

The impact of breast cancer on couple satisfaction and quality of life: a review of the literature

Full report version

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Introduction

Breast cancer is the commonest malignancy in women and comprises 18% of all female cancers (McPherson et al, 2000). The age-standardised incidence and mortality rates in UK are the highest in the world and the disease is the single commonest cause of death among women aged 40-50 (McPherson et al, 2000). Nevertheless, there have been recent improvements in outcomes, with very high proportions of women surviving past 5 years (Peto, 1998). With these gains, it is increasingly important to study the psycho-social impact of breast cancer and its treatment.

Each woman will experience a range of practical, psychological and emotional challenges as a result of her diagnosis and treatment. These include: coping with the shock of diagnosis; concerns about the future and the family; treatment side effects, such as nausea, vomiting, and fatigue; and physical changes in body appearance and functioning. The life and roles of each woman may be further changed according to her family circumstances and her occupational, employment or financial status.

In addition to the challenges associated with any major illness, “ the diagnosis of cancer is often regarded with more fear and as more of a threat than other diagnoses” (Northouse & Northouse, 1987). The cancer patient is “confronted with a web of fears, including fear of pain, recurrence, of progressive deterioration, of dependency on others and of death” (Wortman & Dunkel-Schetter, 1979).

A diagnosis of cancer also involves a high degree of uncertainty regarding its cause, best treatments and prognosis. Unlike many other illnesses, patients have little control over the progression of the disease. Patients in remission do not know whether this will continue and for how long. Survivors continue to experience the uncertainties of the illness (Mullan, 1984). Many will have to come to terms with having a progressive illness and an impending death. The literature indicates that the strongest concerns for women with early stage breast cancer relate directly to cancer as a health and life threat. They are confronted with fear and uncertainty about their own mortality. Women may start to consider a number of existential questions, for example, “What is important in my life?” and “What meaning does my life have?”(Shapiro et al, 2001).

Women with breast cancer confront additional stresses and anxieties. In western society, the female breast is seen as an important symbol of both womanhood and sexuality (Schover, 1991). Many women regard their breasts as a major part of their potential to attract or retain a partner, and surgery is perceived as having a major impact on a woman’s feelings of attractiveness and sexual desirability (Schover, 1991). Breast cancer and its treatment can change the way a woman thinks and feels about her whole body, her femininity, her self esteem and the way she behaves. The treatment of breast cancer with chemotherapy or hormonal therapy may also affect self image, fertility and libido. Loss of hair and early menopause may constitute a serious threat to a woman’s image of herself (Schover, 1991).

Along with these concerns regarding attractiveness and sexuality, women may fear that their partners will leave them or that their couple relationship may deteriorate. There is a lay belief that

many husbands desert their wives when they have breast cancer (Taylor-Brown et al, 2000). These beliefs, along with all the other concerns, may lead to increased anxiety, fears and distress in the women involved.

The focus of this literature review is the impact of breast cancer on the relationship between the patient and her partner. It mainly concerns the period shortly after diagnosis and treatment rather than any later stages that might occur, such as the time of recurrence or terminal stages. This review will focus on the evidence available concerning the following issues:

- 1) the incidence of relationship breakdown in couples after a diagnosis of breast cancer
- 2) changes in marital quality and satisfaction following diagnosis and treatment
- 3) changes in body image, sexual activity and satisfaction
- 4) predictors of couple adjustment after breast cancer - psycho-social factors
- 5) predictors of couple adjustment after breast cancer - demographic, illness and treatment factors
- 6) The role of the health professional

Method

While much research has typically explored the experience of the patient, much less has been conducted of the impact of cancer on the individual's intimate relationships and family. In this study, computer searches were made on Medline, CancerLit, PsychLit, BIDs and other appropriate searches. The following text words were used: breast cancer or breast neoplasms in combination with marriage, marital breakdown, marital satisfaction, divorce and psychosocial adjustment. Relevant journals, articles and reviews were read to identify other studies or review papers on related areas including communication issues, psychological adjustment and gender differences in coping.

Methodological issues

In undertaking any literature review, it is important to assess the quality of the studies as well as their findings. In order to assess the impact of breast cancer, changes to couples occurring specifically as a result of the diagnosis or treatment (or its effects) need to be assessed, rather than changes that may occur over time to couples without the illness. Most studies have addressed this issue by conducting pre and post assessments of adjustment and satisfaction using couples' retrospective accounts. However, retrospective accounts are notoriously biased, especially as the past may be perceived differently after a diagnosis has been made.

Comparisons between studies are sometimes made more difficult because of the differences in methodologies used. Some studies have used cross-sectional designs while others have used more longitudinal methods. Some researchers have used open ended interview methods, others have used standardised questionnaires which have been tested for reliability and validity and have published norms, while others have developed questionnaires specifically for the study.

The way the information is collected is likely to be of considerable importance. Many studies have used questionnaires which may be rather brief and there is some evidence to suggest that women find it difficult to be negative about their partner and admit to difficulties (Pistrang & Barker, 1995), possibly because this is seen as disloyal. Women are therefore probably much less likely to admit to problems on a questionnaire (especially a simplified one with few specific questions) than in an interview. One to one interviews with an empathetic interviewer may elicit much franker responses from women about their intimate relationships.

