

CHAPTER 2

LITERATURE STUDY: THE PSYCHOLOGICAL IMPACT OF INITIAL BREAST CANCER AND ITS RECURRENCE

2.1 Introduction

In this chapter, studies of the emotional impact of the diagnosis of initial breast cancer on women and their partners are presented. It describes the fear of recurrence that seems to start soon after the initial diagnosis and seems to stay with patients until death, be it from cancer, an accident or any other disease.

These studies are discussed in terms of methodology used and findings. Most of these studies were done within a medical paradigm. The description of these studies is an attempt to show that there is a need for a more comprehensive multifactorial study of the psychological impact of breast cancer and its recurrence. The understanding of the emotional experience of cancer becomes even more important, as some research shows that psychological intervention may have an impact upon initiation and recurrence of breast cancer (Levenson & Bemis, 1991; Grossarth-Maticcek, Eysenck, Boyle, Heeb, Costa & Diel, 2000).

Firstly, studies dealing with the diagnosis of breast cancer and the fear about the recurrence of breast cancer are presented. Thereafter, studies describing the psychological impact of recurrence are discussed. These are followed by discussions on the possible influence of psychological predisposition on coping with cancer and the severity of a diagnosis of a first cancer versus the diagnosis of recurrent cancer.

These are succeeded by the discussion of themes that are of importance to the retention of hope and the discussion of coping with cancer. Studies dealing with the emotional impact of the news of cancer on partner relationships will follow after that. Lastly, the difficulties in doing research with patients with recurrent cancer are pointed out.

2.2 Studies referring to the diagnosis of initial breast cancer and the fear of recurrence.

Women who have been diagnosed with breast cancer often express fear that it may start again. Fallowfield and Clark (1991) described this fear as a pre-eminent worry for most women, especially during the first few years after treatment. Wong and Bramwell (1992) and Guez (1994) found that mastectomy patients experienced anxiety regarding the effectiveness of their treatment soon after they had been discharged from hospital. This fear of recurrence was not only shown by formal scientific studies, but also expressed in the media and in a particularly well written report by an English reporter, expressing the fear of recurrence vividly (Rook, 1989).

She wrote that the underlying thought that the cancer had not been totally eradicated by the treatment for the initial cancer and might recur in spite of reassurances by doctors made her feel as if:

"There's been no battle. Braver folk than I may 'take on' and 'fight' cancer, I wouldn't dare to tempt the Unseen Enemy. I accept that it and I will play Russian Roulette for the rest of my life but just hope that its pistol remains jammed. It's presumptuous to triumph over cancer. While your luck holds and you're winning, best to shut up and just enjoy it." (Rook, 1989).

These expectations of whether or not their disease will start again may have an

influence on the severity of the psychological impact of the news when it actually happens. Holland (1977) described this fear as a disquieting concern about the future. Cancer patients have to live with the disease and are uncertain of its outcome. Some women describe this fear as living with a time bomb inside their bodies; it just waits to explode again. Others are overconcerned about the healthy breast and will examine it repeatedly to check for lumps.

The fear of recurrence and uncertainty about the outcome of cancer seem to stay with these patients whatever treatment they receive. Lasry and Margolese (1992) found that fear of recurrence was independent of type of treatment received. They found that patients who underwent radical surgery did not manifest less fear than women who had breast conservation. In a review of ten studies comparing psychosocial outcome of different treatments of breast cancer, Fallowfield (1990) concluded that patients who underwent lumpectomy and radiotherapy rather than a mastectomy, had an advantage of body image, but found little difference between the treatment groups in terms of psychological morbidity. Whatever the treatment, they were still confronted with the fact that they had cancer which might recur. In spite of these convincing studies, some behavioural researchers still undertake studies with much smaller groups. For example, in a study of only three patients, it was found that the patient who had breast reconstructive surgery was more satisfied with general bodily appearance (Lo Castro & Schlebusch, 1998) which possibly influenced her general attitude towards cancer and its recurrence. The investigation of patients' perceptions of body image and satisfaction with treatment results, is however, another research issue.

