychological adjustment was significantly related to satisfaction with support from (a) family members at the time of surgery and at 3 months post surgery, and (b) surgeons at 1 and 3 months post surgery. This indicates patients' need for continuing support from surgeons, and possibly demonstrates a misfit between patients' and surgeons' understanding of the role of the surgeon.

The use of coping strategies indicated that by 1 month post surgery, subjects were taking more control of the situation, and by 3 months they viewed cancer as something in the past. The results of this study did not support Pearlin and Schooler (1978), who claimed that the greater the scope of coping strategies, the less depressed and anxious the subject will be. In fact, Aldwin and Revenson's (1987) findings more closely resembled the rather paradoxical findings of the present study that the greater use of coping strategies was associated with increased anxiety and depression and a lowering of self esteem. Perhaps either coping or adjustment were inadequately measured, or perhaps subjects attempted a variety of strategies when the ones they had already tried did not reduce their stress. It may have been helpful in this respect to have asked subjects how successful they felt their coping attempts were.

Further research indicated by Study 1

Maguire et al. (1980) found that many patients were unwilling to disclose their need for help. Study 1 supported these findings, and indicated that one of the greatest unmet needs of breast cancer patients was the requirement of empathy and information from the surgeon for at least 3 months after surgery. Therefore Study 2 considered other ways of meeting this need. Patients may be able to relate to a previous patient and so overcome some of their fears of disclosure. If patients realized the "normality" of their feelings and fears they may be more inclined to voice them. Therefore the next study extended the present one by investigating more fully the services of the Breast Cancer Support Service, which partly takes the place of friends or families who may be having trouble coping themselves, and partly takes the role of the professional (Kahn, 1978).

Wortman (1984) stated that the family's reaction can be critical to the cancer patient's adjustment. Study 1 found that many marriages improved markedly during the first 6 months after breast cancer surgery, with most married patients confiding in their husbands when they became worried about cancer related problems, and over 90% nominating them as their most supportive family member. However, cancer affects the whole family, and many husbands may feel unequal to the task of being the main source of support for the sufferer. Further, Study 1 indicated a rather exacting degree of patient support needs from families, in that they were more likely than other sources to be resented for giving too much "support". Patients do not wish to be over-protected, yet they need to know that they are loved and cared for. Therefore Study 3 considered the needs of husbands, as nonprofessional sources of support, to determine how they can be helped to handle this situation.

Study 2

The aim of Study 2 was to determine whether the BCSS volunteer hospital visitors were able to meet the needs of breast cancer patients for empathy and information from professional sources. Study 1 had shown that many patients could not talk to surgeons because they felt intimidated or the surgeons were too busy, and there were also aspects of their illness that they were loathe to reveal to close confidants for fear of worrying them or seeming self-centered. Therefore, as BCSS volunteers had time available and would understand the patient's worries, having been patients themselves, and as they were not emotionally involved in the patient's situation, it was hypothesized that patients would be able to disclose fears or problems to them.

Evaluation questionnaires were posted to patients who had recently been visited by the BCSS. Questionnaires were also sent to providers of this service, in order to determine what they, as previous breast cancer patients, saw as the benefits and drawbacks of the service. The sending of questionnaires to both givers and receivers of the Service assisted in determining the congruity of the views of both parties.

This study indicated that the BCSS benefitted both receiver and provider. Hospital visitors achieved a sense of mastery over their own cancer by supporting others, whilst patients were helped to know what to expect, thus reducing the element of fear. The BCSS volunteer was one of the few people who could validly impart to patients the confidence that they can cope with their illness and continue to live a full life.

This study also indicated that BCSS volunteers were aware of the most troubling problems for breast cancer patients, and were able to give useful advice, both from experience and from their training. The BCSS helped patients to understand the "normality" of their feelings, and many patients were grateful for the temporary breast prosthesis left by their visitor.

However, although the BCSS met some patient needs, they were unable to fill the specific need for support from surgeons. BCSS volunteers are not medically trained, do not have access to patient files, and were not permitted to give medical information. Nor, on the other hand, were they able to give the support required from family members. This supports Lieberman's (1986) view that if support is not forthcoming from the source from which it is required, other sources may not be useful.

Study 3

The aims of Study 3 were to determine how husbands of breast cancer patients felt they could best help their wives, and whether they were prevented from doing this. Study 1 indicated that patients saw their husbands as the most important provider of support, yet research has shown husbands of cancer patients to be under severe stress themselves. Study 3 also sought to determine the main stressors for husbands, how they coped with these, and whether they needed help. Questionnaires were sent to husbands of recent breast cancer patients.

Findings indicated that the major concern for husbands of breast cancer patients was the same as for patients, i.e., fear of recurrence. As only 5% nominated their wives' change in appearance as their greatest concern, this should allay any fears of patients in this respect. However, 20% believed that change in appearance was their wives' most difficult problem, whilst Study 1 demonstrated this to be a much lower number. Results also indicated that husbands were significantly more worried than their wives were about the pain or discomfort suffered by cancer patients.

There was no significant difference in anxiety measures between husbands and patients. This indicated that the stress felt by husbands of breast cancer patients was equal to that felt by the patient herself. It also indicated the difficulty that some may have experienced in trying to support another family member whilst themselves feeling an equal amount of anxiety. Depression levels, however, were significantly higher for patients than for husbands.

The majority of husbands joined with their wives from the beginning, in the fight against cancer, by assisting them in the decision-making process. However, 13% wanted no part in this process, thus indicating that there was a significant minority who communicated very little with their wives. There were also a small group of husbands who did not feel the need to discuss their cancer-related concerns. Significantly more husbands than patients coped by keeping their feelings to themselves, and significantly fewer talked about their feelings. However, most husbands felt that they were able to give their wives the support they required, except in the area of giving advice.

Most husbands reported receiving all the support they required. There was, however, some dissatisfaction with the amount of information given by surgeons. This, together with the finding that almost half of the husbands were unable to help their wives due to lack of information, indicated a need for more access to surgeons. However, considerably fewer husbands complained of this lack than did patients in Study 1. It certainly appeared that more husbands were included in discussions with surgeons than was found by Battersby et al. (1978).

Contrary to the findings of Lichtman and Taylor (1986), there was very little indication of lack of communication between husbands and wives on the topic of cancer. Most of the evidence in this study points to husbands and wives mutually supporting each other, with the result that marriage relationships were strengthened.

Conclusions

Theoretical perspectives

Attribution Theory assumes that causes and intentions are attached to events in order to ascribe meaning to them and to gain control of them. It emphasizes the importance of recipient views on (a) the intentions of the support-giver and (b) oneself as support-receiver, and notes the necessity for congruence between the support models of the giver and receiver if the benefits of support are to be optimised. Evidence of the applicability of this theory was found in Study 1 when patients made attributions about surgeons who gave support which was either in excess of, or less than, that normally considered to be role-prescribed. This was particularly interesting as role-prescribed help generally yields very little information about the character of the support-giver (Fisher et al., 1983). Evidence for the accuracy of attribution theory's claim that for support to be most effective there must be congruence between the support models held by the giver and receiver was also found. There were many instances when too much or too little support was given, resulting in recipient dissatisfaction. This indicated that the support model of the givers was different from that of the receivers. However when these models were congruent, recipient satisfaction resulted and people were drawn closer together. This is illustrated by the 42% of marriages which were strengthened; the reported continuing closeness in marriages which were strong before the cancer experience; and the many who claimed close ties with confidants. Future research could more thoroughly investigate evidence for the applicability of support-model congruence as stated by attribution theory, by asking support givers and receivers to state their support models explicitly and then evaluating support effectiveness.

Coping Theory emphasizes the influence of support on primary and secondary appraisals and reappraisals, and the use of support as "socially mediated coping". Evidence for the applicability of this theory was given when patients used the support available to gain information and advice about their situation. This may have been used to evaluate the potential harmful effects of their illness or treatment (primary appraisal); to evaluate the resources available to deal with their problem (secondary appraisal); or to effect a reappraisal of either of the above. "Socially mediated coping" refers to ways of mitigating a problem by social means, and instances of this were the behavioural strategies of talking to someone to find out more about the situation; asking a relative or friend for advice; looking for understanding; and talking about feelings. Another effective way of getting information is through role-models, and there were many instances of this in the present research. Through being in touch with someone who had been in a similar situation and was well adjusted, the patient was helped to evaluate her own reactions and also to feel more confident that she could overcome her problems.

Equity (Social Exchange) Theory describes social support as an exchange of resources, and emphasizes the notion of reciprocity. Evidence for the applicability of this theory was mainly found in the study of the relationships between husbands and wives (Chapter 11), where each received benefit through mutual support, indicating congruency in support models. More husbands and wives discussed cancer-related concerns with each other than with any other person, and this resulted in relationships being brought closer together through the cancer experience and the emotional support they received from each other. This research was not able to fully explore the implications of equity theory, as the sources of support investigated precluded most cases where inequity, and hence feelings of indebtedness, could occur, i.e., surgeons and the most supportive confidant and family member. The notion of equity does not normally apply to professional sources, and there is not generally a strict account kept of equity between people who are very close. However, there was a clear indication of feelings of indebtedness when 42% of the subjects in Study 1 gave, as their main reason for taking part in the research, that they saw it as a way of showing their appreciation for the care received from their doctors. This demonstrates the use of a third party in reciprocation (Fisher et al., 1983). Patients who had received extra support from their doctors were not able to return this directly, but were able to help others in a similar situation by taking part in research. Future research could develop the notion of equity theory applicability by investigating support from acquaintances--a source not explored in this research. The effects that recipient reactions have on support-givers could also be considered, as little has been done in this field (Hatfield & Sprecher, 1983).

Social Comparison Theory posits that people evaluate themselves through comparison with similar others. This is a common way of dealing with uncertain or ambiguous situations. There were many instances of the applicability of social comparison theory in this research, and they related to the use of previous breast cancer patients as volunteer hospital visitors to current patients. New patients being visited by these volunteers were able to gain insights into their cancer experience and learn from some of the coping strategies used by these visitors. This helped them to re-evaluate some of the potentially disruptive elements resulting from the diagnosis and treatment of cancer, and also allowed them to re-assess the resources available to them and hence their ability to adjust to the situation. "Upward" comparisons were made with the volunteer, who was a role-model of one who had adjusted to the situation. Social comparison theory claims that this would give patients confidence that they also could adjust, and this research contains many affirmations of this. Volunteers gained satisfaction from their work as hospital visitors, with most of them claiming that this satisfaction mainly resulted from doing something positive with their cancer experience and giving to, and being valued by, someone in need. This is evidence for the applicability of the social comparison theory. Volunteers made "downward" comparisons with the patients they visited, as illustrated by their seeing them as someone in need. This led to an increase in the volunteers' self esteem and sense of satisfaction. A comparison which left volunteers feeling less happy with the situation was one that was no doubt made when a fellow volunteer died. This may well have caused her to reappraise the power of the stressor, cancer, and thus shake even the confidence of the role-model.

Of these four theories, the applicability of social comparison has been most fully investigated in this research. A diagnosis of cancer is extremely stressful, not only because of society's view of it as a death sentence, but also because of the uncertainty caused by the ambiguities which plague both the course of the illness itself, and the efficacy of its treatments. This research has shown how social comparison allows for the resolution of some of this uncertainty. It has indicated how upward comparisons result in reappraisals and feelings of being more able to adjust. Through the questionnaires answered by role-models, this research has also provided demonstrations of the effect of social comparison on the support-giver. This has resulted in a clear illustration that the support-giver was also a support-receiver. The role-models gained satisfaction from using their cancer experience to help those in need. This indicates that a downward comparison was being made by the hospital visitor whilst at the same time an upward comparison was being made by the patient.

Implications for health services

As Battersby (1981) stated, "The psychological implications of mastectomy may have been underestimated in the past. It is equally important now not to exaggerate them" (p. 303). This research indicated that although there was initially some considerable psychosocial trauma in breast cancer, both for patients and husbands, this was of short-term duration for the majority. The stress felt by husbands of breast cancer patients, however, was equal to that felt by patients themselves. This indicates the difficulty many of them may have had in being the main providers of support when they, themselves, were in a high state of stress. It also demonstrates that husbands have a need of support which may be equal to, or even greater than that of the patient, as men are often less willing to admit this need.

The main stressor in breast cancer was fear of recurrence, with the accompanying element of uncertainty. However, it was interesting to note that both patients and husbands felt that change in body appearance was a much greater stressor for the other party than it actually was. This is an indication that talking through problems and worries with each other would make such issues clear.

Husbands in general were very supportive, and many marriages were brought closer together by the cancer experience. However, there was a minority who could not communicate with their wives on cancer-related issues although they would like to have done this, and another group who did not feel the need to discuss any such concerns, although their wives may have wanted to. A few patients also were afraid of telling others how they felt, in case they worried or upset those close to them. These patients, along with those who were afraid of appearing self-centered, self-pitying, or complaining, were attempting to protect their relationships. The ultimate fear was that those close to them may withdraw their support. However, by not discussing their problems, patients ensured that the support they required was not forthcoming. Not only that, but confidants are more likely to worry when there is no communication than when the patient tells them how they feel. And so not communicating in order to protect a relationship often has the opposite effect, inhibiting a closeness which could benefit both parties. Sharing confidentiality brings people together, often making both feel useful and accepted, yet so many are afraid to take this step.

This research demonstrated that support from surgeons was required for a much longer time than was given by most. There appeared to be a mismatch between patients' and surgeons' perception of the surgeon's role. It was not sufficient for surgeons to assume that patients with problems will disclose them (Maguire, 1985c), because many patients did not feel able to do this. Some surgeons needed to be more sensitive to the requirements of patients and their husbands, and those who felt they lacked either the time or skill to attend to psychosocial problems, should refer patients who needed help to someone else. This person could be a part of the hospital team, such as a specialist nurse, who has access to patient records and so can give individual information and assistance. The results from Study 2 regarding the helpfulness of the BCSS indicated that this Service did not replace the need to communicate with medical professionals.

There are two sides to the communication problem, however, and some patients need help to be assertive. They need to know that they have a right to ask questions that are troubling them, and that part of the surgeon's job is to reassure them on these points. Some patients prefer not to have a lot of information, because it would worry them, and surgeons respect this preference. Thus surgeons have a problem in knowing how much to tell patients who do not communicate their needs. Patients need to understand that the surgeon will not presume lack of knowledge or willingness to know the facts unless it is made explicit.

Directions for Future Research

This research supported the findings of Maguire et al. (1980) that some patients were unwilling to disclose their need for help. This points to the need for awareness on the part of professionals of the factors inhibiting patients from seeking help. One of the benefits of counselling, found by Maguire et al., was that those who needed help were recognised and referred to the appropriate source. Research may be able to assist in the early recognition of those who may be in danger of psychosocial morbidity at a later stage.

It certainly appears that there should be a multidisciplinary effort towards the treatment and rehabilitation of breast cancer patients (Meyerowitz, 1980). However, although it seems reasonable to assume that counselling will alleviate psychosocial stress where it exists, there is as yet no clear evidence of this (Watson, 1983). Research is therefore required to investigate the types of counselling which are most useful, and the characteristics of patients who will reap most benefit.

It may be easier for people who feel hindered from seeking information from surgeons or confidants to get this information in a peer support group. With a group of similar others, patients realize that their worries are not unique, and so may be less reticent to ask questions. In fact, someone else may ask the very question that the patient was worried about but afraid to ask. Participants also learn coping strategies that have proved effective for others, and so give and receive emotional support, with the result that they feel more in control of their situation. Support groups are also economically attractive, as they make efficient use of staff. However, there has not been any conclusive evidence that interacting with similar others, as distinct from getting information, is beneficial to people facing major stressors (Dunkel-Schetter & Wortman, 1982). Some questions that need to be looked at are the determination of when people are able to face the reality of their cancer sufficiently to take part in such a group, and when social comparison may be distressing. Research is also required to determine what kind of support groups are most helpful for breast cancer patients, as some groups are oriented towards information whilst others are purely empathic. As yet there is little empirical evidence available on these issues (Ray & Baum, 1985).

The greater use of coping strategies in this study was significantly associated with higher anxiety and depression levels. Aldwin and Revenson (1987), who had similar findings, noted the necessity to "identify adaptive coping strategies, delineate their contextual appropriateness, and understand how qualitative factors, such as level of effort and skill in using strategies, may affect the complex relation between coping and mental health" (p. 346). They suggested that this may be a result of an inadequate measurement either of coping strategies or of adjustment. As the present study used well-validated and reliable scales of anxiety and depression, which were relevant, non-psychiatric measures, it would be more profitable to take up Aldwin and Revenson's suggestion by reviewing the problems of coping strategy measurement.