Another difficulty with comparing studies is that there is no agreement on how to define and measure marital or sexual adjustment. Some studies assess couple relationship satisfaction, while others try to assess the quality of the relationship including measures such as degree of communication, amount of friction, number of arguments or degree of cohesiveness. Studies of changes in sexual adjustment have also used a range of measures including estimates of sexual satisfaction, frequency of sexual intercourse, changes in desire, arousal or orgasm.

There is also the issue of when the follow up assessments are taken. Most studies have concentrated on the period shortly after the diagnosis rather than longer term follow up. More studies need to be undertaken to consider the impact of the illness at various stages including diagnosis, post surgery or post treatment, recurrence or at the terminal stage of the disease (O'Maloney & Carroll, 1997). Clinicians and researchers have generally identified two stages in the process of marital adaptation to the illness, first the crisis phase and second, the phase of adaptation and incorporation (Giaquinta, 1977; Northouse, 1984). In the crisis stage, couples are faced with the shock of the diagnosis and associated feelings of despair and helplessness (Giaquinta, 1977). During the adaptation phase, the couple must cope with the immediate and long term consequences of the illness, including practical issues and changes in roles, as well as the emotional reactions of fear and uncertainty (Northouse, 1981; 1984). However, this two stage model is likely to be an over-simplification of the process and there may be considerable variation between couples on how they react over time.

Another important point to remember is that most studies have concentrated on couples who are married rather than those in relationships. Many studies are unclear or do not state whether cohabiting couples are included or not (Dorval et al, 1999). However, there is generally less data available on relationship breakdown or the quality of the relationship in couples who are cohabiting but not married. There are also no studies that have compared married couples with those who are living together but unmarried.

1) Incidence of relationship breakdown after diagnosis and treatment for breast cancer

Many relationships will break down over time even in the absence of serious external stresses while others do not survive a stressful event such as redundancy, bankruptcy or difficulties with the children or extended family. The purpose of this literature review is to assess the impact on the couple relationship of the particular stress involved with the diagnosis and treatment of breast cancer. The most appropriate way of testing whether breast cancer leads to a greater incidence of relationship breakdown is to compare couples with a diagnosis of breast cancer with similarly

matched couples that have not. In this way, the impact of the specific stress of breast cancer can be assessed. While many studies have investigated marital quality, only one study was identified that specifically examined whether women with breast cancer experienced an excess of marital breakdown compared with similar women who have not had the disease (Dorval et al, 1999).

The study by Dorval investigated the incidence of marital breakdown among two cohorts of breast cancer patients who had recently received a diagnosis of breast cancer. In the 1984 cohort, they repeatedly interviewed 224 women with a new diagnosis of non-metastatic breast cancer. These interviews were carried out three months, 18 months and eight years post diagnosis. In the second cohort, taking place between 1990 and 1992, 282 women were interviewed two weeks, three months and 12 months post diagnosis.

Dorval and colleagues compared these two cohorts with age matched population based control subjects who were recruited through random digit dialing and from participants in the Quebec health surveys for 1987 and 1992. These women were from the same residential areas as the breast cancer cohorts. Four control groups of over 6,000 women were used.

The women were asked whether they had experienced a marital breakdown including divorce and separation in the previous 12 months period prior to the assessment. For the 8 year survivors and control subjects selected by random-digit dialing, the women were asked if they had experienced divorce or separation in the previous five years.

In all cohorts of patients with breast cancer and corresponding control groups, divorce or separation in the last 12 months were relatively infrequent events, varying from between 1.6% and 5.5% (see table 1). At none of the time periods assessed was marital breakdown higher in women with breast cancer than in the control subjects taken from the general population.

Table 1 Percentage of each cohort divorced or separated (Dorval et al, 1999)

Time between treatment/ interview	% of patient cohort	% of Random digit dialing control cohort	% of 1987 Quebec Health Survey cohort	% of 1992 Quebec Health Survey cohort
12 months (1990-1992 cohort- 12 months outcome)	3.8 (6/158)	-	-	5.2 (148/2866)
18 months (1984 cohort- 12 months outcome)	1.6 (2/128)	-	5.5 (137/2507)	-
8 years (1984 cohort- 12 months outcome)	3.9 (3/76)	4.8 (8/165)	-	4.9 (112/2285)
8 years (1984 cohort- 5 year outcome)	10.0 (8/80)	11.5 (20/174)	-	-

This study only assessed women with breast cancer after the event and therefore does not have any records of pre-existing marital difficulties. However, they found that when marital breakdown did occur, it was mainly among the small proportion of breast cancer patients who initially reported low marital satisfaction within the first three months of diagnosis. However, marital satisfaction at this point was assessed by a single question.

While a number of other studies in this area have focused on quality of relationships, few have either measured or reported on changes in marital status over the time period of the study. Nevertheless, studies that have been conducted with a longitudinal focus have reported few marital breakdowns (Northouse, 1989; Ganz et al, 1996; Maunsell et al, 1996). However, the numbers living apart may be underestimates, as couples who fail to be followed up in later assessment are more likely to be separated. Couples who separate or divorce are much less likely to be traced as well as less likely to agree to take part in follow up assessments.

2) Changes in marital quality and satisfaction in the various phases following diagnosis and treatment

Marital satisfaction

Most studies conducted have suggested that marital satisfaction in couples with breast cancer does not differ significantly from couples from “normal” populations. The few studies that have compared levels of marital satisfaction with the general population have found that levels of marital satisfaction in couples with breast cancer one to two years following the initial diagnosis and treatment are generally equal to or above the levels of marital satisfaction in the normal population (Lichtman et al, 1987; Baider & De-Nour, 1988a; Ptacek et al, 1994; Ganz et al, 1998).