It seems that fear of recurrence may be influenced by a patient's perception of the availability of social support. Northouse (1981) conducted a study to determine the relationship between the presence of significant others and fear of disease recurrence in

patients in cancer remission. A Fear of Recurrence Questionnaire was administered and a Significant Other Interview was conducted with thirty mastectomy patients whose cancer was in remission. There was a strong negative relationship between significant others and fear of recurrence. Those subjects reporting fewer significant others had higher fear of recurrence scores, whereas those subjects reporting more significant others had lower fear of recurrence scores. A strong negative relationship was also found between the number of significant others whom the subject identified as understanding her health concerns and fear of recurrence. It seemed thus that is not only the number of significant others that is important, but also whether they are empathic towards the patient's feelings about having cancer.

In another study on the fear of recurrence, Halttunen, Hietanen, Jallinoja and Lonqvist (1992) interviewed twenty-two breast cancer patients who were relapse-free and had no need for cancer-related treatment. They were interviewed 8 years after mastectomy in order to evaluate their feelings of being cured of breast cancer and the meaning of cancer in their lives. The study was part of a follow-up study of 57 breast cancer patients. Half of the available 22 patients still had frequent or occasional thoughts of recurrence and over two-thirds still thought they had not been 'cured' of cancer. More than half of the patients thought that the experience of breast cancer had made them more mature. Women who had fewer thoughts of recurrence belonged to a group that had gone through an eight-week group psychotherapy intervention, were less depressed and had more other illnesses than the group who had no psychological intervention.

Eight years after mastectomy, the relapse-free women had recovered well; they considered their state of health as good and were satisfied with their lives in general. However, in common with other studies, Halttunen found that a significant proportion of these women did not feel 'cured' and that they suspected recurrence every now and

then.

Munkres, Oberst and Hughes (1992) hypothesised that cancer recurrence may produce unique stressors for patients receiving chemotherapy. The objectives of their exploratory study were to:

- (i) describe perceptions of symptom distress, self care burden, appraisal of illness, and mood in patients undergoing chemotherapy;
- (ii) identify differences in these perceptions according to stage of illness (new versus recurrent cancer);
- (iii) test a theoretical model of the mediating effects of appraisal. They used the cognitive coping model as theoretical framework, according to which patients appraise their situation and act upon the personal meaning that they ascribe to it.

The subjects completed a modified Symptom Distress Scale, the short form of the Profile of Mood States, and a self-report form that included personal and illness characteristics and questions about the subjects' current situation. The 60 subjects were outpatients being treated for initial cancer (n=28) or recurrent cancer (n=32). Those with recurrence had higher symptom distress and health deviation self-care burden scores and more stressful appraisals. Munkres also stated that it was apparent from their clinical observations of many patients' positive attitudes following effective early treatment, that not all patients consciously anticipate a recurrence.

2.3 Comment

Although these studies that dealt with the fear of recurrence were mostly exploratory and

used small groups, they all agreed that the majority of women with an initial diagnosis of cancer were not convinced that they had been totally cured. These studies showed that many lived with the fear that their disease might recur. According to Northouse (1981), this insecure feeling that the treatment had not been adequate seemed to be at its peak when treatment had been completed (Fallowfield & Clark 1991; Wong & Bramwell, 1992), but did not necessarily subside over time. Except in the case of Northouse, who used a fear of recurrence scale, many of the findings that dealt with the issue of "fear of recurrence" were mainly based on anecdotal evidence, as described by Schmale (1976). Other observations about fear of recurrence were made during studies that had other objectives as a major theme (Spiegel & Bloom, 1989; Spiegel, 1993; Moorey & Greer, 1989).

Although the results of these studies left many research questions regarding fear of recurrence unanswered, they confirmed that the majority of women with breast cancer experience a fear of recurrence.

2.4 The psychological impact when recurrence is diagnosed

Many patients can be described as fortunate in the sense that their cancer stays in remission for years and they may die in old age or on account of some other reason. However, not all patients are so fortunate as others may experience a recurrence of their breast cancer. Studies dealing with the psychological impact of the news of recurrence are discussed in the next section. They refer to the patients' emotional reactions to such distressing news – for example, do they become more anxious and/or depressed?