This study illustrated the need to investigate three aspects of the measurement of coping strategies. First is the direction of causality, or whether the most depressed and anxious patients attempted a greater range of coping strategies as a means of relieving their dampened spirits, or whether the depressed and anxious feelings resulted from many unsuccessful coping attempts. It would have been helpful in this respect to have asked subjects how successful they felt their coping attempts were. The second area needing investigation is the possibility of response bias in the Ways of Coping Scale (Lazarus & Folkman, 1985). Socially acceptable items elicited a higher response than those less socially acceptable. The third area is the possibility that subjects may have different criteria regarding their interpretation of the rating scale. As noted previously, it is difficult to quantify how often in the past month one "went on as if nothing were happening".

Results from this research support Fallowfield et al. (1987b) in that patients found taking part in the research to be therapeutic, as it allowed them to express the traumas they were experiencing. At the conclusion of Study 1, 61% of the respondents claimed to have gained something positive for themselves in taking part. This, together with the fact that there was a 98% response rate over the 6 months, should give some reassurance to doctors who may be reluctant to allow psychological studies to be undertaken with their patients in case it upsets them.

APPENDICES

Appendix A: Materials used in the studies

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STUDY 1

STUDY 2

STUDY 3

Appendix B: Tables

Appendix C: Subjects' comments

Appendix D: Publications

Appendix A-1

Study 1: Explanatory Sheet to Prospective Subjects

The purpose of this research is to get a better understanding of the needs of women who have had treatment for breast cancer. A total of three questionnaires will be given -- the others will follow at approx. 1, 3, and 6 months from now.

There are possible benefits to your participation, in that it may cause you to rethink issues of concern to you, and will also add to the understanding of adjustment to breast cancer and thereby benefit other patients.

You may withdraw from this research at any time without affecting your treatment in any way. Your name will not be connected with the questionnaire and all the results will be presented in summary form. Any information that would permit your identification will be regarded as strictly confidential, will be used only for the purposes of the research, and will not be disclosed or released for any other purpose. I stress that doctors and hospital staff will NOT have access to any information that would permit your identification.

Thank you for your help. I hope you find the questions interesting.

I have read the above, and agree to take part

Appendix A-2

Study 1: Questionnaire given in Hospital

Hospital records

Name of patient ____________________________ Age: ______

Address ____

______________________________ Tel: ____________

Religious affiliation
- 0. NONE
- 1. CATHOLIC
- 2. PROTESTANT
- 3. OTHER (specify)

Surgeon __________________________ Date of surgery _____

Type of surgery:
- 1. LESS THAN MASTECTOMY
- 2. MASTECTOMY

Nodes:
- 1. AXILLARY SAMPLING
- 2. AXILLARY CLEARANCE

Adjuvant therapy:
- 0. NONE
- 1. CHEMOTHERAPY
- 2. HORMONAL THERAPY
- 3. RADIOTHERAPY

Type of patient:
- 1. PUBLIC
- 2. PRIVATE

DATE: ______________________________

What is your current marital status?

1 MARRIED/DEFACTO RELATIONSHIP
2 WIDOWED/DIVORCED/SEPARATED
3 NEVER MARRIED

If married, or in a defacto relationship, how long have you been in your current relationship? (Please specify time units, such as months or years) _________

Do you have any children?

1 YES If so, HOW MANY? ____
2 NO
If Yes, HOW MANY ARE LIVING IN THE ADELAIDE AREA? ____

Who besides you lives in your household? (Circle ALL who apply).

1 NO ONE
2 HUSBAND / PARTNER
3 PARENT(S) (how many? _____)
4 CHILDREN (how many? _____)
5 OTHER RELATIVES (how many? _____)
6 NON-RELATIVES (how many? _____)

What is the highest level of education you have completed:

1. PRIMARY SCHOOL OR LESS
2. SECONDARY SCHOOL
3. TRADE SCHOOL
4. COLLEGE OF ADVANCED EDUCATION
5. UNIVERSITY DEGREE OR HIGHER

What is the highest level of education your husband has completed?

1. PRIMARY SCHOOL OR LESS
2. SECONDARY SCHOOL
3. TRADE SCHOOL
4. COLLEGE OF ADVANCED EDUCATION
5. UNIVERSITY DEGREE OR HIGHER

What is your current occupation? ______________________
What is your husband's current occupation? ________________

How important are religious or spiritual beliefs in helping you deal with everyday problems in life?

0. NOT AT ALL IMPORTANT
1. A LITTLE IMPORTANT
2. MODERATELY IMPORTANT
3. VERY IMPORTANT

How long before your operation did you SUSPECT that you may have had cancer? ____

Did you KNOW FOR SURE, before your surgery, that you had cancer?
1. YES
2. NO, NOT FOR SURE

If YES above: How long before your operation did you know for sure that you had cancer? _____

Has anyone else in your immediate family had breast cancer?
1. YES
2. NO

Have you had a breast reconstruction?
1. YES
2. NO

People react in different ways when they know someone has had cancer. Some reactions are helpful, whilst others are not. Please select ONE KEY PERSON from your FAMILY who has helped you to cope in the past month. What is that person's relationship to you? _______________ Now rate how often this person has done each of the following things, and your satisfaction with this frequency.

1. Encouraged you to talk about your (emotional) feelings about your illness

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

2. Encouraged you to talk about your illness experience (physical)

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

3. Listened carefully to what you said, and tried to understand

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

4. Offered advice about how you could help yourself (e.g., diet, nausea control)

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

5. Told you to count your blessings

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

6. Told you not to worry as everything would be all right

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

7. Told jokes and chattered to keep your mind off your illness

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

8. Suggested new ways of looking at your illness

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

9. Offered advice about treatments available

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

10. Told you what to expect

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

11. Told you they loved you, or made you feel loved

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

12. Helped with chores, transoort or childcare

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

13. Took over all your duties and did everything for you

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

Was there any other person IN YOUR FAMILY who gave you support in ways OTHER THAN those given by the named person? If so, please give the relationship of this person to you _________ and explain what kind of help was given.

Please select ONE KEY PERSON from your FRIENDS or CONFIDANTS who has helped you to cope in the past month. What is that person's first name? __________ Now rate how often this person has done each of the following things, and your satisfaction with this frequency.

1. Encouraged you to talk about your (emotional) feelings about your illness

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

2. Encouraged you to talk about your illness experience (physical)

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

3. Listened carefully to you, and tried to understand

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

4. Offered advice about how you could help yourself

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

5. Told you to count your blessings

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

6. Told you not to worry as everything would be all right

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

7. Told jokes and chattered to keep your mind off your illness

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

8. Suggested new ways of looking at your illness

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

9. Offered advice about treatments available

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

10. Told you what to expect

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

11. Told you they loved you, or made you feel loved

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

12. Helped with chores, transport or childcare

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

13. Took over all your duties and did everything for you

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

Was there any other person amongst your FRIENDS who also gave you support in ways OTHER THAN those given by the named person? If so, please give this person's first name ________________ and explain what kind of help was given.

Now please, for the same actions, rate how often your MAIN SURGEON has helped you to cope in each of the following ways, and your satisfaction with this frequency.

1. Encouraged you to talk about your (emotional) feelings about your illness

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

2. Encouraged you to talk about your illness experience (physical)

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

3. Listened carefully to what you said, and tried to understand

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

4. Offered advice about how you could help yourself (e.g., diet, nausea control)

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

5. Told you to count your blessings

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

6. Told you not to worry as everything would be all right

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

7. Told jokes and chattered to keep your mind off your illness

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

8. Suggested new ways of looking at your illness

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

9. Offered advice about treatments available

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

10. Told you what to expect

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

11. Answered all your questions

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

Was there any other PROFESSIONAL HEALTH WORKER who also gave you support in ways OTHER THAN those given by your main surgeon? If so, please give this person's profession ____________________ and explain what kind of help was given.

What was the most helpful thing that was said/done in the last month?

Who said/did this? (relationship: doctor, husband, friend, acquaintance, etc.)

What was the most unhelpful/upsetting thing that was said/done in the last month?

Who said/did this?

The following is a list of clubs and organizations to which people may belong: Parent-teacher groups, church-connected groups, fraternal lodges, neighbourhood or community centres (e.g. YWCA), card clubs, social clubs, civic organizations (e.g. Red Cross), sports teams, and political clubs. In how many such organizations were you active in the past month?

0. NONE OF THEM
1. 1 OR 2 OF THEM
2. 3 OR 4 OF THEM
3. 5 OR 6 OF THEM
4. 7 OR MORE OF THEM

How often IN THE LAST MONTH have you done each of these things?

	NEVER	RARELY	SOMETIMES	OFTEN
1. Telephoned people for a talk	0	1	2	3
2. Written letters	0	1	2	3
3. Played table games with other people (e.g. cards, chess)	0	1	2	3
4. Entertained your relatives or friends at home	0	1	2	3
5. Visited your relatives or friends in their home	0	1	2	3
6. Gone to a restaurant, party or dance with a group of others	0	1	2	3
7. Gone to a meeting at a service club, church, lodge, union or professional organization	0	1	2	3

Cancer is generally a difficult or troubling experience for those who have it. The following are some possible problems associated with cancer. Please indicate which ONE has been THE MOST difficult or troubling for you in the PAST MONTH by circling the appropriate number.

1. Fear and uncertainty about the future due to cancer.
2. Limitations in physical abilities or lifestyle due to cancer.
3. Change in appearance due to cancer.
4. Pain, symptoms, or discomfort from illness or treatment.
5. Problems with family or friends related to cancer.
6. Other (please specify) ____________________

How stressful has this problem been for you?
1. SLIGHTLY STRESSFUL
2. QUITE STRESSFUL
3. EXTREMELY STRESSFUL

Please read each item below and indicate how often you have done this in the past month, in trying to cope with the specific problem circled above.

	NEVER	SOME-TIMES	OFTEN	VERY OFTEN
1. Felt that time would make a difference -- the only thing to do was wait	0	1	2	3
2. Talked to someone to find out more about the situation	0	1	2	3
3. Criticized or lectured yourself	0	1	2	3
4. Went along with fate; sometimes you just have bad luck	0	1	2	3
5. Went on as if nothing were happening	0	1	2	3
6. Tried to keep your feelings to yourself	0	1	2	3
7. Looked for the silver lining, so to speak, tried to look on the bright side of things	0	1	2	3
8. Looked for understanding from someone	0	1	2	3
9. Tried to make yourself feel better by eating, drinking, or smoking	0	1	2	3
10. Avoided being with people in general	0	1	2	3
11. Asked a relative or friend you respect for advice	0	1	2	3
12. Kept others from knowing how bad things were	0	1	2	3
13. Talked to someone about how you felt	0	1	2	3
14. Took it out on other people	0	1	2	3
15. Refused to believe it would happen	0	1	2	3
16. Tried to keep your feelings from interfering with other things too much	0	1	2	3
17. Wished the situation would go away or be over with	0	1	2	3
18. Had fantasies or wishes about how things may turn out	0	1	2	3
19. Prayed	0	1	2	3
20. Prepared yourself for the worst	0	1	2	3
21. Went over in your mind what you would say or do	0	1	2	3
22. Thought of how a person you admire would handle this situation, and used that as a model	0	1	2	3
23. Reminded yourself how much worse things could be	0	1	2	3
24. Tried to find out as much as you could about cancer and your own case	0	1	2	3
25. Treated the illness as a challenge or battle to be won	0	1	2	3

Have you had any change in your routine in the last month, which was caused by factors OTHER THAN having breast cancer? For example:

	YES	NO
1. Have you had health problems (not cancer-related)?	1	2
2. Has a close relative had a SERIOUS illness or injury? .... If YES, what was that person's relationship to you? ______________________________	1	2
3. Has anyone close to you died? .... If YES, what was that person's relationship to you? ______________________________	1	2
4. Have there been increasing serious arguments with your husband/partner?	1	2
5. Have you separated from your husband/partner in the past month?	1	2
6. Has there been a MARKED improvement in the way you and your husband/partner are getting on?	1	2
7. Has there been a serious increase in arguments or problems with someone who lives at home (excluding husband/partner)?	1	2
8. Were there any MAJOR changes in your work situation?	1	2
9. Did you have a MAJOR financial crisis?	1	2
10. Did you have any SERIOUS legal or police problems?	1	2
11. Any other MAJOR changes not mentioned above? .... If YES, please state what they were	1	2

A number of statements which people have used to describe themselves are given below. Please read each statement and then indicate how you feel NOW.

	NOT AT ALL	SOME-WHAT	MODERATELY SO	VERY MUCH SO
1. I feel calm	0	1	2	3
2. I feel secure	0	1	2	3
3. I am tense	0	1	2	3
4. I am regretful	0	1	2	3
5. I feel at ease	0	1	2	3
6. I feel upset	0	1	2	3
7. I am presently worrying over possible misfortunes	0	1	2	3

	NOT AT ALL	SOME-WHAT	MODERATELY SO	VERY MUCH SO
8. I feel rested	0	1	2	3
9. I feel anxious	0	1	2	3
10. I feel comfortable	0	1	2	3
11. I feel self-confident	0	1	2	3
12. I feel nervous	0	1	2	3
13. I am jittery	0	1	2	3
14. I feel "high strung"	0	1	2	3
15. I am relaxed	0	1	2	3
16. I feel content	0	1	2	3
17. I am worried	0	1	2	3
18. I feel over-excited and "rattled"	0	1	2	3
19. I feel joyful	0	1	2	3
20. I feel pleasant	0	1	2	3

	NO, NOT AT ALL	NO, NOT MUCH	YES, SOMETIMES	YES DEFINITELY
21. I feel miserable and sad	0	1	2	3
22. I find it easy to do the things I used to before my operation	0	1	2	3
23. I get very frightened feelings for apparently no reason	0	1	2	3
24. I have weeping spells, or feel like it	0	1	2	3
25. I still enjoy the things I used to	0	1	2	3
26. I am restless and can't keep still	0	1	2	3
27. I get off to sleep easily, without sleeping tablets	0	1	2	3
28. I feel anxious when I go out of the house on my own at daytime	0	1	2	3
29. I have lost interest in things	0	1	2	3
30. I get tired for no reason	0	1	2	3

	NO, NOT AT ALL	NO, NOT MUCH	YES, SOMETIMES	YES DEFINITELY
31. I am more irritable than usual .	0	1	2	3
32. I wake early and then sleep badly for the rest of the night ...	0	1	2	3

	STRONGLY DISAGREE	DISAGREE	YES, AGREE	STRONGLY AGREE
33. On the whole I am satisfied with myself	0	1	2	3
34. At times I think I am no good at all	0	1	2	3
35. I feel that I have a number of good qualities	0	1	2	3
36. I am able to do things as well as most other people	0	1	2	3
37. I feel I do not have much to be proud of	0	1	2	3
38. I certainly feel useless at times	0	1	2	3
39. I feel that I am a person of worth, at least on an equal plane with others	0	1	2	3
40. I wish I could have more respect for myself	0	1	2	3
41. All in all, I am inclined to feel that I am a failure	0	1	2	3
42. I take a positive attitude toward myself	0	1	2	3

This is the end of the questionnaire. Thank you very much for your help.

Appendix A-3

Study 1: Questionnaire given at 1 Month Post Surgery

Thank you for your help, once again. Before you begin, I would like to remind you that your name will not be connected with the questionnaire, and all the results will be presented in summary form. Any information that would permit your identification will be regarded as strictly confidential, will be used only for the purposes of the research, and will not be disclosed or released for any other purpose. I, once again, stress that doctors and hospital staff will NOT have access to any information that would permit your identification. Please answer all questions if you can, but if you feel uncomfortable about certain questions, feel free to omit them.

DATE ____________________

The first set of questions concerns any problems or changes in your routine that you may have had in the past month, and which were caused by factors OTHER THAN having breast cancer?

	YES	NO
1. Have you had health problems other than those related to cancer?	1	2
2. Has a close relative had a SERIOUS illness or injury?	1	2
If YES, what was that person's relationship to you? ____________________		
3. Has anyone close to you died?	1	2
If YES, what was that person's relationship to you? ____________________		
4. Have there been increasing serious arguments with your husband/partner?	1	2
5. Have you separated from your husband/partner in the past month?	1	2
6. Has there been a MARKED improvement in the way you and your husband/partner are getting on?	1	2
7. Has there been a serious increase in arguments or problems with someone who lives at home (excluding husband/partner)?	1	2
8. Were there any MAJOR changes in your work situation?	1	2
9. Did you have a MAJOR financial crisis?	1	2
10. Did you have any SERIOUS legal or police problems?	1	2
11. Any other MAJOR changes not mentioned above?	1	2

If YES, please state what they were

The next set of questions concerns your cancer and its treatment.