Other studies have not compared couples with breast cancer with those without illness but have relied on retrospective accounts, measuring satisfaction pre and post diagnosis. These studies have found that satisfaction had either remained the same or improved after the diagnosis (Morris et al, 1977; Wellisch et al, 1978; Lewis & Hammond, 1992; Maunsell et al, 1996). However, as mentioned before, retrospective accounts can be unreliable. It is also possible that more subtle changes are not revealed when questionnaires are used or that couples find it difficult to disclose the problems they are experiencing.

Dorval and colleagues’s study (1999) is an example of an investigation comparing the couple relationships of women with breast cancer with those of women without the disease. They found that levels of marital satisfaction were generally similar in both survivors and couples without the disease. The percentage of women reporting dissatisfaction with their current marital relationship over time was quite low in both populations, ranging from between 7.1% and 14.3%. This was generally similar in survivors and control subjects. The largest difference was 18 months after the initial treatment for breast cancer where patients more frequently reported low marital satisfaction than controls (14.3% compared with 7.8% in the controls). However at eight years post treatment, the proportion of patients reporting dissatisfaction was higher (10.8%) than the control group

selected by random digit dialing (7.1%) but lower than the control subjects from the 1992 Quebec Health survey (11.6%).

It must be remembered, however, that these figures relate just to perception of marital satisfaction and were obtained by using one question only to assess marital satisfaction or degree of happiness (Dorval et al, 1999) and by classifying the responses into either a positive or negative category. However, high correlations were found between the responses to this one question and the Locke-Wallace Marital Adjustment Test which was used among the eight year survivors of the 1984 cohort, all interviews for the 1990-1992 cohort and the controls selected by random-digit dialing.

Table 2 Percentage of each cohort expressing low marital satisfaction when interviewed (Dorval et al, 1999)

Between treatment/ interview	% of patient cohort	% of Random digit dialing control cohort	% of 1987 Quebec Health Survey cohort	% of 1992 Quebec Health Survey cohort
12 months (1990-1992 cohort)	10.5 (16/152)	-	-	13.0 (354/2715)
18 months (1984 cohort)	14.3 (18/126)	-	7.8 (213/2741)	-
8 years (1984 cohort)	10.8 (8/74)	7.1 (11/156)	-	11.6 (254/2187)

Another way of investigating the impact of breast cancer is to compare the adjustment of couples with breast cancer with the adjustment of couples with benign breast disease. In Northouse and colleagues's study (1998), 73 couples with benign disease were compared with 58 couples with malignant breast disease and information was collected at the time of diagnosis, at 60 days and at one year.

As can be seen from table 3, Northouse and colleagues found that couples facing breast cancer reported greater decreases in their marital satisfaction (as measured by the Dyadic Adjustment Scale- lower scores indicating less satisfaction), more emotional distress (measured by the BSI- higher scores indicating more distress) and more role adjustment problems (measured by the Psychosocial role problems scale – higher scores indicating more problems) than those with benign disease. However, these differences in marital satisfaction were not large (table 3). In addition, their marital satisfaction scores at each assessment did not differ from the norm for well adjusted couples for the scale (Spanier, 1989 M=114.8; SD= 17.8), suggesting that marital satisfaction is not markedly reduced.

In addition to breast cancer, other published papers have reviewed the published literature on cancer and the marital relationship. Manne found that while a small proportion of couples did experience adjustment difficulties, the diagnosis of cancer did not appear to be associated with a decline in the quality of the relationship in most couples (1998).

Table 3. Marital satisfaction, social support, emotional distress and role problems by time, health status and whether patient (F) or partner (M) (Northouse et al, 1998)

	Baseline				60 days				One year			
	Malignant		Benign		Malignant		Benign		Malignant		Benign	
	F	M	F	M	F	M	F	M	F	M	F	M
Marital												
Mean	117	118	117	117	116	118	116	116	113	115	116	117
S.D	14	13	15	14	14	12	14	14	16	16	14	14
Support												
Mean	100	98	99	93	96	83	87	87	94	93	96	94
S.D	12	11	10	9	14	18	21	11	15	11	12	13
Distress												
Mean	0.6	0.4	0.3	0.3	0.6	0.4	0.3	0.3	0.6	0.4	0.3	0.3
S.D	0.4	0.3	0.4	0.4	0.4	0.4	0.3	0.4	0.5	0.3	0.3	0.4
Role Problems												
Mean	24	21	14	16	25	21	9	12	25	20	9	11
S.D	14	12	10	10	15	12	6	7	19	14	7	7

Quality of the relationship and variations in outcome

While there is little evidence of an overall general reduction in relationship satisfaction among couples with breast cancer, this may hide changes that do occur. First, there may be changes occurring in the relationship (for example, increases in marital conflict and decreases in quality) that are not reflected in the measurements of marital satisfaction. Secondly, the overall figures may hide variation between couples. While overall satisfaction may remain the same, there may be some couples who perceive an improvement in marital satisfaction while others perceive a deterioration. The evidence of more qualitative studies suggests that both explanations may be true. Reported marital satisfaction may remain the same although marital conflict may have increased. Secondly, there is considerable variation between couples.