2.4.1 Patient's expectations

A few studies examined how a patient's expectations about recurrence influenced their

coping abilities when they actually had to deal with the situation.

Cella, Mahon, and Donovan (1990) hypothesised that recurrence of cancer can be understood and therefore treated as a traumatic event that places patients at risk for stress response symptoms. To test this hypothesis, they administered the Impact of Event Scale (a measure of response to specific stressors), the Psychological Adjustment to Illness Scale-Self-Report version, (a measure of general adjustment to illness) to 40 patients with recurrent malignancies of mixed sites. They also conducted a semi-structured interview in which the patients were asked about their reactions to and experiences surrounding the recurrence, compared with reactions and experiences of their initial diagnosis. In self-report measures and in the interview, patients clearly perceived that adjustment to recurrence was more problematic than adjustment to initial diagnosis. They pointed out that the findings were consistent with an expectation derived from the stress-disorder literature: patients who reported having been completely surprised by the recurrence and those undergoing their first recurrence, showed significantly more intrusive and avoidance stress response symptoms. They stated that, given the heterogeneity of the patient population and the relatively limited sample size, further study was needed to assess the contribution of other important mediating factors in the development of stress disorders. They suggested that because the predictors in this study (extent of surprise and number of previous recurrences) could be identified before and immediately following a recurrence, primary and secondary interventions might help prevent stress disorders in patients who may have had unrealistic expectations.

Findings from a study of Weisman and Worden (1986) also showed that patients who expected a recurrence were not surprised and, as a result, were less distressed when it happened than were patients who felt at little or no risk of recurrence.

These researchers assessed the emotional and psychological status of 102 patients with recurrent cancer. They studied the impact of recurrence and compared it with the experience of patients when first diagnosed with the disease. Six tumour types were chosen - breast, colon, lung, Hodgkin's disease, malignant melanoma, and gynaecological tumours. They found that 30 per cent of patients with recurrent cancer found the experience less traumatic than their original diagnosis. These were patients who were less surprised by the recurrence and who did not believe that they were cured. These were also patients who, at the time of recurrence, were suffering less physical distress in terms of fewer medical symptoms, and fewer health concerns. They described these patients as less threatened by recurrence and more optimistic about the future. They also experienced fewer problems accompanying the return of their cancer. The authors stated that it was as if a realistic awareness of risk was not inconsistent with optimism and with hope for another remission.

The majority of the group (66%) was completely surprised when cancer recurred and tended to become distressed sooner than at the first diagnosis. In spite of being surprised with the diagnosis, patients with recurrence reported few psychological problems.

The authors came to the conclusion that although recurrence was clearly an ominous development, they found no research evidence that it was actually more distressing than the first diagnosis. They also concluded that recurrence patients were mainly worried about health and existential issues. Although they were distressed, the principal factor seemed to be surprise at the recurrence, rather than any specific psychosocial predisposition.

Research has been done on the following factors relating to the recurrence of breast

cancer. Psychological predisposition, the severity of a diagnosis of recurrent breast cancer, the retention of hope against anxiety and depression after a diagnosis of recurrent breast cancer, the coping strategies after such a diagnosis and the effect of such a diagnosis on locus of control are discussed in the following sections.

2.4.2 The role of psychological predisposition in dealing with the news of recurrent cancer

Jenkins, May and Hughes (1991) found that psychosocial predisposition played a role in coping with the news of recurrence. Psychological predisposition includes the personality of the patient. For example a person with a tendency towards depression may become even more depressed when told that her cancer has started again and may not be willing to undergo any further treatment. It also includes expectations about the development of the disease. One would expect that someone who never gave it a second thought that her cancer may return will be more shocked by the news than a person who knew that there is such a chance.