What other treatment are you having at present, in relation to your cancer?

0. NO OTHER TREATMENT
1. CHEMOTHERAPY
2. HORMONE TABLETS
3. RADIOTHERAPY

Have you had a breast reconstruction?	1. YES 2. NO

Do you suffer from any of the following?

	NOT AT ALL	A LITTLE	SOMEWHAT	YES A LOT
Swelling in arm (or wound)	0	1	2	3
Weakness (or stiffness) in arm	0	1	2	3
Problems of wound healing	0	1	2	3
Rate the extent to which the mobility of your arm has been affected	0	1	2	3

Indicate your degree of discomfort or difficulty (if any) in performing the following: (Please cross a line through any of the items below that you never do, even when in good health).

	NO DISCOMFORT	A LITTLE DISCOMFORT	QUITE A BIT	SEVERE DISCOMFORT
1. dressing	0	1	2	3
2. showering/bathing	0	1	2	3
3. light housework (dishes/dusting)	0	1	2	3
4. preparing meals	0	1	2	3
5. laundering (washing/pegging on line/ironing)	0	1	2	3
6. grocery shopping	0	1	2	3
7. other shopping	0	1	2	3
8. washing hair	0	1	2	3
9. driving car	0	1	2	3
10. heavy cleaning (floors/windows)	0	1	2	3
11. entertaining	0	1	2	3
12. going out	0	1	2	3

Appendix A-3 (cont.)

To what extent do you feel you have returned to your previous normal level of activity?

0. NOT AT ALL
1. NOT MUCH
2. ALMOST COMPLETELY
3. COMPLETELY

In the last questionnaire, you selected ________________ as being the most supportive family member to you. Is that person still the most supportive? YES/NO. If NO, who is now? ______________. Would you please rate how often this family member has done each of the following things in the past month, and your satisfaction with this frequency, by circling the appropriate numbers.

1. Encouraged you to talk about your (emotional) feelings about your illness

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

2. Encouraged you to talk about your illness experience (physical)

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

3. Listened carefully to what you said, and tried to understand

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

4. Offered advice about how you could help yourself (eg diet, exercise, nausea control)

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

5. Told you to count your blessings

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

6. Told you not to worry as everything would be all right

Frequency:
0. NEVER
1. SOMETIMES
2. OFTEN
3. VERY OFTEN

Would you have liked this behaviour:
1. MORE OFTEN
2. LESS OFTEN
or was it
3. JUST RIGHT

7. Told jokes and chattered to keep your mind off your illness

Frequency:
0. NEVER
1. SOMETIMES
2. OFTEN
3. VERY OFTEN

Would you have liked this behaviour:
1. MORE OFTEN
2. LESS OFTEN
or was it
3. JUST RIGHT

8. Suggested new ways of looking at your illness

Frequency:
0. NEVER
1. SOMETIMES
2. OFTEN
3. VERY OFTEN

Would you have liked this behaviour:
1. MORE OFTEN
2. LESS OFTEN
or was it
3. JUST RIGHT

9. Offered advice about treatments available

Frequency:
0. NEVER
1. SOMETIMES
2. OFTEN
3. VERY OFTEN

Would you have liked this behaviour:
1. MORE OFTEN
2. LESS OFTEN
or was it
3. JUST RIGHT

10. Told you what to expect

Frequency:
0. NEVER
1. SOMETIMES
2. OFTEN
3. VERY OFTEN

Would you have liked this behaviour:
1. MORE OFTEN
2. LESS OFTEN
or was it
3. JUST RIGHT

11. Told you they loved you, or made you feel loved

Frequency:
0. NEVER
1. SOMETIMES
2. OFTEN
3. VERY OFTEN

Would you have liked this behaviour:
1. MORE OFTEN
2. LESS OFTEN
or was it
3. JUST RIGHT

12. Helped with chores, transport or childcare

Frequency:
0. NEVER
1. SOMETIMES
2. OFTEN
3. VERY OFTEN

Would you have liked this behaviour:
1. MORE OFTEN
2. LESS OFTEN
or was it
3. JUST RIGHT

13. Took over all your duties and did everything for you

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

Which of the above behaviours was THE MOST HELPFUL from this person?

In the last questionnaire, you selected ________________ as being the most supportive friend to you. Is that person still the most supportive? YES/NO.

If NO, who is now? _______________.

Would you please rate how often this friend has done each of the following things in the past month, and your satisfaction with this frequency, by circling the appropriate numbers.

1. Encouraged you to talk about your (emotional) feelings about your illness

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

2. Encouraged you to talk about your illness experience (physical)

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

3. Listened carefully to what you said, and tried to understand

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

4. Offered advice about how you could help yourself (eg diet, etc.)

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

5. Told you to count your blessings

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

6. Told you not to worry as everything would be all right

Frequency:
0. NEVER
1. SOMETIMES
2. OFTEN
3. VERY OFTEN

Would you have liked this behaviour:
1. MORE OFTEN
2. LESS OFTEN
or was it
3. JUST RIGHT

7. Told jokes and chattered to keep your mind off your illness

Frequency:
0. NEVER
1. SOMETIMES
2. OFTEN
3. VERY OFTEN

Would you have liked this behaviour:
1. MORE OFTEN
2. LESS OFTEN
or was it
3. JUST RIGHT

8. Suggested new ways of looking at your illness

Frequency:
0. NEVER
1. SOMETIMES
2. OFTEN
3. VERY OFTEN

Would you have liked this behaviour:
1. MORE OFTEN
2. LESS OFTEN
or was it
3. JUST RIGHT

9. Offered advice about treatments available

Frequency:
0. NEVER
1. SOMETIMES
2. OFTEN
3. VERY OFTEN

Would you have liked this behaviour:
1. MORE OFTEN
2. LESS OFTEN
or was it
3. JUST RIGHT

10. Told you what to expect

Frequency:
0. NEVER
1. SOMETIMES
2. OFTEN
3. VERY OFTEN

Would you have liked this behaviour:
1. MORE OFTEN
2. LESS OFTEN
or was it
3. JUST RIGHT

11. Told you they loved you, or made you feel loved

Frequency:
0. NEVER
1. SOMETIMES
2. OFTEN
3. VERY OFTEN

Would you have liked this behaviour:
1. MORE OFTEN
2. LESS OFTEN
or was it
3. JUST RIGHT

12. Helped with chores, transport or childcare

Frequency:
0. NEVER
1. SOMETIMES
2. OFTEN
3. VERY OFTEN

Would you have liked this behaviour:
1. MORE OFTEN
2. LESS OFTEN
or was it
3. JUST RIGHT

13. Took over all your duties and did everything for you

Frequency:
0. NEVER
1. SOMETIMES
2. OFTEN
3. VERY OFTEN

Would you have liked this behaviour:
1. MORE OFTEN
2. LESS OFTEN
or was it
3. JUST RIGHT

Which of the above behaviours was THE MOST HELPFUL from this person?

Now for the same actions, rate how often your MAIN SURGEON has helped you to cope in each of the following ways, and your satisfaction with this frequency.

1. Encouraged you to talk about your (emotional) feelings about your illness

Frequency:
0. NEVER
1. SOMETIMES
2. OFTEN
3. VERY OFTEN

Would you have liked this behaviour:
1. MORE OFTEN
2. LESS OFTEN
or was it
3. JUST RIGHT

2. Encouraged you to talk about your illness experience (physical)

Frequency:
0. NEVER
1. SOMETIMES
2. OFTEN
3. VERY OFTEN

Would you have liked this behaviour:
1. MORE OFTEN
2. LESS OFTEN
or was it
3. JUST RIGHT

3. Listened carefully to what you said, and tried to understand

Frequency:
0. NEVER
1. SOMETIMES
2. OFTEN
3. VERY OFTEN

Would you have liked this behaviour:
1. MORE OFTEN
2. LESS OFTEN
or was it
3. JUST RIGHT

4. Offered advice about how you could help yourself (eg diet, exercise, nausea control)

Frequency:
0. NEVER
1. SOMETIMES
2. OFTEN
3. VERY OFTEN

Would you have liked this behaviour:
1. MORE OFTEN
2. LESS OFTEN
or was it
3. JUST RIGHT

5. Told you to count your blessings

Frequency:
0. NEVER
1. SOMETIMES
2. OFTEN
3. VERY OFTEN

Would you have liked this behaviour:
1. MORE OFTEN
2. LESS OFTEN
or was it
3. JUST RIGHT

Appendix A-3 (cont.)

6. Told you not to worry as everything would be all right

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

7. Told jokes and chattered to keep your mind off your illness

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

8. Suggested new ways of looking at your illness

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

9. Offered advice about treatments available

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

10. Told you what to expect

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

11. Answered all your questions

Frequency:	Would you have liked this behaviour:
0. NEVER	1. MORE OFTEN
1. SOMETIMES	2. LESS OFTEN
2. OFTEN	or was it
3. VERY OFTEN	3. JUST RIGHT

Which of the above was THE MOST HELPFUL from your surgeon?

The following is a list of clubs and organizations to which people may belong: Parent-teacher groups, church-connected groups, fraternal lodges, neighbourhood or community centres (e.g. YWCA), card clubs, social clubs, civic organizations (e.g. Red Cross), sports teams, and political clubs.
In how many such organizations were you active in the past month?

0. NONE OF THEM
1. 1 OR 2 OF THEM
2. 3 OR 4 OF THEM
3. 5 OR 6 OF THEM
4. 7 OR MORE OF THEM

How often IN THE LAST MONTH have you done each of these things?

	NEVER	RARELY	SOMETIMES	OFTEN
1. Telephoned people for a talk	0	1	2	3
2. Written letters	0	1	2	3
3. Played table games with other people (e.g. cards, chess)	0	1	2	3
4. Entertained your relatives or friends at home	0	1	2	3
5. Visited your relatives or friends in their home	0	1	2	3
6. Gone to a restaurant, party or dance with a group of others	0	1	2	3
7. Gone to a meeting at a service club, church, lodge, union or professional organization	0	1	2	3

Cancer is generally a difficult or troubling experience for those who have it. The following are some possible problems associated with cancer. Please indicate which ONE has been THE MOST difficult or troubling for you in the PAST MONTH by circling the appropriate number.

1. FEAR AND UNCERTAINTY ABOUT THE FUTURE DUE TO CANCER.
2. LIMITATIONS IN PHYSICAL ABILITIES OR LIFESTYLE DUE TO CANCER.
3. CHANGE IN APPEARANCE DUE TO CANCER.
4. PAIN, SYMPTOMS, OR DISCOMFORT FROM ILLNESS OR TREATMENT.
5. PROBLEMS WITH FAMILY OR FRIENDS RELATED TO CANCER.

How stressful has this problem been for you?

1. SLIGHTLY STRESSFUL
2. QUITE STRESSFUL
3. EXTREMELY STRESSFUL

Appendix A-3 (cont.)

Please read each item below and indicate how often you have done this in the past month, in trying to cope with the specific problem circled above.

	NEVER	SOMETIMES	OFTEN	VERY OFTEN
1. Felt that time would make a difference -- the only thing to do was wait	0	1	2	3
2. Talked to someone to find out more about the situation	0	1	2	3
3. Criticized or lectured yourself	0	1	2	3
4. Went along with fate; sometimes you just have bad luck	0	1	2	3
5. Went on as if nothing were happening	0	1	2	3
6. Tried to keep your feelings to yourself	0	1	2	3
7. Looked for the silver lining, so to speak, tried to look on the bright side of things	0	1	2	3
8. Looked for understanding from someone	0	1	2	3
9. Tried to make yourself feel better by eating, drinking, or smoking	0	1	2	3
10. Avoided being with people in general	0	1	2	3
11. Asked a relative or friend you respect for advice	0	1	2	3
12. Kept others from knowing how bad things were	0	1	2	3
13. Talked to someone about how you felt	0	1	2	3
14. Took it out on other people	0	1	2	3
15. Refused to believe it would happen	0	1	2	3
16. Tried to keep your feelings from interfering with other things too much	0	1	2	3
17. Wished the situation would go away or be over with	0	1	2	3
18. Had fantasies or wishes about how things may turn out	0	1	2	3
19. Prayed	0	1	2	3
20. Prepared yourself for the worst	0	1	2	3
21. Went over in your mind what you would say or do	0	1	2	3
22. Thought of how a person you admire would handle this situation, and used that as a model	0	1	2	3
23. Reminded yourself how much worse things could be	0	1	2	3
24. Tried to find out as much as you could about cancer and your own case .	0	1	2	3
25. Treated the illness as a challenge or battle to be won	0	1	2	3

A number of statements which people have used to describe themselves are given below. Please read each statement and then indicate how you feel NOW.

	NOT AT ALL	SOME-WHAT	MODERATELY SO	VERY MUCH SO
1. I feel calm	0	1	2	3
2. I feel secure	0	1	2	3
3. I am tense	0	1	2	3
4. I am regretful	0	1	2	3
5. I feel at ease	0	1	2	3
6. I feel upset	0	1	2	3
7. I am presently worrying over possible misfortunes	0	1	2	3
8. I feel rested	0	1	2	3
9. I feel anxious	0	1	2	3
10. I feel comfortable	0	1	2	3
11. I feel self-confident	0	1	2	3
12. I feel nervous	0	1	2	3
13. I am jittery	0	1	2	3
14. I feel "high strung"	0	1	2	3
15. I am relaxed	0	1	2	3
16. I feel content	0	1	2	3
17. I am worried	0	1	2	3
18. I feel over-excited and "rattled".......	0	1	2	3
19. I feel joyful	0	1	2	3
20. I feel pleasant	0	1	2	3

	NO, NOT AT ALL	NO, NOT MUCH	YES, SOMETIMES	YES DEFINITELY
21. I feel miserable and sad	0	1	2	3
22. I find it easy to do the things I used to before my operation	0	1	2	3
23. I get very frightened feelings for apparently no reason	0	1	2	3

	NO, NOT AT ALL	NO, NOT MUCH	YES, SOMETIMES	YES DEFINITELY
24. I have weeping spells, or feel like it .	0	1	2	3
25. I still enjoy the things I used to	0	1	2	3
26. I am restless and can't keep still	0	1	2	3
27. I get off to sleep easily, without sleeping tablets	0	1	2	3
28. I feel anxious when I go out of the house on my own at daytime	0	1	2	3
29. I have lost interest in things	0	1	2	3
30. I get tired for no reason	0	1	2	3
31. I am more irritable than usual	0	1	2	3
32. I wake early and then sleep badly for the rest of the night	0	1	2	3

	STRONGLY DISAGREE	DISAGREE	YES, AGREE	STRONGLY AGREE
33. On the whole I am satisfied with myself.	0	1	2	3
34. At times I think I am no good at all ...	0	1	2	3
35. I feel that I have a number of good qualities	0	1	2	3
36. I am able to do things as well as most other people	0	1	2	3
37. I feel I do not have much to be proud of	0	1	2	3
38. I certainly feel useless at times	0	1	2	3
39. I feel that I am a person of worth, at least on an equal plane with others	0	1	2	3
40. I wish I could have more respect for myself	0	1	2	3
41. All in all, I am inclined to feel that I am a failure	0	1	2	3
42. I take a positive attitude toward myself	0	1	2	3

Have you had any opportunity to speak with someone who has had an operation similar to yours?

1. YES
2. NO

If NO, do you wish you had this opportunity? 1. YES 2. NO

If you did NOT speak with someone who had an operation similar to yours, this is the end of the questionnaire for you. Thank you very much for your help.

If you DID speak with someone who had a similar operation to yours, how did this come about?

1. SHE WAS A FRIEND/RELATIVE OF MINE
2. A FRIEND INTRODUCED US
3. THE SURGEON/HOSPITAL STAFF ARRANGED IT
4. OTHER (please explain)

Did you see this person BEFORE your operation? 1. YES 2. NO

How long AFTER your operation did you see her? ______________ days.

Was the timing of this visit

1. TOO EARLY
2. TOO LATE
3. JUST RIGHT

Was this lady helpful in any of the following areas?

	NOT APPLICABLE	NOT VERY HELPFUL	QUITE HELPFUL	VERY HELPFUL
Information about:				
how to communicate with				
doctor	0	1	2	3
husband	0	1	2	3
children	0	1	2	3
Advice about:				
what treatment you should have .	0	1	2	3
side effects of treatments	0	1	2	3
exercising of arm	0	1	2	3
prostheses	0	1	2	3
financial matters	0	1	2	3
resuming work	0	1	2	3
playing sport	0	1	2	3
resuming social life............	0	1	2	3

Would you recommend that other patients see such a lady? YES/NO

Did this lady provide any kind of help that was not available to you from other sources? (If YES, please explain what this was).