Increased strain or conflict

The results of a number of studies suggest that many couples with breast cancer report more conflict and strain (Wellisch, 1985; Lichtman et al, 1987; Baider & De-Nour, 1988a). Strained communication was a common problem in Lichtman and colleagues’s study, particularly when the patient felt that her fears were discounted by those close to her, especially her spouse.

In addition, studies suggest that troubled communication and disagreements were common even in couples who report high marital satisfaction (Lichtman et al, 1987; Carter & Carter, 1993). In the 1990-2 cohort of Dorval (1999), about 15% of women who rated themselves as being in satisfying relationships had still mentioned emotional problems with their spouse at some time during the year after initial treatment to the social worker involved.

One source of difficulty and conflict is that couples may have to learn to redistribute pre-morbid roles and responsibilities. Rolland (1994) suggests that a serious illness places many demands and there may be difficulties if the spouse has to take on role functions previously performed by the patient as well as carry on with their own.

Apart from practical roles, emotional roles may change following breast cancer. Women traditionally tend to be more nurturing, putting the family needs before their own. This may change after a diagnosis: women may become more self absorbed and have less time to give to the family (Lewis et al, 1985). Their partners may need to take on more of the emotional roles within the family, causing role confusion and conflict. This may be especially difficult for those who naturally do not show their feelings or who assume the role of protector rather than confidant (O'Maloney & Carroll, 1997). However, families with older children may find it easier to adjust and reallocate roles (Vess et al, 1985 a and b) as well as more families with more flexibility who can tolerate role change (Vess et al, 1985a and b).

A few studies have begun to document the problematic interactions that may occur within the couple relationship when one member is seriously ill. Some partners may be overprotective (Coyne et al, 1990), critical (Manne & Zautra, 1989), they may minimise or maximise the impact of the illness (Lehman & Hemphill, 1990) or withdraw from talking openly about it (Lichtman et al, 1987; Vess et al, 1988). Partners have their own feelings of distress as well as anxieties over the threat of cancer. They may find it difficult to separate out their own psychological needs from those of the patient and this can sometimes result in unhelpful behaviours such as criticism and withdrawal (Coyne et al, 1990).

These reactions will be considered in more detail later.

Post-traumatic growth

A number of clinicians and researchers have suggested that the diagnosis of cancer does not always lead to negative outcomes in quality of life. The experience of cancer may have a number of positive outcomes for the individual and their partner including an increased recognition of the importance of their relationship. This has been labeled post-traumatic growth: individuals and couples developing an increased appreciation of their life and relationships following a life-threatening event (Cordova & Andrykowski, 1999). Indeed, the evidence suggests that many couples report that they have become closer after surviving the diagnosis and treatment of breast cancer. This increased closeness is more likely to happen to couples in originally strong relationships, while those in weaker relationships may experience more difficulties and a decline in satisfaction and quality (O'Mahoney & Carroll, 1997).

The results of other studies, including those using open ended interviews rather than questionnaires, suggest that many couples experience increased closeness and satisfaction post illness. In the studies of Carter and Carter (1993) and Lichtman and Taylor (1986), some of the couples considered that their relationship had been strengthened by surviving the experience of breast cancer and that there had been increased emotional closeness and improved communication. In Ganz and colleagues's study (1996), 59 women were interviewed two or three years post treatment. Women were asked whether having had breast cancer had changed their priorities in life, their plans for the future, their views about themselves or the world that they live in. About 80% felt that some good things had happened in their lives as a result of the cancer and many cited examples such as closer family relationships as well as a new appreciation and a positive outlook on life. Weiss (2004) also found that the majority of husbands (88%) reported positive changes such as enhanced interpersonal relationships and a greater appreciation of life following their wife's breast cancer.

In Lichtman and colleagues' study of 78 breast cancer patients and their partners, husband and wives typically reported that their marital satisfaction had remained the same or improved following the breast cancer (1987). As one patient said "If anything, our relationship is better than it was before, which must sound strange. It's just that I've known some couples who fell apart, but we pulled together". Couples were often able to better recognise the importance of their relationship with their partner for their emotional well-being and its centrality in their lives.

Another similar term for closeness is "cohesion" which has been defined as the degree of emotional bonding and closeness experienced (Olson, 1986). Several studies have found considerably increased levels of cohesion and closeness in couples following a diagnosis and these have lasted throughout recovery (Friedman et al, 1988; Hannum et al, 1991; Zahlis & Shands, 1991; Carter and Carter, 1993; Carter & Carter, 1994; Ptacek et al, 1994; Northouse et al, 1995; Hoskins, 1995; O'Mahoney, 1997).

This increase in closeness following a traumatic event may facilitate the couple to develop a combined coping response to the illness, thus leading to a better adjustment. Alternatively, it may be that the way that the couple has coped together in adversity that has enabled a greater cohesion and closeness.

Length of time to adjust

There is some disagreement according to how long it takes to recover and adjust after the diagnosis and treatment. Some investigators consider that the crisis resolves within the first year following surgery (Krouse & Krouse, 1981; Hannum et al, 1991) while others consider it can take between two to three years (Baider & De-Nour, 1984; 1988a; Northouse, 1989).

Most studies report that emotional distress reduces over time and daily ability to function increases. A study by Lichtman and colleagues followed up 78 women and 47 husbands/partners and time since surgery ranged from two to five years (1987). Most people had seen an improvement in marital satisfaction since diagnosis and treatment. Collins and colleagues (1990) interviewed 55 cancer patients within five years of their initial diagnosis or cancer recurrence and commonly found reports of significant positive changes in personal relationships, views of self and life priorities. However, Ganz and colleagues's study found no differences in adjustment between the assessment

conducted one year after surgery from those conducted two and three years after surgery (1996). They concluded that breast cancer patients attain maximum recovery after one year.