Jenkins, May and Hughes (1991) interviewed twenty-two individuals who suffered from local recurrence of breast cancer to determine psychosocial morbidity. Psychometric assessment included the Hamilton Anxiety Scale, the Eysenck Personality Questionnaire and the Montgomery Asberg Depression Rating Scale. This assessment was conducted prior to clinical evaluation and included a structured interview, the Composite International Diagnostic Interview. Current psychiatric diagnosis was established. Ten (45%) of the recurrence group had current psychiatric illness (anxiety and depression) at the time of local recurrence. Previous psychiatric illness and trait neuroticism were predictive of vulnerability to psychiatric morbidity at local recurrence. They concluded that their results showed that a significant proportion of patients with local recurrence suffered from major depressive illness.

They stated that results of their small study suggested that factors similar to those identified in patients initially diagnosed and treated for breast cancer were also significant in influencing psychosocial morbidity at the time of local recurrence. These factors included personality factors such as trait neuroticism, the presence of a previous psychiatric history and the presence or absence of supportive family and marital relationships. Their findings showed a higher prevalence of morbidity in their patient group and they recommended that screening and psychiatric consultation should routinely be employed to treat and alleviate the anxiety and depressive illness found in many patients.

Results from these studies showed concordance in that those patients who expected that a recurrence might occur, were less depressed when it actually happened, while those patients who were optimistic and believed that they were fully cured were more devastated by the news of recurrence. These results presented a difficult practical dilemma of the extent to which the patient should be made aware of the chances of recurrence of breast cancer.

2.4.3 Severity of a diagnosis of recurrent breast cancer versus initial cancer

Research results of the severity of the impact of the news of an initial diagnosis of breast cancer versus the severity of the effect of the news of recurrence, are contradictory. Weisman and Worden (1986) stated that they could find no evidence that the news of recurrence was more distressing than the first diagnosis. On the other hand, Cella, Mahon and Donovan (1990) and the Jenkins, May and Hughes (1991) studies showed that patients experienced the news of recurrence as being more distressing than that of a first diagnosis and many suffered from depression. These contradictory findings may be attributed to many factors, e.g. the differences in terms used by the researchers, age and population of groups and the methodology of the research. When depression is

used as measure of the effect of the news of recurrence, the studies agree that patients who received a diagnosis of recurrence were more depressed than those whose cancer was in remission.

2.4.4 The retention of hope as reaction against overwhelming anxiety and depression

In spite of the evidence that women with recurrence suffered from depression and anxiety and had existential concerns, a significant number seemed to retain hope and optimism.

Levy, Lee, Bagley and Lipman (1988) described it as: "somewhat puzzling" that a woman, who experienced recurrent breast cancer, could express feelings of being "glad", "cheerful" and "joyous". They did find, however, that some of the patients in their sample of 36 women with recurrent breast cancer reported experiencing these feelings, as measured by the Affect Balance Scale. In an effort to explain how the women could experience these positive feelings in such adverse conditions, they speculated that those items on the scale reflect hope or optimism in some dispositional sense. Bearing in mind how well some cancer patients used denial as a coping strategy; these "joyous" feelings could just as well be expressions of denial.

Munkres, Oberst, Hughes (1992) showed that although members of the recurrence group considered themselves to be more seriously ill than did members of the initial-treatment group, no differences in expectations about treatment effectiveness existed between the two groups. This suggested that those with recurrence, while having a realistic understanding of their prognosis, were able to maintain at least some hope for cure or control.

It is often difficult to distinguish this element of hope from denial when patients cling, against all odds, to unrealistic hope until right at the end. Patients' thoughts and feelings

about the implications of having experienced a recurrence of their disease can vary from moment to moment. This provides a challenge to those who attempt to study the psychological impact of the news of recurrence. New evidence suggests that the news of a diagnosis of cancer may have a physical effect on a patient's central nervous system which may have the effect of losing hope of recovery (De Brabander, Gerits, Sacre, Lamote, 1989).

2.4.5 Coping with recurrence and survival from breast cancer

Some studies on recurrence dealt with the possible influence of psychosocial factors on survival. These studies aimed to determine if psychosocial factors in conjunction with the better-known physical prognostic factors had an effect on survival.