Appendix A-4

Study 1: Questionnaire given at 3 Months Post Surgery

This questionnaire was the same at that given at 1 month post surgery, with the exception that the last page (on volunteer hospital visitors) was omitted and the following Intolerance of Ambiguity Scale was included.

Please do not spend too much time on the following items. There are no right or wrong answers and therefore your first response is important.

	TRUE	FALSE
1. A problem has little attraction for me if I don't think it has a solution .	1	2
2. I am just a little uncomfortable with people unless I feel that I can understand their behaviour	1	2
3. There's a right way and a wrong way to do almost everything	1	2
4. I would rather bet 1 to 6 on a long shot than 3 to 1 on a probable winner .	1	2
5. The way to understand complex problems is to be concerned with their larger aspects instead of breaking them into smaller pieces	1	2
6. I get pretty anxious when I'm in a social situation over which I have no control	1	2
7. Practically every problem has a solution	1	2
8. It doesn't bother me when I cannot follow another person's train of thought	1	2
9. I have always felt that there is a clear difference between right and wrong	1	2
10. It doesn't bother me when I cannot tell how others react to me	1	2
11. If I were a doctor, I would prefer the uncertainties of a psychiatrist to the clear and definite work of someone like a surgeon or X-ray specialist .	1	2
12. Vague and impressionistic pictures have some appeal for me	1	2
13. If I were a scientist it wouldn't bother me that my work would never be completed (because science will always make new discoveries)	1	2
14. Before an examination, I feel much less anxious if I know how many questions there will be	1	2
15. The best part of working a jigsaw puzzle is putting in that last piece	1	2
16. I don't mind working on a problem where there is no possibility of coming out with a clear-cut and unambiguous answer	1	2
17. I like to fool around with new ideas, even if they turn out later to be a total waste of time	1	2
18. Perfect balance is the essence of all good composition	1	2

Appendix A-5

Study 1: Questionnaire given at 6 Months Post Surgery

Thank you for your help, once again. Before you begin, I would like to remind you that your name will not be connected with the questionnaire, and all the results will be presented in summary form. Any information that would permit your identification will be regarded as strictly confidential, will be used only for the purposes of the research, and will not be disclosed or released for any other purpose. I, once again, stress that doctors and hospital staff will NOT have access to any information that would permit your identification. Please answer all questions if you can, but if you feel uncomfortable about certain questions, feel free to omit them.

DATE ____________________

The first set of questions concerns any problems or changes in your routine that you may have had in the past month, and which were caused by factors OTHER THAN having breast cancer?

	YES	NO
1. Have you had health problems other than those related to cancer?	1	2
2. Has a close relative had a SERIOUS illness or injury?	1	2
If YES, what was that person's relationship to you? ____________________________________		
3. Has anyone close to you died?	1	2
If YES, what was that person's relationship to you? ____________________________________		
4. Have there been increasing serious arguments with your husband/partner?	1	2
5. Have you separated from your husband/partner in the past month?	1	2
6. Has there been a MARKED improvement in the way you and your husband/partner are getting on?	1	2
7. Has there been a serious increase in arguments or problems with someone who lives at home (excluding husband/partner)?	1	2
8. Were there any MAJOR changes in your work situation?	1	2
9. Did you have a MAJOR financial crisis?	1	2
10. Did you have any SERIOUS legal or police problems?	1	2
11. Any other MAJOR changes not mentioned above?	1	2
If YES, please state what they were		

The next set of questions concerns your cancer and its treatment.

What other treatment are you having at present, in relation to your cancer?

0. NO OTHER TREATMENT
1. CHEMOTHERAPY
2. HORMONE TABLETS
3. RADIOTHERAPY

To what extent do you feel you have returned to your previous normal level of activity?

0. NOT AT ALL
1. NOT MUCH
2. ALMOST COMPLETELY
3. COMPLETELY

Were you employed before your operation? YES / NO

If YES, have you returned to work?

1. YES - Please state the date you returned ______________
2. NO

The following is a list of clubs and organizations to which people may belong: Parent-teacher groups, church-connected groups, fraternal lodges, neighbourhood or community centres (e.g. YWCA), card clubs, social clubs, civic organizations (e.g. Red Cross), sports teams, and political clubs. In how many such organizations were you active in the past month?

0. NONE OF THEM
1. 1 OR 2 OF THEM
2. 3 OR 4 OF THEM
3. 5 OR 6 OF THEM
4. 7 OR MORE OF THEM

How often IN THE LAST MONTH have you done each of these things?

	NEVER	RARELY	SOMETIMES	OFTEN
1. Telephoned people for a talk	0	1	2	3
2. Written letters	0	1	2	3
3. Played table games with other people (e.g. cards, chess)	0	1	2	3
4. Entertained your relatives or friends at home	0	1	2	3
5. Visited your relatives or friends in their home	0	1	2	3
6. Gone to a restaurant, party or dance with a group of others	0	1	2	3
7. Gone to a meeting at a service club, church, lodge, union or professional organization	0	1	2	3

A number of statements which people have used to describe themselves are given below. Please read each statement and then indicate how you feel NOW.

	NOT AT ALL	SOME-WHAT	MODERATELY SO	VERY MUCH SO
1. I feel calm	0	1	2	3
2. I feel secure	0	1	2	3
3. I am tense	0	1	2	3
4. I am regretful	0	1	2	3
5. I feel at ease	0	1	2	3
6. I feel upset	0	1	2	3
7. I am presently worrying over possible misfortunes	0	1	2	3
8. I feel rested	0	1	2	3
9. I feel anxious	0	1	2	3
10. I feel comfortable	0	1	2	3
11. I feel self-confident	0	1	2	3
12. I feel nervous	0	1	2	3
13. I am jittery	0	1	2	3
14. I feel "high strung"	0	1	2	3
15. I am relaxed	0	1	2	3
16. I feel content	0	1	2	3
17. I am worried	0	1	2	3
18. I feel over-excited and "rattled"	0	1	2	3
19. I feel joyful	0	1	2	3
20. I feel pleasant	0	1	2	3

	NO, NOT AT ALL	NO, NOT MUCH	YES, SOMETIMES	YES DEFINITELY
21. I feel miserable and sad	0	1	2	3
22. I find it easy to do the things I used to before my operation ..	0	1	2	3
23. I get very frightened feelings for apparently no reason	0	1	2	3

	NO, NOT AT ALL	NO, NOT MUCH	YES, SOMETIMES	YES DEFINITELY
24. I have weeping spells, or feel like it	0	1	2	3
25. I still enjoy things I used to	0	1	2	3
26. I am restless, can't keep still.	0	1	2	3
27. I get off to sleep easily, without sleeping tablets	0	1	2	3
28. I feel anxious when I go out of the house on my own at daytime	0	1	2	3
29. I have lost interest in things	0	1	2	3
30. I get tired for no reason	0	1	2	3
31. I am more irritable than usual	0	1	2	3
32. I wake early and then sleep badly for the rest of the night	0	1	2	3

	STRONGLY DISAGREE	DISAGREE	YES, AGREE	STRONGLY AGREE
33. On the whole I am satisfied with myself	0	1	2	3
34. At times I think I am no good at all	0	1	2	3
35. I feel that I have a number of good qualities	0	1	2	3
36. I am able to do things as well as most other people	0	1	2	3
37. I feel I do not have much to be proud of	0	1	2	3
38. I certainly feel useless at times	0	1	2	3
39. I feel that I am a person of worth, at least equal to others.	0	1	2	3
40. I wish I could have more respect for myself	0	1	2	3
41. All in all, I am inclined to feel that I am a failure	0	1	2	3
42. I take a positive attitude toward myself	0	1	2	3

Many people with cancer worry about the illness at least some of the time after being diagnosed. Even if the cancer has been successfully treated, it is common to be concerned once in a while. For example, one's concerns might have to do with the consequences of the illness and its treatment, or maybe with what the future holds in store.

How stressful have these concerns been for you IN THE PAST MONTH?

1. SLIGHTLY STRESSFUL
2. QUITE STRESSFUL
3. EXTREMELY STRESSFUL

How often have you shared your concerns or worries IN THE PAST SIX MONTHS with:

	I HAVE NO SUCH RELATIONSHIP	NEVER	RARELY	SOMETIMES	OFTEN
1. Your husband/defacto	0	0	1	2	3
2. Any close friend	0	0	1	2	3
3. Either parent	0	0	1	2	3
4. Any brother or sister	0	0	1	2	3
5. Any of your children	0	0	1	2	3

If you RARELY or NEVER share your concerns about cancer, what are your reasons? (Please circle only the most important reason).

1. I'M A PRIVATE PERSON AND DON'T WANT OTHERS TO KNOW.

2. I DON'T WANT TO WORRY OR UPSET ANYONE.

3. I DON'T REALLY NEED TO TALK ABOUT MY WORRIES OR CONCERNS.

4. I DON'T WANT TO UPSET MYSELF BY THINKING ABOUT MY WORRIES.

5. I DON'T WANT TO SEEM LIKE SOMEONE WHO IS SELF-CENTRED, SELF-PITYING, OR COMPLAINING.

6. OTHER REASONS (please specify) ______________________
____

7. NONE OF THE ABOVE APPLIES BECAUSE I DO TALK FAIRLY OFTEN ABOUT CANCER WITH OTHERS.

Would you prefer:

1. TALKING TO ONE PATIENT WITH A SIMILAR DIAGNOSIS AND TREATMENT TO YOURSELF
2. MEETING WITH A GROUP OF BREAST CANCER PATIENTS
3. NEITHER

CANCER SUPPORT GROUPS

We are interested in what kinds of group experience (if any) might be useful in dealing with cancer.

In an ideal cancer support group, how much time do you consider should be devoted to each of the following:

	NONE	A LITTLE AMOUNT OF OF TIME	A MODERATE AMOUNT OF OF TIME	A LOT OF TIME
1. Providing medical information......	0	1	2	3
2. Offering information on alternative treatment or therapies (eg diets)..	0	1	2	3
3. Providing an opportunity for sharing feelings and emotions	0	1	2	3
4. Providing an opportunity to solve specific cancer-related problems ..	0	1	2	3
5. Being a source of companionship ...	0	1	2	3
6. Talking with others in a similar situation	0	1	2	3
7. Offering specific skills such as how to deal with pain or nausea ...	0	1	2	3
8. Providing information about coping.	0	1	2	3
9. Helping those who need it to deal with cancer-related crises	0	1	2	3
10. Being a place to give and receive love	0	1	2	3
11. Being a place away from the harshness of the health care system	0	1	2	3
12. Learning how others are solving similar problems	0	1	2	3
13. Offering advice	0	1	2	3
14. Offering reassurance (hope)	0	1	2	3

Have you ever attended a cancer support group?
1. YES
2. NO

If NO, please turn to the last page of the questionnaire.

Appendix A-5 (cont.)

If you HAVE attended a cancer support group, what group did you attend?

Name ______________________________

Run by ____________________________

On what date (approx.) did you first attend? _________________

Does/did this group run for a specific number of sessions, or is it ongoing (i.e. attend whenever you need to)?

1. SPECIFIC NUMBER. (How many sessions does/did it run for?_____)
2. ONGOING.

How frequently do/did you attend the meetings of this group?

1. ONLY ONCE OR TWICE
2. ABOUT HALF OF THE TIME
3. MORE THAN HALF OF THE MEETINGS, BUT NOT ALL
4. ALMOST EVERY MEETING

In general, how would you rate your health when you first joined the group?

0. POOR
1. FAIR
2. GOOD
3. EXCELLENT

How would you rate your coping efforts when you first joined the group?

0. POOR
1. FAIR
2. GOOD
3. EXCELLENT

Rate the importance of each of the following to your decision to attend a cancer-related support group:

	NOT IMPORTANT	A LITTLE IMPORTANT	MODERATELY IMPORTANT	VERY IMPORTANT
1. To gain medical information....	0	1	2	3
2. To share concerns with others having similar experiences	0	1	2	3
3. To satisfy my curiosity	0	1	2	3
4. To share with others what I have learned	0	1	2	3
5. To gain more knowledge of the services available for cancer patients and their families ...	0	1	2	3
6. To learn to be able to talk more freely with my family about breast cancer	0	1	2	3

	NOT IMPORTANT	A LITTLE IMPORTANT	MODERATELY IMPORTANT	VERY IMPORTANT
7. To learn to be able to talk more freely with my doctor	0	1	2	3
8. To increase my own understanding of my feelings about my self-image after breast cancer	0	1	2	3
9. To learn how others are solving problems similar to mine	0	1	2	3
10. To share feelings and emotions with others	0	1	2	3
11. To give and receive friendship	0	1	2	3
12. To be a place away from the harshness of the health care system	0	1	2	3
13. I was depressed	0	1	2	3
14. To gain skills (such as relaxation and visualization) to help me deal with my illness	0	1	2	3
15. To be with other cancer patients	0	1	2	3
16. I was desperate	0	1	2	3
17. To gain comfort and reassurance	0	1	2	3
18. For advice	0	1	2	3
19. To help others	0	1	2	3
20. For something to do	0	1	2	3
21. There was no one else to turn to	0	1	2	3

Compared with others in the group, how did you seem to be coping?

1. MUCH WORSE THAN MOST OF THEM
2. ABOUT THE SAME AS MOST OF THEM
3. MUCH BETTER THAN MOST OF THEM

How much do you feel others in the group have helped you?

0. NOT AT ALL
1. A LITTLE
2. SOMEWHAT
3. VERY MUCH

Appendix A-5 (cont.)

How much do you feel you have been able to help others in the group?

0. NOT AT ALL
1. A LITTLE
2. SOMEWHAT
3. VERY MUCH

How often did something that was said or done at the meetings make you feel:

	NEVER	SOMETIMES	OFTEN	VERY OFTEN
1. Angry	0	1	2	3
2. Loved/cared about	0	1	2	3
3. Anxious, tense, or nervous	0	1	2	3
4. Depressed	0	1	2	3
5. Hopeful	0	1	2	3
6. Relaxed	0	1	2	3

Overall, how would you sum up your experience in the group:

1. EXTREMELY POSITIVE
2. QUITE POSITIVE
3. NEITHER POSITIVE NOR NEGATIVE
4. QUITE NEGATIVE
5. EXTREMELY NEGATIVE

Did the support group provide any kind of help that was not available to you from other sources?
(If YES, please explain what this was)

I have now come to the end of this part of my study of breast cancer patients, and wish to thank you very sincerely for your participation. However, I am interested in your reactions to this study, as a guide for future work.

How did you feel about filling out these questionnaires?

1. I wish I hadn't been asked, but someone has to do it.
2. I feel I gained something positive for myself by the experience.
3. I really didn't care either way -- I didn't mind doing them, but I also don't think I gained anything personally from them.

Any comments:

What was your motivation in doing the questionnaires? (Mark only the ONE that best fits your thoughts).

1. I didn't really want to do the questionnaires, but didn't know how to say "no" politely.
2. I wanted to do the questionnaires, because I was able to express thoughts and feelings that I didn't feel I could tell other people about.
3. I was pleased to do the questionnaires because somehow they made me feel less alone--they helped me to believe that others were also having the same experiences.
4. I wanted to do the questionnaires, to help other breast cancer patients.
5. I wanted to do the questionnaires because it was a way of showing my appreciation for the care I had received from my doctor.
6. Other reasons (please specify) ______________________________
   ____

Any comments:

Would you like a summary of the findings from this research, when available?

1. YES.
2. NO.

Thank you very much for your help over the past few months.

Appendix A-6

Study 1: Questionnaire given to Husbands

Would you please fill out the following questionnaire, giving your impression of your wife's physical and social adjustment after her operation. It is important that you do not ask your wife to help you with the answers, as it is YOUR OPINION that is important for this part of the research. Thank you very much for your help.

Does your wife suffer from any of the following?

	NOT AT ALL	A LITTLE	SOMEWHAT	YES A LOT
Swelling in arm (or wound)	0	1	2	3
Weakness (or stiffness) in arm	0	1	2	3
Problems of wound healing	0	1	2	3
Rate the extent to which the mobility of her arm has been affected	0	1	2	3

Please indicate the degree of discomfort or difficulty (if any) your wife has in performing the following: (Please cross a line through any of the items below that she never does, even when in good health).