The results of this study indicate the need to carry out more longitudinal studies of adjustment over time. Couples may vary not only according to how much they are affected but also according to when these changes occur. For some couples, difficulties may occur immediately post diagnosis and surgery and diminish over time; while others may find that difficulties arise at a later stage after the initial crisis is over.

Recurrence

In general, the diagnosis of recurrence of disease has been shown to impact negatively on the marital and other relationships (Lewis & Deal, 1995). Gotay compared problems reported by early stage cancer patients and their partners and those at advanced stages and the latter reported significantly more problems (1984). Given and Given (1992) also found that the caregivers of patients with recurrent disease were especially vulnerable to the impact of illness and reported more depression than caregivers of newly diagnosed patients with breast cancer. The literature suggests that recurrent phase of cancer can be a very stressful time for both patients and their family members.

Families may react very differently to each other. In some, the women may feel let down by their partner failing to appreciate the devastating impact of the disease progression (Mahon et al, 1990). In others, family members may be even more distressed than the women themselves (Given & Given, 1992). The situation may be made worse by family members avoiding any discussion about the recurrence of the disease or the possibilities of dying because this is so painful. They often do not know what to say or how to say it.

Overall

While there is no strong evidence of an increase in marital breakup or a substantial decrease in satisfaction, there is evidence of more conflict and strain. The research findings suggest that there is considerable variation among couples on how they react to the diagnosis and treatment effects of breast cancer. Some of the reasons for these individual differences will be discussed in more detail later.

3) Changes in body image, sexual activity and satisfaction

Methodological issues and classification

As with marital satisfaction, it is often difficult to separate out changes in sexual functioning, desire or activity that occur in most couples over time from those that arise as a result of the diagnosis of the illness or its treatment. Changes in sexual desire and sexual activity normally occur with increasing age or during the course of a couple relationship. In addition, sexual activity and functioning are closely associated with the quality of the relationship; a deterioration in the couple relationship is likely to have an impact on sexual functioning, as well as vice versa.

Sexual difficulties are normally classified according to whether they relate to desire, arousal or orgasm. First, individuals or their partners vary in the intensity of their feelings of desire or frequency of these feelings, while some people might feel strongly disinclined or aversive to sex. The second area is arousal. A woman with a diagnosis of breast cancer (or their partner) may not experience the same feelings of excitement/arousal or their body may not be so easily aroused. The third area relates to difficulties with orgasm: women may not be able to experience an orgasm or experience it less frequently or with less intensity and their partners may be similarly affected. Other difficulties include painful intercourse or impotence in the partner.

One of the difficulties involved with comparing the results of different studies is that a number of different measures are used, some of which are crude and untested. Some investigators have used untested self report questionnaires that they have developed specifically for the study (Barni & Mondin, 1997). Others have used more established measures which have been tested for reliability and validity as well as having published norms. One commonly used measure is the CARES, a quality of life instrument that includes an eight item subscale measuring sexual interest and sexual dysfunction (Schag et al, 1983).

Comparison groups are especially important as healthy women may also experience sexual difficulties and dysfunction. Some studies have compared the responses of breast cancer survivors to published data on comparable populations. The most common method of assessing change is to ask the women (and sometimes their partners) to provide retrospective ratings of their sexual functioning prior to diagnosis but this can be unreliable. However, not all studies have taken into account pre-cancer functioning.

Prevalence of sexual problems in breast cancer survivors

Studies have generally found evidence of sexual dysfunction post diagnosis or post treatment but a wide range of prevalent rates have been reported. Decreased sexual interest, reduced frequency of intercourse, and difficulties with orgasm, have been found in 21-39% of breast cancer patients (Morris et al, 1977; Jamison et al, 1978; Maguire, 1981; Anderson & Jochimsen, 1985). However, rates range from 15% for reduced physiological arousal (Schover et al, 1995) to 64% for reduced sexual desire (Barni & Mondin, 1997). The variability can in part be due to what is being measured and how it is measured. It also depends on the timing of the assessment (how many months or year post treatment); the demographic and medical characteristics of the patients studied; and the type of treatment for breast cancer received.

Barni and Mondin (1997) administered a questionnaire (designed by themselves) about pre and post sexual functioning to 50 breast cancer survivors. These were women aged between 20- 65, who have had surgery for breast cancer at least 12 months previously and were currently disease-free. The median age for the group was 48 (ranging from 38-63); 98% were married or in a partnered relationship and 96% were sexually active at the time of assessment. Nearly sixty percent of the women had had a mastectomy and 42% had had a lumpectomy. After the surgery, 88% were treated with chemotherapy; 46% with radiotherapy; and 4% with hormone therapy. Prior to treatment, 64% of the participants judged their sex life to be good, 30% judged it to be fair and 6% judged it to be poor. This reduced post treatment to only 28% judging it to be good, 48% fair, and 24% poor.

This study found that 96% of participants had one or more sexual problems. These included absence of sexual desire (48%), reduced sexual desire (64%), inability to reach an orgasm (44%) lubrication difficulties (42%), and painful intercourse (38%). Problems were therefore occurring at all stages of sexual activity, including desire, arousal, and orgasmic stages.