A study by Levy, Lee, Bagley and Lipman (1988) identified predictors of survival time in patients with first recurrence of breast cancer. The predictors included psychological as well as biological factors. Beginning in 1979, 36 women were treated for histologically proven recurrent disease. These women were enrolled in a prospective study. At the time of data analysis in 1988, 24 had died from their malignancy. Four factors predicted survival time in the sample:

- i) Patients with a longer disease-free interval;
- ii) those who expressed positive feelings of being glad, cheerful and joyous at baseline testing;
- iii) women whose physicians predicted that they would live longer;
- iv) those who had fewer metastatic sites tended to live longer with recurrent disease than others in the sample ($p < 0.0001$).

The authors concluded that factors at a number of levels - behavioural, as well as biologic - needed to be considered in accounting for disease outcome variance.

Levy, Lee, Bagley and Lippman (1988), however, stated that the most important predictor of survival time for their sample of patients with recurrent breast carcinoma, was biological, namely the disease free interval. The second most potent factor was the report of positive mood.

In another study Levy, Herberman, Lipman, D'Angelo, and Lee (1991) reported further support for their earlier findings that psychosocial factors might have an influence on survival. Ninety women with recently diagnosed breast cancer were entered into a behavioural immunology protocol. When the disease outcome variable was defined as time to recurrent disease, the psychosocial factors were strongly predictive of the rate of disease progression for patients who had a recurrence. They concluded once again that immunological and psychological variables such as mood, contribute more to the great variation in outcome of early-stage breast cancer, than has been believed in the past.

Dean and Surtees (1989) interviewed one hundred and twenty-two women with primary operable cancer before and three months after mastectomy. The outcome of 121 of the women was assessed 6-8 years after operation. Those who were assessed three months after the operation as coping by using a strategy of denial, had a better chance of remaining recurrence-free than those women employing other coping strategies. They warned that this finding should be viewed with caution because of the inherent difficulties in measuring coping strategies, particularly on account of the fact that the patients were not consistent in the coping strategy they used before and after the mastectomy. They claimed however that psychological measures improved the prediction of recurrence-free survival beyond that achieved by other variables (e.g. histological node status,

tumour size and treatment).

In contrast to the above, Cassileth, Lusk, D.S. Miller, Brown, and C. Miller (1985) studied 155 breast cancer patients and came to the conclusion that psychological factors played a minor, if any, role in the survival of breast cancer. They followed up these patients to determine the time to relapse. Analysis of the data indicated that social and psychological factors did not influence the length of survival or the time to relapse. They concluded that although these factors may contribute to the initiation of morbidity, the biology of the disease appeared to predominate and to override the potential influence of life-style and psychosocial variables, once the disease process was established.

Worden (1989) found that among demographic variables, gender and socio-economic status did not predict distress levels, while age did. They hypothesised that the younger patients with recurrence would be among the most distressed, and this proved to be the case. The distress levels of younger recurrent patients were high, as were their existential concerns, and they were more likely to blame themselves for the recurrence of their disease. They found self-blame interesting in the light of current popular literature that espouses the need to take responsibility for the condition of one's health, whether good or bad.

2.4.6 Comment

Although these studies had the same objective, namely to determine whether psychological disposition had an influence on survival, they used different psychometric measurements, different types of analysis and took different predictive factors of survival into account. These differences may well account for the contrasts in outcome. In an effort to improve on research techniques, studies of this complexity are very rarely duplicated. This makes it almost impossible to confirm or dispute previous research

findings. The answer to whether or not psychological disposition has an influence on survival time in breast cancer remains elusive.

However, more recent studies such as those by Grossarth-Maticek, Eysenck, Boyle, Heeb, Costa and Diel (2000) showed that psychosocial factors might have an effect on the causation of breast cancer and its prevention.