	NO DISCOMFORT	A LITTLE DISCOMFORT	QUITE A BIT	SEVERE DISCOMFORT
1. dressing	0	1	2	3
2. showering/bathing	0	1	2	3
3. light housework (dishes/dusting)	0	1	2	3
4. preparing meals	0	1	2	3
5. laundering (washing/pegging on line/ironing)	0	1	2	3
6. grocery shopping	0	1	2	3
7. other shopping	0	1	2	3
8. washing hair	0	1	2	3
9. driving car	0	1	2	3
10. heavy cleaning (floors/windows)	0	1	2	3
11. entertaining	0	1	2	3
12. going out	0	1	2	3

To what extent do you feel your wife has returned to her previous normal level of activity?

0. NOT AT ALL
1. NOT MUCH
2. ALMOST COMPLETELY
3. COMPLETELY

In how many organizations was your wife active in the past month - e.g. parent-teacher groups, church-connected groups, fraternal lodges, neighbourhood or community centres (e.g. YWCA), card clubs, social clubs, civic organizations (e.g. Red Cross), sports teams, and political clubs.

0. NONE OF THEM
1. 1 OR 2 OF THEM
2. 3 OR 4 OF THEM
3. 5 OR 6 OF THEM
4. 7 OR MORE OF THEM

How often IN THE LAST MONTH has your wife done each of these things?

	NEVER	RARELY	SOMETIMES	OFTEN
1. Telephoned people for a talk	0	1	2	3
2. Written letters	0	1	2	3
3. Played table games with other people (e.g. cards, chess)	0	1	2	3
4. Entertained your relatives or friends at home	0	1	2	3
5. Visited your relatives or friends in their home	0	1	2	3
6. Gone to a restaurant, party or dance with a group of others	0	1	2	3
7. Gone to a meeting at a service club, church, lodge, union or professional organization	0	1	2	3

Study 2: Explanatory Letter to Volunteer Hospital Visitors

May, 1987.

SURVEY OF B.C.S.S. VISITORS.

This letter is to ask for your help with a study of the Breast Cancer Support Service, which I am undertaking as part of my research at the Adelaide University. As explained at the last Refresher, Margaret Tobin (the BCSS Co-ordinator) and Ronda Mundy (a foundation member of the BCSS) have worked with me on this questionnaire in the hope that the replies received from people such as yourself will enable the BCSS to improve their services.

It is important to us that you feel quite free to express your true feelings. In this way you will help us to provide the best possible service in the future.

No names are required, and replies will be strictly confidential even from the Breast Cancer Support Service. The reply paid envelope is addressed to me at the University, and your completed questionnaire will NOT be seen by anyone else. The results that will be made available to the Breast Cancer Support Service will be in summary form only (e.g. 20% of women visited said......)

By participating in this research, you can help me to get feedback on the BCSS, and in the end we expect this to benefit those for whom the Service exists -- new breast cancer patients. Also, a summary of the research findings, will be made available to interested participants.

If you need more information about this research, please phone me on 228 5849, or 228 5693 (sec.).

Thank you for your help. I hope you find the questions interesting.

Sandy Neuling.

Study 2: Explanatory Letter to Breast Cancer Patients

May 1987.

SURVEY OF BREAST CANCER PATIENTS.

Recently you were visited by a volunteer from the Breast Cancer Support Service. The purpose of the visit was to assist you in recovery from your operation by placing you in contact with another woman who had had similar surgery.

Several women have suggested changes to the service which they feel would have made the visit more helpful. We are considering the possibility of making such changes, but first would appreciate comments from women, such as yourself, who have had a visit from the Breast Cancer Support Service.

Mrs Sandra Neuling, a postgraduate student at the Adelaide University, who herself has had a mastectomy, has offered to evaluate the service as part of research she is conducting on support available to breast cancer patients. However, in order to ensure confidentiality, she has not been given your name or any details about you.

We would be very grateful if you would help in this matter by answering the enclosed questionnaire. No names are required, and replies will be strictly confidential even from the Breast Cancer Support Service. The reply paid envelope is addressed to Mrs Neuling at the University, and your completed questionnaire will NOT be seen by anyone else. The results that will be made available to the Breast Cancer Support Service will be in summary form only (e.g. 20% of women visited said......)

It is important to us that you feel quite free to express your true feelings. In this way you will help us to provide the best possible service in the future.

If you need more information about this research, please phone Mrs Neuling on 228 5849 or 228 5693 (sec.).

Thank you for your help.

(Mrs) Margaret Tobin.
CO-ORDINATOR,
BREAST CANCER SUPPORT SERVICE.

Appendix A-9

Study 2: Questionnaire sent to Volunteer Hospital Visitors

SURVEY OF B.C.S.S. VISITORS.

For how long have you been a BCSS visitor?
(Circle the number next to the answer which best applies).

1. LESS THAN ONE YEAR.
2. BETWEEN ONE AND THREE YEARS.
3. THREE YEARS OR MORE.

Approximately how many visits have you made for the BCSS?

1. LESS THAN FIVE.
2. BETWEEN FIVE AND TEN.
3. TEN OR MORE.

How did you come to be a BCSS visitor?

1. I WAS ASKED BY THE A.C.F.
2. I WAS ASKED BY MY SURGEON.
3. I VOLUNTEERED.

If your answer was 1 or 2, did you feel any <u>OBLIGATION</u> to be a BCSS visitor?

1. YES.
2. NO.

Why did you become a BCSS volunteer?
(Put a number beside THREE of the following in order to rate their importance i.e. 1 for the most important, and 2 and 3 for the next most important).

( ) I had a visit from the B.C.S.S. which I considered very valuable to me, and I wanted to pass on the help I had received.

( ) I didn't have a visit from the B.C.S.S., but would have loved the opportunity to talk to someone who had gone through a similar experience.

( ) I felt that if I helped others, I would feel better about my own operation.

( ) Some doctors don't have time to find out what really worries a person, and I wanted to help fill this gap.

( ) I believed that no-one could help a breast cancer patient in the way that someone who has been through the same operation herself could.

( ) I felt that I had the ability to reassure people.

( ) Other (please explain).

What do you see as the <u>BENEFITS TO YOU</u> in being a BCSS volunteer?
(Rate 1, 2, & 3 in order of importance: 1 = the greatest benefit)

( ) Getting a sense of fulfilment in giving to someone in need and being valued by them.

( ) Gaining some status or recognition in the hospitals I visit, as being a person of competence.

( ) Gaining some status or recognition in the Anti-Cancer Foundation, as being a person of competence.

( ) Finding an excellent group of friends amongst the other BCSS volunteers.

( ) Feeling I was doing the right thing.

( ) Getting satisfaction from doing something positive with my cancer experience.

( ) Getting satisfaction from knowing that I was, in some way, repaying the services given to me.

( ) Other (please explain). ....
....

What do you see as the <u>NEGATIVE ASPECTS</u> of being a BCSS volunteer?
(Rate 1, 2, & 3 in order of importance: 1 = the most negative aspect).

( ) Feeling emotionally drained after a visit.

( ) Feeling upset because I've had a visit which didn't go well.

( ) Feeling depressed when I have identified too closely with a lady I visited.

( ) Feeling upset when a fellow BCSS visitor dies of cancer.

( ) Feeling depressed because visits are a constant reminder of the fact that I have had cancer.

( ) Feeling depressed when I hear information about breast cancer that I'd rather not know.

( ) Worrying that my family feel I spend too much time with the BCSS.

( ) Feeling guilty when I'm asked to do a visit but am unable to because of prior commitments.

( ) Feeling guilty when I'm asked to do a visit but am unable to because of illness.

( ) Other (please explain). ....
....

What do you consider to be the MOST IMPORTANT CHARACTERISTICS of a BCSS volunteer visitor?
(Rate 1, 2, & 3 in order of importance: 1 = the most important).

( ) To have empathy. (i.e. the ability to put yourself in the position of the other, and so understand where she is coming from).

( ) To have sympathy. (i.e. the ability to feel sorry for the other person's misfortunes).

( ) To be a good listener

( ) To be able to give information about treatment.

( ) To be able to give information about prostheses.

( ) To be able to explain what happened to you.

( ) To look fit and well, and to wear appropriate clothing.

( ) To be able to relate to people different from yourself. (e.g. in background or education).

( ) To be friendly.

( ) To have a sense of humour.

TRAINING OF VOLUNTEERS:

Do you feel that the training you have had FROM THE ANTI-CANCER FOUNDATION has prepared you sufficiently as a hospital visitor?
(Circle the number which best applies).

1. EXCELLENT PREPARATION.
2. ADEQUATE PREPARATION.
3. SOMEWHAT INADEQUATE PREPARATION.
4. TOTALLY UNPREPARED.

What about training after this? Are the 'Refreshers' sufficient? Do you see other needs?

Other comments on training.

SUPPORT FOR VOLUNTEERS:

How often have you talked your visit over with each of the following people:
(Circle the number which best applies to you).

	NEVER	HARDLY EVER	SOME-TIMES	OFTEN
A FRIEND (confidentially).	0	1	2	3
YOUR HUSBAND.	0	1	2	3
ANOTHER BCSS VOLUNTEER.	0	1	2	3
THE BCSS CO-ORDINATOR.	0	1	2	3
OTHER ANTI-CANCER FOUNDATION STAFF. ...	0	1	2	3
ANY OTHER PERSON (who?).	0	1	2	3
HAVE YOU EVER WANTED TO TALK TO SOMEONE BUT FOUND NO-ONE AVAILABLE	0	1	2	3

If you wished to have a "holiday" from visiting for a while, or to leave the service altogether, would you feel guilty about doing this?

1. NOT AT ALL GUILTY
2. A LITTLE BIT GUILTY
3. QUITE GUILTY -- I WOULD POSTPONE MY DECISION FOR A WHILE
4. VERY GUILTY -- I WOULD REALLY LIKE A BREAK AT TIMES, BUT HAVEN'T FELT ABLE TO SAY SO.

What do you consider to be the <u>MOST DIFFICULT</u> or <u>TROUBLING PROBLEM</u> for patients who have just had a <u>MASTECTOMY</u>? (Please mark only ONE).

( ) Fear and uncertainty about the future due to cancer.

( ) Limitations in physical abilities or lifestyle due to cancer.

( ) Difference in appearance due to cancer.

( ) Pain, symptoms, or discomfort from illness or treatment.

( ) Problems with family or friends related to cancer.

Patients who had recently had a mastectomy were asked (amongst other things) whether their BCSS visitor was helpful in any of the following areas. Please mark each item as you think most mastectomy patients would have done.

	NOT APPLICABLE	NOT VERY HELPFUL	QUITE HELPFUL	VERY HELPFUL
Advice about:				
communicating with the doctor ..	0	1	2	3
communicating with the family ..	0	1	2	3
what treatment you should have .	0	1	2	3
side effects of treatments	0	1	2	3
exercising of arm	0	1	2	3
prostheses	0	1	2	3
financial matters	0	1	2	3
resuming work	0	1	2	3
playing sport	0	1	2	3
resuming social life...........	0	1	2	3

Patients recently visited by the BCSS were asked what they considered to be the possible strengths and weaknesses of the BCSS hospital visitor system. Please mark each item as you think most mastectomy patients would have done.

	NOT TRUE	SOMEWHAT TRUE	VERY TRUE
Just seeing someone who had recovered helped me feel I could too	0	1	2
Her visit came too soon after my operation	0	1	2
She could understand my worries because she could remember feeling the same way	0	1	2
She talked too much about herself	0	1	2
Talking to her made me feel less isolated & alone	0	1	2
I already knew everything she told me	0	1	2
She lifted my spirits	0	1	2
She was too cheerful and I wasn't in the mood for that	0	1	2
I asked her questions I couldn't ask anyone else.	0	1	2
She was too different; I couldn't talk to her ...	0	1	2

Appendix A-10

Study 2: Questionnaire sent to Patients

SURVEY OF BREAST CANCER PATIENTS.

Please circle the number next to the answer which best applies to you.

Was your visitor approximately the same age as you?

1. YES.
2. NO.

How important was this to you?

1. NOT VERY IMPORTANT.
2. A LITTLE IMPORTANT.
3. VERY IMPORTANT.

Did your visitor have the same type of operation as you?

1. YES.
2. NO.
3. I DON'T KNOW.

How important was this to you?

1. NOT VERY IMPORTANT.
2. A LITTLE IMPORTANT.
3. VERY IMPORTANT.

Did your visitor have the same course of treatment after her operation as is planned for you (i.e. chemotherapy, radiotherapy, hormone treatment).

1. YES.
2. NO.
3. I DON'T KNOW.

How important was this to you?

1. NOT VERY IMPORTANT.
2. A LITTLE IMPORTANT.
3. VERY IMPORTANT.

Was your visitor helpful in any of the following areas:

	NOT APPLICABLE	NOT VERY HELPFUL	QUITE HELPFUL	VERY HELPFUL
Information about:				
how to communicate with				
doctor	0	1	2	3
family	0	1	2	3
Advice about:				
what treatment you should have .	0	1	2	3
side effects of treatments	0	1	2	3
exercising of arm	0	1	2	3
prostheses	0	1	2	3
financial matters	0	1	2	3
resuming work	0	1	2	3
playing sport	0	1	2	3
resuming social life	0	1	2	3

What do you consider to be the possible strengths and weaknesses of the BCSS hospital visitor system?

	NOT TRUE	SOMEWHAT TRUE	VERY TRUE
Just seeing someone who had recovered helped me feel I could too	0	1	2
Her visit came too soon after my operation	0	1	2
She could understand my worries because she could remember feeling the same way	0	1	2
She talked too much about herself	0	1	2
Talking to her made me feel less isolated and alone	0	1	2
I already knew everything she told me	0	1	2
She lifted my spirits	0	1	2
She was too cheerful and I wasn't in the mood for that	0	1	2
I asked her questions I couldn't ask anyone else.	0	1	2
She was too different from me; I couldn't talk to her	0	1	2

If she was too different -- in what way was this?
....
....

Would you recommend that other breast cancer patients have a visit from the BCSS?
1. YES.
2. NO.

Any other comments?

THIS IS THE END OF THE QUESTIONNAIRE.
PLEASE POST THIS IN THE ENCLOSED ENVELOPE -- NO STAMP REQUIRED.

THANK YOU VERY MUCH FOR YOUR HELP.

Appendix A-11

Study 2: Reminder Letter to Volunteer Hospital Visitors

5th June, 1987.

SURVEY OF BREAST CANCER SUPPORT SERVICE VISITORS.

Recently I sent you a letter asking for your help with a study of the Breast Cancer Support Service.

If you have already completed and returned the questionnaire, please accept my sincere thanks. If not, I would be very grateful if you would please take the time to do so. As there are only a limited number of volunteer visitors, it is important that your opinion is received so that the BCSS can be correctly evaluated and improved.

If by some chance you did not receive the questionnaire, or it got misplaced, please call me right away and I will get another one in the mail to you today. Or if you need more information about this research, please phone me on 228 5849 or 228 5693 (sec.).

Thank you very much,

(Mrs) Sandy Neuling.

Study 2: Reminder Letter to Patients

Dear

Recently we sent you a letter seeking your opinion on our Breast Cancer Support Service.

If you have already completed and returned the questionnaire, please accept our sincere thanks. If not, we would be very grateful if you would take the time to do so. As this questionnaire is only being sent to a small group of people, it is important that we receive your opinion so that we can correctly evaluate and improve our service.

If by some chance you did not receive the questionnaire, or it got misplaced, please call us on 228 5070 right away and we will get another one in the mail to you today. Or if you need more information about this research, please phone Mrs Neuling on 228 5849 or 228 5693 (sec.).

Yours sincerely,

(Mrs) Margaret Tobin.
CO-ORDINATOR,
BREAST CANCER SUPPORT SERVICE.

Appendix A-13

Study 3: Explanatory Letter to Patients

BREAST CANCER SUPPORT SERVICE.

Dear Mrs.

Recently you were visited by a volunteer from the Breast Cancer Support Service. The purpose of the visit was to assist you in recovery from your operation by placing you in contact with another woman who had had similar surgery.

Several women have suggested that their husbands would also appreciate some assistance at this time. Mrs Sandra Neuling, a postgraduate student at the Adelaide University, who herself has had a mastectomy, has offered to evaluate our service as part of research she is conducting on support available to breast cancer patients. Her previous research surveyed a large group of breast cancer patients, but we are now seeking comments from husbands of new patients such as yourself. However, in order to ensure confidentiality, she has not been given your name or any details about you.