These problems can relate to physical changes (including the physiological side effects of cancer treatments); psychological factors such as change in body image, low self esteem, depression and anxiety; or changes in relationship quality. How the person regards themselves after the cancer diagnosis and treatment may have an impact on their level of interest in sex and their ability to allow themselves to enjoy sex. Women may experience fears about loss of desirability and sexual attractiveness (Lichtman et al, 1987; Schain, 1988; Schover, 1991; Schultz et al, 1992). These fears may result in sexual avoidance (Schain, 1988; Rolland, 1994).

There may also be a change in the partner's attitude due to a wide range of reasons, worries and concerns. This may bring about a decrease in interest in the partner, a decreased ability to respond sexually, or fears about initiating sex. The husband may react adversely to the scars of treatment and this can have an impact on both his and his partner's future responses (Wellisch et al, 1978; Meyerowitz et al, 1983).

Loss of sexual desire is a common symptom of depression and anxiety and can therefore result in sexual dysfunction for both partners (Anderson, 1986; Schover & Johnson, 1988). Depression, anger and fear during treatment may also contribute to a lack of interest in intimacy (Dean et al, 1983). Psychological factors may increase performance anxiety in the partner (Kaplan, 1992). Premorbid sexual problems are also important predictors and researchers and clinicians suggest that the sooner couples resume sexual activity, the fewer problems will be encountered (Wellisch et al, 1978; Schain, 1988;).

Relationship conflict can also manifest in sexual dysfunction (and vice versa). There is an increased risk for sexual difficulties in those with problematic relationships, especially those with communication difficulties who avoid disclosure or showing their feelings (Sabo et al, 1986; Lichtman et al, 1987). These problems in communication may increase the emotional intimacy between partners which may result in less sexual intimacy (Kaplan, 1992; Rolland, 1994).

A number of studies have compared adjustment in couples with breast cancer with changes in healthy couples or those with other types of conditions. They have generally found mixed results. Two studies compared women treated with mastectomy with women with benign breast disease, with women with cholecystectomy, and with women without health problems (Psychological Aspects of Cancer Study Group, 1987; Vinokur et al, 1989). In both studies, the women treated for breast cancer did not have an increased rate of psychological maladjustment or a decreased frequency of sexual activity compared with the other groups. Another study compared women post-mastectomy (who were undergoing chemotherapy when interviewed) with matched groups of healthy women as well as patients who had treated for gynaecological cancer (Andersen & Jochimsen, 1985). The women post-mastectomy had sex less often and felt less subjective excitement than healthy women but their orgasmic capacity and sexual practices were not affected. They had a very similar incidence to the women who had been treated for gynaecological cancer.

Ganz and colleagues interviewed 139 breast cancer survivors one year post primary treatment and then by post two and three years post surgery (Ganz et al, 1996). They compared the breast cancer survivors with the outcomes of patients with chronic medical conditions. While breast cancer survivors had relatively good physical and emotional functioning according to health status and quality of life compared with the other groups, they frequently mentioned problems with body image, sexual interest, and sexual functioning.

Schover has hypothesised that the increase in sexual problems in women with cancer may have been mainly in a vulnerable subgroup with pre-existing problems in their relationships, prior sexual difficulties or poor psychological adjustment (Jamison et al, 1978; Schover et al, 1987; Schover et al, 1989). He suggested that sexual dysfunction or dissatisfaction is not an inevitable consequence of breast cancer and that other factors such as pre-existing difficulties may be far stronger predictors of post-cancer sexual adjustment than the extent of surgery done to the breast (Schover, 1991).

Schover (1991) and Ganz and colleagues (1996) also suggest that chemotherapy or hormonal therapy used in conjunction to the operation may be more likely to bring about sexual dysfunction than the actual surgery itself. These therapies are likely to bring about a premature menopause and physiological changes. These issues will be considered later when the different treatments for breast cancer are compared.

4) Predictors of couple adjustment after breast cancer - psycho-social factors

Quality of pre-morbid relationship and ambivalent reaction in the partner

There is strong evidence that the quality of the pre-morbid relationship is the strongest predictor of relationship quality and satisfaction post diagnosis (Worden & Weisman, 1977; Wellisch et al, 1978; Lichtman et al, 1987), although this has been usually gathered by retrospective accounts. Thus couples who report greater satisfaction pre diagnosis are much more likely to report a similarly high level after the illness (Worden & Weisman, 1977; Wellisch et al, 1978; Lichtman et al, 1987)

Studies that have not used retrospective accounts have compared the quality of the relationship at diagnosis with the quality of relationship at later stages. However, this is problematic as it may not reflect the relationship prior to the onset of illness. The study by Dorval and colleagues (1999) found that when marital breakdown did occur, it was mainly among the small proportion of breast cancer patients who initially reported low marital satisfaction within the first three months of diagnosis.

Northouse and colleagues's study also found strong evidence of couples at risk(1988). Those that were experiencing distress and role problems shortly after diagnosis were more likely to be still experiencing them later. In this study, they divided the couples in the malignant disease group into four groups: those who both experienced high distress; those who both experienced low distress; those where the wife experienced high and the husband low; and vice versa (see table 4). Over half of the couples in the high distress group at the time of diagnosis were still in this group at 60 days and 50% remained in this group one year later. They also investigated role problems at diagnosis

and later. Sixty one percent of the couples with a high number of role problems at diagnosis were still in this group at 60 days and 56% were in this group at one year (table 4).