Furthermore, most of the above research and the interpretation of their results followed a paradigm for research from a positivistic point of view. It rests on the assumption that there is causality in effects. This viewpoint may attempt to provide answers without taking into account that a specific theoretical framework influences research. For example, most of these studies did not take a patient's religion or views on death into account, as influences on coping behaviour. When talking to someone with a terminal illness or with someone, who is dying, one realises that those are very important issues. Furthermore, the research itself may become a stress factor that influences a patient's ways of coping. For example, a study about the fear of recurrence, where measurements are taken from a group of patients whose disease is in remission, may remind them even more that the cancer may start again. Such a study in itself may add to their fear that it may start again. This line of thought is revisited in the last chapter where the merits of a medical model of research in psychological investigations are discussed.

2.5 The emotional impact of the news of breast cancer on partner relationships

It seems that relatively stable and good quality marriages enhance mental health according to studies done by Hughes and Gove (1981) and Gove, Hughes and Style

(1983). It also improved adjustment to cancer according to Friedman, Baer, Nelson, Montague, Smith and Dworkin (1988). It showed an increase in survival time in cancer patients according to studies done by Goodwin, Hunt, Key and Samet (1987); Funch and Marshall (1982) and Marshall and Funch (1983). According to Manne (1999) criticism and avoidance from partners seemed to have a negative effect on patients' adjustment to cancer.

The interaction between patients and their partners thus seem to be an important aspect in coping with cancer. Living with cancer does not have an effect on the patients only; it also has an emotional effect on their partners (Fallowfield, 1995; Northouse, Laten & Reddy, 1995; Barraclough, 1994; McCorkle, Yost, Jepson, Baird, & Lusk 1993; Gotay, 1984). It may even have a physiological effect on those persons close to them, such as husbands and partners according to Baron, Cutrona, Russell, Hicklin and Lubaroff (1990).

A study by Hilton (1993) showed that a diagnosis of cancer caused disruption in marital relationships, but the emotional distress experienced by partners has not received much attention in the literature. Moorey and Greer (1989) stated that it seemed as if the patient's problems have overshadowed those of the spouse.

Compas, Worsham and Epping-Jordan (1994) confirmed that spouses reported similar levels of distress as patients at the time of diagnosis. Spouses and other family members also reported uneasiness and difficulty in communication with cancer patients in a study done by Krant and Johnston (1977).

A variety of complications in communication or sexual relationships may begin as adjustments have to be made as couples adapt to the emotional demand of living with cancer. For example Leiber, Plumb, Gerstenzang, and Holland (1976) reported that

patients and spouses of both sexes experienced an increased desire for physical closeness, but a decrease in the desire for sexual intercourse. Zarcone, Smithline, Koopman, Kraemer and Spiegel (1995) found that the majority of their patients with metastatic breast cancer and their spouses were interested in experiencing sexual pleasure, but less than a quarter of them reported experiencing sexual pleasure. Patients and their spouses may find it difficult to talk to each other about the cancer. Chaitnik, Kreitler, Rapaport and Algor (1992) found that communication between patients and spouses was good only where patients were well informed about their disease.

Those patients who reported strong family ties (Mc Corkle, 1993), and interpersonal support (Grassi, Rosti, Lasalvia and Marangolo, 1993; Ell, Mantell, Hamovitch, & Nishimoto 1989; Bloom & Spiegel, 1984; Gayle, Taylor, D. & Taylor, S.E., 1990, Zemore & Shepel, 1989) tended to adjust more positively to living with cancer. This emphasised the importance of healthy social and particularly marital relationships. When people who were emotionally close to patients reported poor psychological functioning, it was associated with patients mentioning more physical symptoms, according to a study done by Ell, Nishimoto, Mantell and Hamovitch (1988).

Schaefer, Coyne and Lazarus, (1981) also warned that a formal social relationship such as marriage, did not guarantee social support but could actually add stress to people's experience. Houts, Yasko, Kanhn, Schelzel and Marconi (1986) found that patients expressed a need for help in dealing with emotional problems. Some reported that support given to them was often inappropriate, according to Revenson, Wollman and Felton (1983). Peters-Golden (1982) found that healthy persons often misunderstood the concerns patients had. For example, patients who had a mastectomy might be more concerned with the life-threatening implications of having cancer than the fact that they

had lost a breast. Data from a study by Gayle, D. Taylor and S.E. Taylor (1990) showed that patients found emotional support to be "the most helpful" type of support they received from spouses; that they valued their spouses physical presence (just being there); and their spouses calm acceptance of the illness. Wortman (1984) found that patients who did not experience emotional support, might fear that they would be rejected and abandoned by friends and family.