We would be grateful if you would help in this matter by passing on the enclosed questionnaire to your husband and asking if he would be willing to answer it and return it in the reply paid envelope. In order to get a balanced view we would like all husbands to take part, whether or not they feel the need for help. In this way we will be able to assess whether we should expand our services in this area.

No names are required, and replies will be strictly confidential even from the Breast Cancer Support Service, as the reply paid envelope is addressed to Mrs Neuling at the University, and the completed questionnaire will NOT be seen by anyone else. The results that will be made available to the Breast Cancer Support Service will be in summary form only (e.g., 20% of husbands said...).

If you or your husband need more information about this research, please phone Mrs Neuling on 228 5849 or 228 5693 (sec.).

Thank you for your help.

(Mrs) Margaret Tobin
Co-ordinator
Breast Cancer Support Service

Appendix A-14

Study 3: Explanatory Letter to Husbands

Dear Sir,

I am a post-graduate student at the University of Adelaide, and for the past two years have been researching the psychological and social issues associated with breast cancer. My interest in this area began in 1982 when I had a mastectomy, and since that time I have been working in a voluntary capacity with the Anti-Cancer Foundation. I began my research by interviewing 60 women who had breast cancer operations between June-December last year. This is the first research of this type to be conducted in Australia.

The purpose of this part of the research is to get a better understanding of the needs of husbands of breast cancer patients.

Past research overseas has indicated that the husband is often the most important source of encouragement to a woman in this situation, and this places many men in an unenviable position. The husband not only has to face the realities of his wife's cancer, but he also has the added responsibility of being a comfort and a source of reassurance to his wife. Many men are unsure of how to react, and may feel overwhelmed by the situation.

The aim of this project is to determine the main areas of concern for husbands of breast cancer patients as they attempt to give support in the early stages of treatment.

No names are required, and replies will be strictly confidential. Results will be presented in summary form only, and a copy of the findings will be sent to those who take part, if they wish.

Thank you in anticipation of your support. Please feel free to phone me if you would like more details.

Yours faithfully,

(Mrs) Sandra J Neuling.
Psychology Department.
Phone: 228 5849
228 5693 (sec.)

Appendix A-15

Study 3: Questionnaire sent to Husbands

Please answer by circling the number next to the answer which best applies. Only circle one number for each question, unless otherwise specified. There are no right or wrong answers.

1. Before your wife had her operation, were you involved in deciding what type of surgery she should have?

1. YES -- I WENT WITH HER TO THE SURGEON, AND WE ALL DISCUSSED IT TOGETHER.
2. YES -- I DIDN'T GO WITH HER TO THE SURGEON, BUT WE DISCUSSED IT AT HOME.
3. NO -- I WENT WITH HER TO THE SURGEON, BUT WE LEFT THE DECISION TO HIM.
4. NO -- I BELIEVE IT SHOULD BE HER DECISION.

Would you like to have had more part in this decision?

1. YES, BUT MY WIFE PREFERRED TO DO IT HER WAY.
2. YES, BUT THE SURGEON DIDN'T GIVE ME ANY OPPORTUNITY.
3. NO.

2. How often have you been able to talk about <u>your</u> concerns or worries regarding your wife having had cancer?

0. NEVER
1. SOMETIMES)
2. OFTEN) To whom have you talked about this? (circle all who apply)
3. VERY OFTEN)

   1. YOUR WIFE'S SURGEON
   2. ANY OTHER HEALTH PROFESSIONAL
   3. YOUR WIFE
   4. ANY OTHER CLOSE RELATIVES
   5. A FRIEND

Would you have liked to talk about your concerns more often?

1. YES (with whom) ....
2. NO

3. How often have you been given advice on how you could help your wife?

0. NEVER
1. SOMETIMES)
2. OFTEN) Who has given you this advice? (circle all who apply).
3. VERY OFTEN)

   1. YOUR WIFE'S SURGEON
   2. ANY OTHER HEALTH PROFESSIONAL
   3. YOUR WIFE
   4. ANY OTHER CLOSE RELATIVES
   5. A FRIEND

Would you have liked to have more advice?

1. YES (from whom) ....
2. NO

4. How often have others helped with practical chores such as housework, transport or shopping since your wife's operation?

0. NEVER
1. SOMETIMES
2. OFTEN
3. VERY OFTEN

Would you have liked this help more often?

1. YES
2. NO

5. Have you had the opportunity to talk with a man whose wife has had a similar operation to your wife?

1. YES
2. NO

IF NO: Would you like to have this opportunity? YES/NO

Have you had the opportunity to talk with a woman who has had a similar operation to your wife?

1. YES
2. NO

iF NO: Would you like to have this opportunity? YES/NO

FOR THE REST OF THE QUESTIONNAIRE, PLEASE CIRCLE ONLY ONE NUMBER FOR EACH QUESTION.

1. Would you like to talk more often with your wife about how she feels about having had cancer?

1. YES -- I WOULD LIKE TO TALK MORE OFTEN, BUT MY WIFE WOULDN'T LIKE IT.
2. YES -- I WOULD LIKE TO TALK MORE OFTEN, BUT I FEEL UNCOMFORTABLE.
3. NO -- MY WIFE WOULD LIKE TO TALK MORE OFTEN, BUT IT'S NOT GOOD FOR HER TO DWELL ON THESE THINGS.
4. NO -- WE TALK AS MUCH AS WE BOTH WANT TO.

2. Would you like to give your wife more advice regarding her treatment or how she could help herself?

1. YES -- I WOULD LIKE TO GIVE MY WIFE MORE ADVICE, BUT SHE WOULDN'T LIKE IT.
2. YES -- MY WIFE WANTS MORE ADVICE, AND I WISH I HAD MORE KNOWLEDGE.
3. NO -- MY WIFE WANTS MORE ADVICE, BUT IT'S THE DOCTOR'S JOB TO GIVE IT.
4. NO -- MY WIFE DOESN'T WANT ANY MORE ADVICE.

3. Would you like to help your wife more often with practical household chores since her operation?

1. YES -- I WOULD LIKE TO HELP MY WIFE MORE OFTEN, BUT SHE WOULDN'T LIKE IT.
2. YES -- I WOULD LIKE TO HELP MY WIFE MORE OFTEN, BUT I DON'T HAVE THE TIME.
3. NO -- MY WIFE WOULD LIKE ME TO HELP MORE OFTEN, BUT ITS BETTER FOR HER TO GET BACK TO ROUTINE AS SOON AS POSSIBLE.
4. NO -- WE ARE BOTH HAPPY WITH THE WAY THINGS ARE.

What is your age? .... years.   And your wife's age? .... years.

How long is it since your wife's surgery? .... weeks

Is your wife currently having CHEMOTHERAPY? YES/NO
RADIOTHERAPY? YES/NO

----------ooo000ooo----------

Cancer is generally a difficult or troubling experience for those who have it and for their families. The following are some possible problems associated with cancer. <u>IN YOUR OPINION</u>, which one has been the most worrying for <u>your wife</u> since she knew she had cancer? (Please don't ask her, as it is your opinion we require.) (Please circle only <u>ONE</u>).

1. FEAR AND UNCERTAINTY ABOUT THE FUTURE DUE TO CANCER.
2. LIMITATIONS IN PHYSICAL ABILITIES OR LIFESTYLE DUE TO CANCER.
3. CHANGE IN APPEARANCE DUE TO CANCER.
4. PAIN, SYMPTOMS, OR DISCOMFORT FROM ILLNESS OR TREATMENT.
5. PROBLEMS WITH CHILDREN OR FRIENDS RELATED TO CANCER.
6. ANY OTHER ....

How stressful do you think this problem has been for <u>her</u>?

1. SLIGHTLY STRESSFUL
2. QUITE STRESSFUL
3. EXTREMELY STRESSFUL

Which of these problems has been the most worrying for <u>you</u>? (Please circle only one).

1. FEAR AND UNCERTAINTY ABOUT THE FUTURE DUE TO CANCER.
2. LIMITATIONS IN YOUR WIFE'S PHYSICAL ABILITIES OR LIFESTYLE DUE TO CANCER.
3. CHANGE IN YOUR WIFE'S APPEARANCE DUE TO CANCER.
4. PAIN OR DISCOMFORT SUFFERED BY YOUR WIFE AS A RESULT OF THE ILLNESS OR TREATMENT.
5. PROBLEMS WITH CHILDREN OR FRIENDS RELATED TO YOUR WIFE'S CANCER.
6. ANY OTHER ....

How stressful has this problem been for <u>you</u>?
1. SLIGHTLY STRESSFUL
2. QUITE STRESSFUL
3. EXTREMELY STRESSFUL

Appendix A-15 (cont.)

Please read each item below and indicate how often you have done this in the past month, in trying to cope with the stress felt <u>by you</u> since your wife has had cancer.

	NEVER	SOME-TIMES	OFTEN	VERY OFTEN
1. Felt time would make a difference--the only thing to do was wait	0	1	2	3
2. Talked to someone to find out more about the situation	0	1	2	3
3. Criticized or lectured yourself	0	1	2	3
4. Went along with fate; sometimes you just have bad luck	0	1	2	3
5. Went on as if nothing were happening	0	1	2	3
6. Tried to keep your feelings to yourself	0	1	2	3
7. Looked for the silver lining--looked on the bright side	0	1	2	3
8. Looked for understanding from someone	0	1	2	3
9. Tried to make yourself feel better by eating, drinking or smoking	0	1	2	3
10. Avoided being with people in general	0	1	2	3
11. Asked a relative or friend you respect for advice	0	1	2	3
12. Kept others from knowing how bad things were	0	1	2	3
13. Talked to someone about how you felt	0	1	2	3
14. Took it out on other people	0	1	2	3
15. Refused to believe it would happen	0	1	2	3
16. Tried to keep your feelings from interfering with other things too much	0	1	2	3
17. Wished the situation would go away or be over with	0	1	2	3
18. Had fantasies or wishes about how things may turn out	0	1	2	3
19. Prayed	0	1	2	3
20. Prepared yourself for the worst	0	1	2	3
21. Went over in your mind what you would say or do	0	1	2	3
22. Thought of how a person you admire would handle this situation, and used that as a model	0	1	2	3
23. Reminded yourself how much worse things could be	0	1	2	3
24. Tried to find out as much as you could about cancer and your wife's case	0	1	2	3
25. Treated the illness as a challenge or battle to be won	0	1	2	3

Appendix A-15 (cont.)

A number of statements which people have used to describe themselves are given below. Please read each statement and then indicate how <u>you</u> feel NOW.

	NOT AT ALL	SOME-WHAT	MODERATELY SO	VERY MUCH SO
1. I feel calm	0	1	2	3
2. I feel secure	0	1	2	3
3. I am tense	0	1	2	3
4. I am strained	0	1	2	3
5. I feel at ease	0	1	2	3
6. I feel upset	0	1	2	3
7. I am worrying over possible misfortunes	0	1	2	3
8. I feel satisfied	0	1	2	3
9. I feel frightened	0	1	2	3
10. I feel comfortable	0	1	2	3
11. I feel self-confident	0	1	2	3
12. I feel nervous	0	1	2	3
13. I am jittery	0	1	2	3
14. I feel indecisive	0	1	2	3
15. I am relaxed	0	1	2	3
16. I feel content	0	1	2	3
17. I am worried	0	1	2	3
18. I feel confused	0	1	2	3
19. I feel steady	0	1	2	3
20. I feel pleasant	0	1	2	3

	NO, NOT AT ALL	NO, NOT MUCH	YES, SOMETIMES	YES DEFINITELY
21. I feel miserable and sad	0	1	2	3
22. I find it easy to do the things I used to ....:	0	1	2	3
23. I get very frightened feelings for apparently no reason	0	1	2	3
24. I have weeping spells, or feel like it	0	1	2	3
25. I still enjoy the things I used to ...	0	1	2	3
26. I am restless and can't keep still ...	0	1	2	3
27. I get off to sleep easily, without sleeping tablets	0	1	2	3
28. I feel anxious when I go out of the house on my own	0	1	2	3
29. I have lost interest in things	0	1	2	3
30. I get tired for no reason	0	1	2	3
31. I am more irritable than usual	0	1	2	3
32. I wake early and then sleep badly for the rest of the night	0	1	2	3

This is the end of the questionnaire. If you would like a summary of the findings from this research when it is available please write your name and address below, or, if you prefer to keep this questionnaire anonymous, write to me soon, under separate cover, requesting a summary of the findings.

Thank you very much for your help. Please use the enclosed envelope for your reply -- there is no postage required.

Appendix A-16

Study 3: Reminder Letter to Patients

BREAST CANCER SUPPORT SERVICE.

Dear Mrs.

Recently we sent you a letter asking for your husband's help with a study aimed at getting a better understanding of the needs of husbands of breast cancer patients.

If your husband has already completed and returned the questionnaire, please accept our sincere thanks. If not, we would be very grateful if he would please take the time to do so. As this questionnaire is only being sent to a limited number of people, it is important that we receive his response.

If by some chance you did not receive the questionnaire, or it has been misplaced, please call us right away and we will get another one in the mail to you today. Or if you need more information about this research, please phone Mrs Neuling on 228 5849 or 228 5693 (sec.).

Thank you very much,

Yours sincerely,

(Mrs) Margaret Tobin,
CO-ORDINATOR.

Appendix B-1

Study 1: Mean Frequency and Standard Deviations of Potentially Supportive Behaviours from each Source at each Interview

	In hospital		1 month post-op.		3 months post-op.	
	M	*SD*	*M*	*SD*	*M*	*SD*
Family	(*n* = 55)		(*n* = 54)		(*n* = 52)	
Talked about emotional feelings	1.96	(1.05)	1.37	(0.94)	0.77	(0.81)
Talked about physical feelings	1.58	(1.08)	1.24	(0.80)	0.81	(0.77)
Listened and tried to understand	2.64	(0.78)	2.32	(0.93)	2.14	(1.05)
Made you feel loved	2.76	(0.61)	2.48	(0.86)	2.33	(0.94)
Offered advice about helping yourself	0.38	(0.85)	0.72	(0.98)	0.50	(0.67)
Suggested ways to look at your illness	0.27	(0.59)	0.24	(0.51)	0.12	(0.38)
Offered advice about treatments	0.24	(0.58)	0.28	(0.69)	0.14	(0.40)
Told you what to expect	0.26	(0.55)	0.30	(0.66)	0.23	(0.55)
Helped with chores	2.49	(0.90)	2.43	(0.88)	2.02	(1.09)
Did everything for you	0.95	(1.22)	1.17	(1.21)	0.50	(0.80)
Told you to count your blessings	0.64	(0.95)	0.61	(0.96)	0.33	(0.76)
Told you not to worry	1.56	(1.20)	1.30	(1.27)	0.85	(1.14)
Told jokes and chattered	1.27	(1.27)	1.04	(1.20)	0.54	(0.67)
Friend	(*n* = 56)		(*n* = 52)		(*n* = 49)	
Talked about emotional feelings	1.50	(1.16)	1.37	(0.89)	0.69	(0.87)
Talked about physical feelings	1.01	(1.08)	1.33	(0.90)	0.67	(0.83)
Listened and tried to understand	2.54	(0.87)	2.37	(0.77)	2.02	(0.99)
Made you feel loved	2.32	(0.94)	2.12	(1.11)	1.65	(1.22)
Offered advice about helping yourself	0.29	(0.73)	0.60	(0.85)	0.31	(0.71)
Suggested ways to look at your illness	0.14	(0.52)	0.31	(0.64)	0.14	(0.35)
Offered advice about treatments	0.07	(0.42)	0.15	(0.46)	0.04	(0.20)
Told you what to expect	0.13	(0.54)	0.23	(0.65)	0.08	(0.28)
Helped with chores	0.66	(1.08)	0.92	(1.08)	0.53	(0.77)
Did everything for you	0.16	(0.53)	0.14	(0.35)	0.08	(0.45)
Told you to count your blessings	0.45	(0.78)	0.42	(0.78)	0.25	(0.56)
Told you not to worry	0.93	(0.93)	0.94	(1.02)	0.37	(0.73)
Told jokes and chattered	0.93	(1.14)	0.96	(1.07)	0.47	(0.82)
Surgeon	(*n* = 58)		(*n* = 47)		(*n* = 40)	
Talked about emotional feelings	1.02	(1.19)	0.77	(1.09)	0.50	(0.82)
Talked about physical feelings	1.52	(1.08)	1.49	(1.10)	0.95	(0.90)
Listened and tried to understand	2.79	(0.61)	2.11	(1.03)	1.98	(1.21)
Offered advice about helping yourself	1.14	(1.19)	0.92	(0.93)	0.40	(0.63)
Suggested ways to look at your illness	0.07	(0.26)	0.11	(0.38)	0.15	(0.43)
Offered advice about treatments	1.40	(1.15)	0.72	(1.04)	0.63	(0.98)
Told you what to expect	1.93	(1.06)	1.34	(1.15)	1.08	(1.14)
Answered all your questions	2.74	(0.72)	2.43	(1.04)	2.10	(1.08)
Told you to count your blessings	0.21	(0.59)	0.21	(0.62)	0.03	(0.16)
Told you not to worry	0.85	(0.95)	0.79	(1.06)	0.33	(0.69)
Told jokes and chattered	0.76	(1.00)	0.55	(0.93)	0.18	(0.39)

Note. Maximum score = 3.