Table 4 Stability of adjustment from diagnosis to one year (Northouse et al, 1988)

Time period		Low distress/ role problems (both)	High distress/ role problems (patient only)	High distress/ role problems (partner only)	High distress/ role problems (both)
Emotional distress					
Diagnosis to 60 days	No	8	6	5	10
	%*	47	50	46	56
Diagnosis to one year	No	10	5	6	9
	%	59	42	55	50
60 days to one year	No	8	5	8	10
	%	50	36	62	67
Role problems					
Diagnosis to 60 days	No	13	4	5	11
	%	68	40	46	61
Diagnosis to one year	No	12	5	5	10
	%	63	50	46	56
60 days to one year	No	15	4	6	15
	%	71	50	60	79

* percentage of couples in category at earlier time who remain in that category at the later time.

Findings of research studies show that as with other types of stressful situations or transitions, the diagnosis and treatment of breast cancer, can exacerbate pre-existing problems (Silberfarb, 1978). Any change in a family system may disrupt established patterns of equilibrium and support within the family (Hilton, 1996). There will be a need to re-negotiate family roles and relationships which may bring about conflict. Couples with more rigid and inflexible relationship patterns may also have more difficulties adjusting to illness and adapting to the new roles that may be necessary (Carter & Carter, 1993; Rolland, 1994). In addition, those in good relationships are more likely to confide in their partner and report more support and involvement from their partners than those in initially poorer relationships (Worden & Weisman, 1977; Wellisch et al, 1978; Lichtman et al, 1987).

Cancer can create a number of conflicting reactions in significant others; for example, feelings of fear and aversion to cancer or the belief that it is important to maintain a cheerful optimism (Wortman & Dunkel-Schetter, 1979). Peters- Golden (1982) compared the perception of 100 breast cancer patients with 100 disease free individuals. He found that 61% of healthy individuals said that they might avoid cancer patients while 52% of cancer patients said that others avoided them. Patients indicated that often when interactions did occur, the others tried to cheer them up and be

positive. This forced cheerfulness made them feel less normal and made it very difficult for patients to disclose their true feelings.

Partners may also feel ambivalent feelings, they may be fearful of the future and how they will cope if the patient becomes increasing ill or dies. This conflict may lead the partner to start withdrawing from his partner, avoiding any intimacy, open communication about the illness, or show of affection. They may also exhibit ambivalent feelings including positive verbal and negative non-verbal behaviour. This ambivalence can lead the patient to feel confused, rejected, unloved or abandoned (Weisman & Worden, 1976; Wellisch et al, 1978; Wortman & Dunkel-Schetter, 1979; Peters- Golden, 1982).

Although the evidence suggests that the majority of couples who split up post breast cancer will have had pre-existing problems, it is still possible that there are a small proportion of couples who break up who do not have apparent pre-existing difficulties. This may be because the partners cannot cope with the uncertainty and distress of living with a life threatening disease or subsequent problems that might arise. Lichtman and colleagues interviewed 78 breast cancer patients and their significant others. Although responses of isolation, rejection, withdrawal or blame were infrequent, they do cite an example of one woman interviewed who described the following response by her husband:

“ He said that he loved me so much that the thought of my dying was more than he could bear, and so the only thing he could do was to leave me. To me, it is almost incomprehensible that someone could treat a person like that if they really loved them. I think he withdrew from me emotionally, and I have a lot of bitterness.”

(Lichtman et al, 1987)

No other details of this woman were given in the paper and it is therefore possible that there might have been a number of pre-existing difficulties (that the woman might or might not have known about).

In general, there is little information on these partner reactions in the research literature, case studies and accounts from clinicians may provide alternative resources to take this investigation further.

Psychological distress

Another important predictor of couple adjustment after breast cancer may be the degree of psychological distress experienced by either the patient or their partner as well as its chronicity. A partner may be able to cope with short term distress but continued difficulties may bring about an increased detachment in order to cope with the situation. There is some evidence to support this. One study of 89 women over a two year period found that while social support from others reduced psychological symptoms in the patient, there was even greater evidence that psychological symptoms reduced social support (Simpson et al, 2002). Brady and Helgeson (1991) found that psychosocial distress in women with breast cancer predicted a decrease in partner emotional support over a six month period. Bolger found that spouses increased the level of support they gave when their wife's physical symptoms increased, but decreased their level of support in response to

increased psychological and emotional distress (Bolger et al, 1996). Weissman and Worden found that patients who react adversely to the diagnosis may alienate their partners or those that are closest to them (Weisman & Worden, 1976). This prolonged psychological distress may not always be limited to the patient, as the partner may also react adversely including maladaptive physical and psychological reactions and this may also have an effect on the relationship (Wellisch et al, 1978).

Not all individuals react adversely to the diagnosis. It has been estimated that between half to two thirds of those diagnosed with breast cancer handle it well psychologically (Spiegel, 1996). However, research suggests that between 20-40% of women experience significant psychological distress following surgery for breast cancer (Jamison et al, 1978; Dean, 1986; Worden & Weisman, 1987). Depression is the most prevalent problem for cancer patients while anxiety is second in frequency (Derogatis, 1983). Most women with breast cancer experience symptoms of anxiety with 12-30% exhibiting clinically significant anxiety problems (Campora et al, 1992; Maraste et al, 1992; Pinder et al, 1993). However, in most cases, the psychological symptoms tend to be moderate rather than severe, and to reduce over time (Dean, 1986; Hughson et al, 1988).