Spiegel (1993) found that certain types of family interaction at home predicted how well the sick members of the family felt over time. Open discussion about the cancer and the problems it caused as well as shared problem solving had a positive effect on the emotional well being of patients and family members.

Very few studies described the effect of the news of recurrence on partner relationships. Silberfarb, Maurer and Crouthamel (1980) studied 146 breast cancer patients representing three different treatment regimens by means of a structured interview, open ended questions, and a modified Psychiatric Status Schedule. They found that the most emotionally disturbing time was the first recurrence of the breast cancer, and the most common disturbance reported was in the area of mate role functioning.

They found that it was at the recurrent stage that patients articulated most concern for "how much longer" as well as expressing apprehension about other family members and of being a burden on them both financially and physically.

Checkryn (1984) reported a descriptive correlational study about the meaning of cancer recurrence to patient and spouse and the communication they exchanged about it. Twenty-two subjects, 12 women with cancer recurrence and 10 spouses, participated in separate interviews and completed a standardised measure of marital adjustment.

Their findings indicated that cancer recurrence posed individual and family hardships. It also caused difficulties with closure, uncertainty, grief, feelings of injustice, fear, anger, a concern with coping, a concern with the impact on the family, and an absence of a communicated shared understanding between patient and spouse about the cancer recurrence. They reported that a substantial number of subjects said that they did not talk with their spouse about the recurrence. Furthermore, those who said they did talk about it, did not share their spouse's understanding of the recurrence. Nevertheless, patients attributed a significant degree of support from spousal communication. The lack of a communicated-shared understanding did not suggest dysfunction as measured by the marital adjustment scale.

It was, however, clear from previous studies such as those done by Silberfarb et al. (1980) and Hall, Fallowfield and A'Hern (1995) that the news of recurrence of cancer caused psychological morbidity in the patients and one would expect it to have a relative detrimental effect on partner relationships.

Another question, from another viewpoint, can be asked. If the recurrence of breast cancer has the effects as discussed above, do the treatments and/or complementary treatments play a role in the patient's reactions to the diagnosis of recurrent breast cancer? It is thus important to investigate the literature concerning the treatment and complementary treatment with regard to breast cancer.

2.6 Other factors influencing the experience of the recurrence of breast cancer

Researchers who investigated recurrence of cancer also found that the following factors influenced the experience of recurrence of breast cancer.

Schaefer, Coyne and Lazarus (1981) found that the availability of nurse counsellors, created an opportunity for patients to express their feelings upon learning their diagnosis. This opportunity had an influence on the coping ability of patients. Patients in units where there were no counsellors available did not cope as well as patients in those units where counsellors were available.

Schmale (1976) emphasised that it was important for the patient to know that the physician was not going to abandon them or their family, but would remain available to discuss concerns and would provide comfort during the final stages of the illness.

Silberfarb (1980) found that it was at the recurrent stage that patients articulated the most concern for "how much longer?" as well as expressing concerns about other family members and of being a burden on them both financially and physically. He recommended that routine psychiatric evaluation might be appropriate at the stage of first recurrence.

Mahon (1991) emphasised the challenge that patients who experienced a recurrence of malignancy presented to nurses. She remarked that one of these challenges was to assist patients in coping with the psychosocial impact of a recurrence of malignancy. She found that the patients clearly expressed their dependency on the nurse and although the role of medical staff was not a primary focus of their study, the subject of emotional support by medical staff often cropped up during interviews.

Munkres, Oberst and Hughes (1992) also emphasised the importance of communication with patients. She stressed that people being treated for recurrent disease needed different pre treatment educational interventions than those receiving initial treatment. Providing a reasonable set of expectations about symptoms might help patients to set more reasonable activity goals.