Appendix B-2

Study 1: Percentages of Subjects Dissatisfied with the Frequency of each Item of Potentially Supportive Behaviours Received from each Source at each Interview

	In hospital		1 month post-op.		3 months post-op.	
	Needed more %	Needed less %	Needed more %	Needed less %	Needed more %	Needed less %
Family	(n = 55)		(n = 54)		(n = 52)	
Talked about emotional feelings	9	4	4	0	6	0
Talked about physical feelings	9	2	4	0	4	0
Listened	13	0	9	0	6	0
Made you feel loved	5	0	4	0	4	0
Offered advice about helping yourself	4	0	0	2	0	2
Suggested ways to look at your illness	2	0	0	0	0	0
Offered advice about treatments	0	2	0	0	2	0
Told you what to expect	2	0	0	2	0	0
Helped with chores	4	0	6	4	6	0
Did everything for you	2	0	2	4	2	4
Told you to count your blessings	0	0	0	2	0	0
Told you not to worry	0	4	0	2	0	2
Told jokes and chattered	7	2	6	4	4	0
Friend	(n = 56)		(n = 52)		(n = 49)	
Talked about emotional feelings	4	2	0	0	2	0
Talked about physical feelings	2	2	0	0	0	0
Listened	4	0	0	2	0	0
Made you feel loved	0	0	0	0	0	0
Offered advice about helping yourself	4	2	2	0	0	0
Suggested ways to look at your illness	2	2	0	2	0	0
Offered advice about treatments	0	0	0	2	0	0
Told you what to expect	0	0	0	0	0	0
Helped with chores	0	0	0	0	0	0
Did everything for you	0	0	0	0	0	0
Told you to count your blessings	0	0	0	2	0	0
Told you not to worry	4	0	2	0	0	0
Told jokes and chattered	0	2	0	0	0	0
Surgeon	(n = 58)		(n = 47)		(n = 40)	
Talked about emotional feelings	14	0	26	0	28	0
Talked about physical feelings	12	0	19	0	25	0
Listened	9	0	21	0	25	0
Offered advice about helping yourself	3	0	13	0	20	0
Suggested ways to look at your illness	5	0	2	0	10	0
Offered advice about treatments	2	0	9	0	10	0
Told you what to expect	5	2	21	0	10	3
Answered all your questions	10	0	19	0	25	3
Told you to count your blessings	3	0	0	0	0	0
Told you not to worry	0	0	4	4	5	0
Told jokes and chattered	0	0	4	0	3	0

Note. Percentages have been rounded to the nearest whole number.

Appendix C-1

Study 1: Patients' Comments Regarding Taking Part in the Research

Sub.	Comments
1	The questions asked made me realize that many people would be very anxious about themselves.
5	If there's anything else I can do to help you, just let me know.
7	Thank you so much for your work.
8	Thank you for your help.
9	Thank you for coming, it's good to talk to you.
10	Will you come back? I'm happy to do anything that might help.
12	I felt this was a very worthwhile study. Thanks for your interest.
14	I didn't go to a support group because I don't want to talk to a "do gooder". You're good to talk to because I respect you--you're intelligent.
15	I am grateful for the opportunity of giving my opinion in this questionnaire....It makes people in my position and likewise feel cared for and thought of. Thank you.
17	When are you coming back?
18	I look forward to seeing you again. You should come more often. You should keep this research going for about 3 years because it takes people a long while to get over it often. I would be happy to be in extended research.
19	How many more are there? Don't I ever get away from it?
21	Thank you for including me in your psychology questionnaire. I hope I was helpful in some small way.
22	I enjoyed doing the questionnaire. Can I do more?
24	Like I told the nurse at outpatients--"I couldn't begin to tell you how helpful it (doing the questionnaire) has been to me."
26	Some questions were unnecessary. There should be more specific questions relating to cancer--check-ups, feelings, treatments.
29	Come again.
30	Now I'm happy, now that you've come. You should come more often.
32	I really loved it when you breezed into the hospital room. The page about "any other problems" is irrelevant.

Appendix C-1 (cont.)

Sub.	Comments
34	I have enjoyed taking part in the research. The 6 months passed very quickly for me as I am such a busy person....Thanks for your interest in me.
36	I hope my answers will be of some help to you in your research.
38	I'm pleased to help.
39	Please visit me. There's lots of things I want to ask you--like "is it normal to feel the way I do".
40	I look forward to seeing you.
41	How long do these questionnaires go on for? I prefer to forget it and get on with life. Some friends ring up and that's all they want to talk about--it doesn't help me....But I will do it to help others
45	How good you were for me. You were wonderful, because you had been through it yourself. I don't have much time for people with questionnaires etc., who don't know what it's really like.
55	I hope you will come again.
57	This is a chalk-up for you. You are the only person I've ever let in to talk to me. Too many people ask nosey questions. (I asked why she talked to me)--I never know when I might need help myself.
58	I was talking to another patient at chemotherapy last week, and we both agreed that everyone should have someone like you to talk to. Doing the questionnaire made me look at my situation and realize I'm not the only person in this situation.

Appendix C-2

Study 1: Patients' General Comments Regarding Having Cancer

Sub.	Comments
3	I've looked at alternative methods--coffee enemas; psychologist; diet; visualization; relaxation; reflexology. (The nursing sister said that this subject found her lump seven weeks ago, but tried alternative methods first).
4	I'm afraid of going home. I have trouble getting to sleep because of depression.
7	My husband has had heart trouble and thinks psychology should look at needs for these patients.
8	(This divorced 52 year old did not see her doctor for more than 13 years after finding her breast lump, because her friend had breast cancer and was all right until the surgeon "got to her" and then within 6 months the cancer spread and she died). I don't want chemotherapy. When the doctor told me I was to have chemotherapy I got upset and I think I upset him, because I just didn't want to know about it. I have a lot of nightmares and keep waking at night and feeling scared. (She went to a naturopath for a "good diet"). I'm so unhappy I can't even go to church. I feel much worse during radiotherapy than I ever felt just after my operation. I want someone to be with me all day--just to knit and be company.
9	Why me? Why not my mother-in-law that I have to look after? I am nervous about having chemotherapy. I am very worried about losing my hair, but more worried about getting rid of cancer. It is depressing seeing others in chemotherapy. It would be better to have it by myself. I don't like to talk about cancer because I feel "why me" and cry. I would rather try to forget. I still say it was a big mistake and not really cancer. It's not fair.
12	I will probably live in fear of it recurring for the rest of my life because of the sort of person I am. Cancer was found in my lymph nodes but I haven't told my husband because it is too stressful for me.
14	I am more depressed now than before, because I see cancer patients at work (This subject is a nurse). I worry about symptoms, but I know this is irrational. Now that I need support I'm not getting it. My family don't want to know about it now.
16	Why did it happen?
17	I'd rather die than have chemotherapy. (Three months later) Chemotherapy was not as bad as I thought, but I hope I don't lose any more hair.

Sub.	Comments
24	I feel cheated--after I've looked after the others (grandchild and husband died of cancer), I don't deserve it. Hormone tablets are a constant reminder of cancer. Fear is a dreadful thing. I haven't eaten much and have lost weight. I never cry, until now; but I'm scared. Every small pain worries me. I always write a note to my son if I have a funny feeling in the night, in case I'm not here in the morning. I'm glad I didn't have to have radiotherapy. My husband had this, and I'm afraid of it.
27	I don't ask my surgeon much because I'm afraid of the answers.
28	I don't talk to my friends much about my feelings about having cancer, because I don't like them seeing me upset. I just wanted to die in my husband's arms. I have asked him to find out about euthanasia. I can't imagine things being any worse.
32	I do meditation at the Cancer Care & Resource Centre.
34	I still don't know if I had cancer.
35	I meditate at the Malvern Cancer Care Centre. I still don't like to look at my scar (at 1 month post surgery). There's no point in dwelling on things, but in my quieter moments I worry.
37	Life continues as usual and I certainly don't feel as though I have had an illness at all.
38	It seems unfair. I don't know what I've done to have this trouble. I've had a very "uncharmed" life. I can't cry but sometimes I get tearful.
39	I've put on two kilograms since my operation. I'm hooked on food.
40	I don't count my blessings—I've none to count.
41	I sometimes think of suicide, but wouldn't do it because my only daughter tried last year and is now in Glenside with a "half dead" brain. My sister has me buried and so has my husband. They know people who've died of breast cancer. I've been putting on a brave face, but I'm terrified. Who am I to survive when so many haven't?
44	I'm regretful that I ever bothered to help anyone else, because no-one cares for me now. I just gave my life away for nothing. Cancer people never really have any good luck.
48	I have a tape and Ainsley Mears' book on meditation, and do yoga. I also keep to a special diet. It's better not to talk about emotional feelings because I get too upset. I think cancer is the worst thing.
49	I want to normalize my life instantly.
50	I'm having side effects already from chemotherapy, and that's good because I know it's working.

Sub.	Comments
51	I will commit suicide if the cancer spreads. (This subject was very worried about body image, but more worried about cancer spread. Before the follow-up home visits she checked that there was nothing on either the researcher or her car that would enable people to recognise that she had anything to do with cancer. The subject referred to cancer as "c", and asked why she couldn't say "that word"). I only tell people I have a chest infection. Any other part of the body you would tell them, but I don't even tell those who have had the same thing. I don't look at it. I look up when I put on my bra. I'm "substandard" now. I look at everyone's breast--isn't that awful? Only the doctor sees me. I'm "mutilated"; "butchered"; "singled out". Are there a lot like us?
55	I believe cancer can't be cured.
57	If I have to go back with more cancer that's when I'll break. So I don't think about it. I saw people who came back with more cancer in the hospital. I don't sleep much. I try to keep busy.
58	I'm thinking about ringing the Anti-Cancer Foundation about meditation. Chemotherapy gets me down.

Appendix C-3

Study 1: Patients' Comments Regarding Support Received from Husband and Family Members

Sub.	Comments
1	My husband helped in the house and with shopping and washing, but let me do what I could myself slowly.
2	My daughter is denying it; she's angry at me; she says everyone who gets cancer dies; she won't talk to anyone--doesn't want to know.
9	My husband said 'You will be all right'.
10	My husband said 'Once this is all over we'll be back to normal--it'll all be behind us'. But when I told my sister that I had to have chemotherapy, she said that it is terrible. That upset me.
12	My husband just being there was helpful. (One month later) I have cancer in my lymph nodes. I find this very stressful but haven't even told my husband.
14	When I had kidney problems, my husband put <u>himself</u> to bed, so I don't talk to him about how I feel. My younger daughter (nurse) and my mother don't want to know.
20	My husband was helpful just by his general support and attitude.
21	This has brought the family together. They all pulled together.
24	My daughter-in-law said 'stop complaining'.
29	My husband listens carefully to me. He's never been ill and it's a shock for him. But my parents and sister are totally unsupportive. They will not discuss cancer at all.
35	As soon as they (teenage sons) see you up and about, they expect you to do things.
39	My son looked at me like I was a stranger. I cried a lot after that. It was the only time I cried. I was very disappointed.
40	My husband is a compulsive gambler. He's hard and aggressive. He says 'Don't talk about it' and tries to laugh me off.
41	My sister has me buried, and so has my husband. They know people who've died of breast cancer. I've been putting on a brave face, but I'm terrified. Who am I to survive when so many haven't?
46	My daughter said how lucky I am because it was caught early. That was good.
48	My husband and I talk more now. He makes me think positive. We do everything together. (3 months later) We don't talk so much now. I don't want to scare him, so I only say the good things.

Sub.	Comments
55	My husband is rude to me. He's terrible. My illness upsets him and then he gets mad. On the day I got back from hospital he said 'Are you going to make sandwiches for lunch?'
57	I don't want to complain because my husband gets upset.
59	When the bone scan came back clear my husband said, 'We've had our Christmas present'.

Appendix C-4

Study 1: Patients' Comments Regarding Support Received from Friends

Sub.	Comments
1	My friend phones or visits often, and brings soup or cake etc.
3	She just sat and looked upset; then she cried. (Another friend who had had radiotherapy for stomach cancer) She is very positive, and she told me to get someone to cook and shop for me and not to live alone.
4	Some of my friends said upsetting things, so I confided in a workmate who I've never confided in before. My friends shut me out. I've learnt to keep my feelings to myself, because I want to keep my dignity. My workmates are most helpful by just being there to be company and ask how I am, without interfering. One of my friends, a younger girl, said 'Don't have the breast removed'. She said that doctors don't know what they're talking about and told me just to ring them up and tell them that I won't have it done.
5	My friend sent me tapes and note on relaxation and positive thinking
6	A friend who had had a mastectomy said 'It's a bloody nuisance, but you'll get over it'. This helped me to think of it as just a nuisance value—a temporary setback.
7	A mere acquaintance (the daughter of my friend's boyfriend) just made herself available.
8	She told me to trust God. This was comforting. (6 months later) I need someone around to talk to—a friend to knit with and be with all day.
11	My boss was most helpful. He just said 'Don't worry about your job. Your health is of paramount importance.' He was also very discrete.
12	My friend visited but couldn't talk to me. She just watched television.
14	Everyone's got a medical opinion and that just craps me off.
20	I'm sick of people saying 'poor...' and worrying about me.
24	My neighbour doesn't visit much, but she is ready to help immediately I need it.
26	She said 'You're lucky because it's in a place you can get to'.
30	I don't want friends—they die. In the last 3 years I lost 23 friends from cancer or heart trouble. The lady who lives near me knows I'm in hospital but not why I'm here. I won't tell her because it will frighten her. (3 months later) I've still not told anyone except that one person. I don't tell because it frightens them.
31	My boss organized time off work for me.

Sub.	Comments
32	She has a sad, puppy-dog look. She rings my mother to see how I am, and doesn't ring me. When she came she said 'You look good after all you've been through', as though I'm already dead.
35	She talked about her friend's husband who died of cancer last year, and compared me to him. Most friends have their own problems. I want to keep it in the family and not burden anyone.
36.	My minister helped me. He said he was thinking of me and praying.
43	She said 'Now you won't have anything to scrape on the sand when we go nude body surfing'.
44.	When I asked my niece for help she said 'You didn't want to go to the nursing home to recuperate; you said you could manage; so I'm not going to manage for you'.
48	Some people want to talk about cancer and this makes me feel worse. They feel sorry for me. I wish I hadn't told anyone. They put their arms around me like I'm going to die. But Pam's not emotional. I can talk to her.
53	My sister-in-law was most helpful. She just spent time with me.
55	She said 'You're going to be loppy, aren't you', and then she said 'The lady next door didn't last long after her cancer operation'. I don't say too much anyway. I don't want people to think I'm whinging.

Appendix C-5

Study 1: Patients' Comments Regarding Support Received from Medical Practitioners

Sub.	Comments
1	He gave me explicit explanations before and after the operation, and of treatment and effects.
4	I asked the surgeon how I could get more even, and he said there's nothing I can do except get some fat off the rest of me. He 'pooh poohed' it in a way. I feel miserable, but he tried to jolly me along, and I covered up how I felt.
5	I have complete access to the surgeon. I can ring and speak to him any time of the day or night when he is at the hospital. He is very accepting.
8	The surgeon is so educated and I'm a very simple person, so I can't expect him to encourage me to talk about my feelings. He's so busy, but I would like to be asked if he had time. I would have liked to ask him some questions, but I didn't. The doctor (general practitioner--GP) doesn't talk much. He evades questions. For example, I asked why it was necessary to have radiotherapy, and he said 'it was planned like that'. He also told me there were no side effects from chemotherapy, but I got information from the nurse.
9	The surgeon cried with me and stayed all afternoon with me. He warned me that I would feel more depressed and more tired towards the end of chemotherapy. I found this very helpful to know.
11	The doctor (GP) gave me the impression that I'm wasting his time. The first time I went with the lump he said it was a swollen gland, and the second time (2 months later) he said I was over-anxious.
12	The surgeon told me my cancer can be treated with hormones if it reappears. Everything was explained to me in detail, and I felt at ease. It is much better to have a woman surgeon.
14	I appreciate his efficiency and honest reassurance. He makes me feel very secure, and has told me where to reach him at any time. He is supportive and honest. But I would like to have seen him by himself just before the operation. I feel stupid asking some things in front of the nurse.
15	Knowing he would be honest with me regardless of the questions asked, was the best thing.
16	He makes me feel wonderful, like everything's under control. But then he said, 'Have you planned your life, because if you haven't, I suggest you do'. It makes you wonder what he meant. I have three 'floating' cells.
18	My doctor told me that I was not a panic merchant when I found my lump; and the surgeon said 'We're looking at a cure'.

Sub.	Comments
22	Although the surgeon does the chemotherapy in groups, everyone's scared of him, so you can't really talk to these people, they're all scared of him. He doesn't answer my questions.
24	The surgeon said 'We can do so much now'. He was such a comfort. Some doctors may as well be vets; they just feel around and don't talk. I wouldn't have got through if it hadn't been for three lovely doctors.
27	He said he won't know until Monday if I need any further treatment, but I don't ask questions because I'm afraid of the answers.
29	I appreciate his swift action in getting the cancer out.
30	My surgeon explains everything, so I'm not frightened.
32	He is patronizing. I have to pick my time to ask questions.
34	He is quietly spoken and this makes me feel relaxed.
35	I felt rushed, but I don't blame the surgeon. He was busy because of the nurses' strike. I didn't get around to asking what I wanted to.
38	I don't need to ask; he tells me everything. It's better for him to tell me what to expect even if I don't have side effects.
39	The surgeon didn't speak to me at all. If he had more time for me, just to let me know what to expect--whether what I'm going through is normal--it would help a lot. He chatted to patients in the other room, but was abrupt with me. Post-operative advice is most important. I was more frightened after than before. Also, I was sent home too early.
40	I thought after he had examined me I would see him back in the consulting room, but I didn't. He 'side-steps' a bit.
41	The chemotherapist told me too much. I don't want to know everything. He said (regarding chemotherapy trials) it's too late for me now, but it might help someone else. I thought he had my results, but he hadn't. I refused to see him again. He intruded on my privacy: He told me I'm not going to recover. My doctor (GP) is very gentle, but I'm on the wrong track with the surgeon. He doesn't listen because he likes to do all the talking. He is abrupt and cold and I can't converse with him. I've 'wiped' him. He's not interested in me. He told me not to cry and not to insult his colleague (chemotherapist) in front of others.
44	You get more attention if you make out you're sicker than you are. If you make an effort they say you're all right. I always ask what I want to and tell the doctors what I think. I've had doctors, they're so casual. They've never cured anything yet. No doctor cares about you--it's just their job. Everything seems so vague. My notes are at the hospital, and he doesn't know anything about me at his rooms.

Sub.	Comments
48	It took my doctor (GP) 2 months to open my x-rays and look at the results. The chemotherapist says it's my choice whether to have chemotherapy or not, and I don't know what to do. (This subject was invited to take part in chemotherapy trials). My surgeon is too quiet, and I'm too scared to ask him questions, because of the answers. Also, the doctors come in a group and talk to each other about the operation, so I don't have much chance to ask questions. (At 3 months post surgery) I miss radiotherapy. I felt safe, like someone was looking after me. Now I feel on my own.
49	He lies sometimes. He didn't tell me it was malignant until I read it in the notes and questioned him.
51	I don't tell the surgeon how I feel, because I don't want to waste his time. I don't want to keep on at him about how bad I look.
55	I didn't need to tell the surgeon how I felt, because he just understands. (1 month later) The surgeon gave me 5 minutes of his time. His nurse was also very abrupt. He intimated that my physiotherapist may not know what he is doing--I think he was upset because he likes to use his own physiotherapist. I asked for pain tablets and he said 'See your doctor'. He's very rushed, but his bills keep coming in!
57	(At 1 month post surgery) The surgeon treats me as though I'm dopey. He almost reduces me to tears. He doesn't explain anything. For example I asked him why my arm feels so numb and he said 'That will resolve itself'. He was very good the way he broke the news to me initially, but now he's business-like. I'm just another patient he's got to get out of the road. He's angry with me because the tape he used on my wound affected my skin, and also my drain came out. When the nurses fixed it I asked them not to tell the surgeon because I was afraid he would tell me off. (At 3 months post surgery) I don't tell him how I feel because I'm frightened of his replies. He's not understanding. I did complain of pain in my breast because I wanted to know if everything was all right, but he just said 'Take pain-killers'.
58	He's very busy. I'm over the operation now, and don't like to worry him with my feelings.

Note. In this section the surgeon was referred to as "he", because there was only one woman surgeon in this research and therefore any comments in the feminine gender would have referred to her.

Study 1: Patients' Comments Regarding Support Received from the Volunteer Hospital Visitor

Sub.	Comments
1	I appreciated the supply of a temporary prosthesis and attaching it to my bra ready for use, and the advice on the new prosthesis I have to get.
2	The volunteer visited me at home and showed me and my husband the scars from her reconstruction. I was afraid and she gave me the confidence to see my scars. Her attitude implied that everything would be all right, as she was so positive. She's gone through it. The doctor can't tell you about the practicalities of how to live with cancer, e.g. have a bed to yourself, and get others to do the shopping. She told me I would have difficulty with some things like showering, so I knew what to expect and could start thinking about how to cope. She helped me to get practical things sorted out in advance.
3	She talked a lot about herself.
9	She didn't have chemotherapy, and so she couldn't help there. I would like to see a lady who has had chemotherapy. Also, I would like to have seen a volunteer hospital visitor before my surgery.
16	I could see how well she was. This gave me confidence that I could be the same. Also, I felt that I was not alone.
22	At the Cancer Support Group, the surgeon told me things I couldn't ask my own surgeon.
30	She wasn't much help. She hadn't had any trouble and I had, so I had to do for myself.
33	She didn't offer advice unless I asked her for it, which was appreciated.
38	She gave me the confidence that I would be OK. She had a mastectomy 20 years ago, and is the same age as me.
39	She gave me confidence.
55	She made me feel sick. I cried for the first time. She was very brash and bouncy, and said 'see how far I can stretch my hand up the wall'. She laughed when a very heavy prosthesis weighed my hand down, and said 'that happens to everyone'. I didn't think it was funny. She rambled on and on and on. I closed up and didn't let too much penetrate. I do not recommend that she visit other patients.

Appendix C-7

Study 1: Patients' Comments Regarding Hospital Staff and Conditions

Sub.	Comments
1	The chemotherapy nurse explained the side effects, and told me what diet to follow if I'm affected. She also gave me a diet book.
2	The nurse put my mind at ease. She chatted while I was waiting for results. She pointed out the indicators of good health without discounting probabilities. She is very available, and is down-to-earth, mature, and sensitive, and not 'pretty' but ordinary looking.
4	I didn't want to do the questionnaire at first, because I had trouble with the nurse, but didn't want to tell anyone.
5	The plastic surgeon works with a nurse and I can ring her whenever I'm worried. The first hospital I went to offered me no alternatives, so I came here. (She wanted an immediate reconstruction). They were abrupt.
8	The social worker saw me 2 days after my operation and wanted to know if I was upset by losing a breast. When I said 'No', she stuck out her chest and said 'I would be'.
9	Seeing others having chemotherapy is depressing. It would be better if I were by myself.
17	The tea lady cheered me up by saying 'You look so well'.
19	The social worker just said 'You've got cancer'. This gave me the impression that I haven't long to live.
22	The social worker made me feel negative. Also, she continued to talk when I asked her not to, when the children came in.
27	I did not want to go to a cancer support group as I did not want to feel I had cancer. I felt I needed someone at the hospital to answer my questions without scaring me about cancer. There was no one there. It was too clinical, with no feeling for how the patient feels.
29	The chiropractor (not from the hospital) had me in tears the morning before I came to hospital. He said 'Learn to cut down on stress and change your lifestyle, and you can fight it. You created your cancer by not having enough time for yourself. Doctors are butchers'.
30	Three nurses in blue, ready for the operation, asked me what I was going in for. I was annoyed. They said they wanted to make sure they did the right operation. Fancy not knowing what they were doing!
35	When I complained to the nurse about being kept awake, she just said 'That's hospitals'.

Sub.	Comments
39	It was great to be given a private room.
42	I was glad to have an immediate reconstruction. I dreaded waking up with a scar.
58	Another patient was depressed because her cancer had spread, and I found this the most upsetting thing.

Appendix C-8

Study 2: Patients' Reactions to the Visit

made by the BCSS Volunteer Hospital Visitor

Sub.	Comments
1	You needed a column for "not helpful" as well as "not applicable", as my visitor was just that in some areas e.g. exercising of arm, playing sport, and resuming social life. She seemed to have large psychological problems of her own. I felt she was doing this to prop herself up and would have spent the whole time talking about her problems, given a chance. I felt I had adjusted better at 2 weeks than she had at 2 years. I feel I might need another visit, but wouldn't want the same visitor again.
2	Her illness seemed to be a big priority in her life. I did not request counselling, but rather information concerning types of prostheses for bilateral requirements. This information offered was of no help whatever, and although I appreciated the volunteer's time and effort in visiting me, I can honestly say that I found the whole visit depressing.
3	I would prefer an 80 year old who had a mastectomy 20 years before, rather than a 35 year old who had had two in 10 years. My visitor had a mastectomy 10 years ago--this was reassuring. After 5 years she had a reconstruction. She showed me this, which I found interesting but premature. What I considered to be depressing and unsuitable was that my visitor had a second mastectomy a year ago--it was only a couple of days after my operation (when I saw her) and only 1 week after first finding out I had cancer. I hadn't as yet (and still haven't) come to terms with the cancer, without having the added worry of future recurrences.
7	I was most impressed by her appearance--smart, femine and normal. I was also helped by her attitude to her prosthesis. I had been feeling angry that I wouldn't be a whole person any more, that I'd have to attach something to become complete. But she had a positive attitude--the prosthesis was a part of her, though separate, and she felt the same love and care for it as for the rest of her body.
8	My visitor was very pleasant, down to earth, and very nice to talk to.
9	I found my visitor very helpful. At the time I didn't want to see anybody, even my close friends. I wanted to shut everybody out and fade away, but my visit from...opened me up to recognising that it had really happened to me and it wasn't a cruel mistake. I feel that these visits should continue as they are marvellous people to do this voluntary work helping people to adjust.
10	I found the lady who came to visit me most helpful, and since being home I have spoken to her twice on the phone. She has offered to meet me when I go to have my prosthesis fitted. I also found the lady who showed me the prostheses at the BCSS most helpful.

Sub.	Comments
11	A very pleasant lady, and very helpful.
13	I had to wait for 10 days after my operation for results from the lymph glands, and although I had asked for a BCSS visitor straight after the operation I didn't get one for about 8 days, and having little knowledge about the whole thing, I had worked myself into a bad state of anxiety by the time I saw her. I couldn't eat or sleep and wasn't recovering as fast as I should have, and was terrified, and had convinced myself I was going to die very soon, so that when I had the visitor I was not able to talk to her sensibly. I couldn't take in anything that was said to me by anyone, so I got very little help from her visit. I think if I'd seen her a week earlier it would have helped to stop me from getting into the state I was in. I think it's very important to actually talk to someone who had been through it and survived as soon as you know what is wrong, and to have support afterwards, which I will follow up. My results were negative, so I was lucky, but I still need support.
14	I found my visitor a very understanding person, and would have perhaps liked to talk to her before the operation, because she put my mind at ease. I enjoyed every minute of her visit--a very pleasant and understanding lady. I know in my mind there is still someone I can still talk to.
17	A follow-up visit would be helpful.
18	It was wonderful to talk to someone who had had the same experience. It gave me a great feeling of relief.
19	I approached the BCSS prior to surgery, on the advice of my specialist, as my apprehension was quite apparent to him. I found the lady to whom I spoke extremely helpful, kind, understanding and informative, and she had great empathy for my situation although her own surgery had been many years ago. She quickly established rapport with my husband and me, and what started as a tearful interview on my part, was completed on a very cheerful note, and I left the premises full of hope for the future. The hospital visit after surgery, from the same wonderful lady, was equally friendly, cheerful, informative and supportive, and she gave unstintingly of her time. Unsolicited promises of further help were given, even to accompany me when I go to have my prosthesis fitted. The only questions which were not answered were those I didn't ask--those which have since occurred to me. I have only the highest praise for such a bunch of unselfish, community-minded women.
21	The information the BCSS issued about prostheses and reconstruction was good. Also the insert to wear home was beneficial. But I think I was more cheerful and coping with the situation better than my visitor. She was a bit reluctant on her information regarding treatment, feelings etc., and I think perhaps she still had not come to terms with her own situation. Not enough positive attitude for me.

Sub.	Comments
23	I looked forward to a visit from the BCSS. She was exceedingly helpful and willing to devote time to me and to my questions, and to show and explain the samples, prices, and uses of prostheses she brought with her. I was very grateful for this free service, and hope it will be long continued. As far as the lady who visited me is concerned, I don't think the service could be improved.
24	I enjoyed the visit of the BCSS lady. The literature she brought me is very helpful, also the soft prosthesis made me feel normal when I had to visit my doctor etc., and is much appreciated. I can understand that a woman without the wonderful support I had from my church, husband and family would derive great benefit from these visits. In my case it was very helpful.
32	I was sceptical of a visit at first, but after seeing this hospital visitor I was extremely grateful for her help and support.
35	My BCSS hospital visitor was not only a lovely lady but a very genuine and caring person. Her practical and emotional help was invaluable. I felt she was a real friend. Her grooming was very important to me. She was dressed very, very nicely although not expensively, and I felt if I could look half as good as she did when I get out of hospital, I would be happy. Please keep up the good work.
36	Unfortunately the lady came at night during visiting, which made it a bit awkward because I had visitors.
37	I was worried the visitor would go on about losing a breast and feeling not like a woman any more. She didn't do this, which I was pleased about. I was worried about getting better, not losing a breast.
40	I feel that her visit was wonderful, and not only relaxed my fears, but helped me also with what to expect when leaving hospital. I truly feel I benefitted from her visit.
41	I appreciated the visit from the volunteer, but this came far too early for me. In my case the visit would have been more advantageous after leaving hospital, as I felt quite confused, as the result of the anaesthetic and trauma of the operation, and consequently was not really able to properly communicate with the visitor. I also don't feel that I am very upset about having a mastectomy, as my prognosis is good. Being a trained nurse may help in my attitude. However, I feel very grateful to have the BCSS to advise on prostheses and any other queries which I may have in the future.
42	I was very pleased to see my visitor. I found her very helpful.
47	The visitor I had was very helpful and cheerful and I appreciated her visit. Until I had the operation I was not aware of having a visit from the BCSS, and I am grateful for such a visit.

Sub.	Comments
54	The visitor I had was able to talk in such a way that it made me realise I wasn't on my own even though I lost my husband of 43 years last Christmas with cancer. She gave me telephone numbers to ring when I was finding things difficult to cope with, and this means a lot.
55	I found the volunteer from BCSS very helpful indeed, and could see no reason for any changes.
56	I found the visit very enlightening. I had already discussed most of these questions with my family and doctor prior to the visit, however I thoroughly recommend this service.
58	Thank you very much for your help.
59	Because I have a supportive husband and a doctor with whom I could talk, I did not need a lot of the above information. Having such loving support, I was not isolated or low and did not require cheering up. However, some items were important and the visit, information and temporary breast form were very much appreciated.
60	I still find it very difficult to go into crowds or drive my car, which is very hard to come to terms with as I was formerly a very happy outgoing free and easy person. I feel still very isolated and wish to have contact with people who are undergoing the same problems at the same time, and give each other help and strength. I have been very well bodily, but do get the dreadful anxiety attacks and doubts certain days. I have had this problem because of the dreadful chemotherapy treatments. They got me down almost to the point of suicide. I could have coped well with just the operation. I feel there must be more person-to-person help more often, such as to visit others that are going through the same problem, and help each other.
61	The lady seemed to be very understanding. Thank you.
62	My visitor was very nice and helpful. Her visit to me was virtually about prostheses.
64	It was 4 days from the time I discovered the lump until the biopsy, and then 7 days later the mastectomy. The volunteer visited me 3 days after the operation. I was still too withdrawn and shocked to really appreciate her visit, but it was the only time she was available, as she is an extremely busy lady. But later I really did appreciate her visit, and the information she gave.
65	There should be more explanation of exercises and their importance.
67	I was very thankful for the visit from the BCSS.

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