Checkryn (1984) pointed out the responsibility of nurses to recognise grief as a normal response to the lost "cured" status. They can assist patient and family by acknowledging their grief. In so doing, nurses can help families feel comfortable about expressing their losses and sharing their grief.

In a prospective study on the psychological impact of recurrence of breast cancer, Hall, Fallowfield and O'Hern (1995) also emphasised the importance of the communication between doctor and patient, particularly at the interview when the diagnosis of recurrence is given. They found that women with recurrence were significantly more likely to suffer from anxiety and depression after the diagnosis had been made than the comparison group. This difference was absent before diagnosis with recurrence. The importance of two way communication was further emphasised by the results of this study, that showed that psychiatric morbidity appeared to be more closely related to the interpretation that patients gave to the information given to them, than with the accuracy of the information.

2.7 Difficulties in research with recurrence patients

Previous research showed that where cancer recurred, patients seemed to be a problematic group.

Weisman and Worden (1986) reported that it was much more difficult to enlist patients whose cancer recurred for research and intervention purposes. These patients reported few psychosocial problems and wanted only to get on with the cancer treatment. Family and friends tended to discourage the patients' participation in a research program or in an intervention study. They also found that physicians who had referred newly diagnosed or extremely vulnerable patients in the past, also seemed disinclined to

suggest that their team see the patients during recurrence. The most common reason given was that nothing would be gained.

They noted that many patients whose cancer had recurred and who consented to take part in research, gave only perfunctory answers to their questions. They seemed preoccupied, even indifferent, and far less eager to admit to problems than were first-diagnosed patients. When asked to return for subsequent interviews, the recurrence patients' rate of refusal was high, exceeding that of first-diagnosis patients. In the Spiegel (1993) study, where patients were randomly assigned to two groups who would either receive psychological support in support groups or not, 18 of the 109 patients who were approached to take part in the study, refused. An additional problem with studying patients with advanced disease is that a high number of patients are impossible to follow up during the study period because many are lost because of death or are too ill to be psychologically assessed. In Spiegel's study, only 24 of the 50 patients in the experimental group survived long enough to fill in at least one follow-up questionnaire, (which was done at four-month intervals), after the commencement of the study.

Checkryn (1984) also found that it was difficult to examine patients whose cancer had recurred and their families. Their sample consisted of 22 subjects: 12 women patients and 10 spouses. The unequal number of subjects was due to the fact that two women agreed to participate, but later refused the investigator permission to approach their spouses.

Hall, Fallowfield and A'Hern (1995) who undertook a three year prospective study of breast cancer patients interviewed them at one year intervals. They also incurred the problem that many patients died before they could be interviewed. Hall suggested that, to maximise in research projects the number of patients whose cancer had recurred,

would be to conduct follow-up interviews more frequently.

One should start out with large numbers of patients whose cancer had recurred if the study requires assessment over a long period because there will be many deaths during the study period. It may also imply that the "survivors" had a better prognosis at the beginning of the study and the doctor may have told them so. This information may have softened the blow of the news of recurrence considerably. To add to these confounding factors in measuring psychological morbidity of recurrence patients, Hall also showed that there were differences in psychological morbidity, depending on the way that women interpreted the information conveyed about their prognosis.

Difficulties in research with patients whose cancer has recurred do not lie only in aspects such as the declining number of patients available for follow-up interviews but also in the availability of suitable psychological measuring instruments. The instruments used currently are mostly measurements of general anxiety and depression and do not deal with the impact of the news of recurrence directly.

These difficulties in conducting a psycho-oncological study should not deter scientists from conducting studies, but rather motivate them to find more answers to a complex phenomenon. As Schlebusch (1998) pointed out, there have been some answers to the complex relationship between health, behaviour, stress, physiological responses and immunity but much still needs to be clarified regarding cancer. These challenges in research can only be met by a multidisciplinary team, as indicated by Holland (1991) in a review of the progress in oncological research from the fifties to the nineties. The advantages of the improvement in quality of life that insight and understanding provide to the patients, far outweigh the difficulties inherent in this type of research.