A number of factors have been found to be associated with an increased risk of psychosocial problems (figure 1); greater levels of distress are positively associated with greater severity of disease or with recurrence (Maunsell et al, 1992; Schag et al,

Figure 1: Factors associated with an increased risk of psychosocial problems (adapted from NHMRC, 1999)

Factors associated with an increased risk of psychosocial problems
<p>Characteristics of the woman</p> <p>Younger Single, separated, widowed or divorced Children younger than 21 years Economic adversity Perceived poor social support Poor marital or family functioning History of psychiatric problems Cumulative stressful life events Past history of alcohol and other substance abuse</p>
<p>Characteristics/stages of disease and treatment</p> <p>At the time of diagnosis and recurrence During advanced stage of the disease More treatment side effects Experiencing lymphoedema Experiencing chronic pain</p>

1993). Generally younger patients demonstrate greater levels of distress than older patients (Simonton & Sherman, 1998; Compas et al, 1999).

While degree of emotional distress can have an impact on the relationship, the opposite is also the case. Pistrang and Barker (1995) found that satisfaction with the partner relationship was positively associated with psychological well being. If there was low satisfaction with this relationship, a helping relationship with another did not compensate. Coyne and DeLongis (1986) also reported similar findings with little evidence to suggest that support from other relationships can alleviate the impact of strains or lack of support within the marriage.

Pistrang and Barker (1995) also found that the quality of the help received from the partner was a more important determinant of degree of distress felt than general relationship satisfaction. Overall the husband's responses and the wife's perception of husband's support were stronger predictors of marital satisfaction than were the wife's emotional adjustment and characteristics such as prognosis. Barry (1970) suggests that the more stable the husband's personality and role functions, the more he can provide his wife with the environment she needs. This will not only support her but increase her marital satisfaction.

Studies suggest that it is important for the male partner to be empathetic and low in withdrawal. The more the women felt that their partner understood their experience of breast cancer, the more helpful they felt it was to talk to him. Withdrawal was very unhelpful, particularly when partners were avoiding open discussion about the cancer experience (Vess et al, 1988). Criticism was not necessarily associated with the quality of the relationship as it was sometimes interpreted as positive engagement rather than withdrawal.

Who is more affected? Husband or wife?

Generally, there are mixed findings regarding who is most concerned after a diagnosis of breast cancer, the husband or the wife. In the study conducted by Lichtman and colleagues (1987), husbands were worried about recurrence and death more than their wives but could not usually express these concerns. Oberst and James (1985) found that spouses had higher levels of anxiety than the patients during the hospitalisation. Baider and De-Nour found higher levels of distress and lower levels of adjustment for husbands of mastectomy patients than for the patients themselves over a three year period (Baider & De-Nour, 1984) and the study by Given and Given showed similar findings (1992). One reason for these findings may be that the spouse may feel overwhelmed with feelings of helplessness and powerlessness when he learns that a previously healthy spouse has been diagnosed with a potentially life-threatening illness such as cancer.

Some other studies have found similar amounts of distress among partners (Northouse & Swain, 1987; Baider et al, 1996) while others have shown lower levels of distress for the husband than the wife (Hoskins, 1995; Northouse et al, 1998).

Findings of chronic illness, in general, suggest that women often do much of the carrying of the psychological burden of illness, regardless of whether they are the patient or the partner (Coyne and Fiske, 1992). The well being of women is considerably influenced by the physical, psychological and social condition of their partner. Men, on the other hand, are more influenced by their own condition than their partner's (Northouse et al, 1995; Baider et al, 1996). The findings of Hagedoorn and colleagues's study (2000) also suggested that women were equally distressed regardless of

whether they were the patient or the partner. The same was not so true for men, who were more likely to be distressed if they were the one who was ill.

Similar or complementary responses?

The results of studies are also conflicting regarding whether a high degree of distress in one member of the couple is more likely to be accompanied by a high degree of distress in the other partner, or whether some form of compensation occurs.

Theoretical models on the stress response would tend to suggest that if one member of a couple is distressed, then the partner will be similarly affected. A number of studies have shown that this is usually the case with breast cancer (Baider & De-Nour, 1984, 1988b; Sabo et al, 1986; Northouse, 1989), where high levels of depression or anxiety in the women were associated with higher levels in their partners.

Alternatively, the family system paradigm would suggest that compensatory mechanisms operate, changes in one member of the family being accompanied by changes in another member in order to restore balance and equilibrium (Minuchin, 1974; Jackson, 1975). This paradigm would suggest that if one spouse is affected very adversely, the other spouse will be less so as the couple can only tolerate a finite amount of discomfort at any one time. Other studies have results supporting this suggestion (Lichtman et al, 1987; Keitel et al, 1990; Hannum et al, 1991).

It is possible, however, that both explanations have value. The findings of Walker's study suggests that at low or medium levels of distress, the distress levels experienced among husbands and wives are generally similar. However at very high levels of distress, another pattern may emerge. If one partner becomes extremely distressed, the other partner compensates by experiencing or reporting less distress. The less distressed partner is thus enabled to have the resources to give support to their distressed partner, thus protecting the couple relationship (Walker, 1997). However, it can be seen that prolonged distress in either partner or both would place considerable strain on the couple relationship.

Adjustment over time

As with studies of marital satisfaction, there is conflicting evidence about how long it takes for individuals to recover emotionally and psychologically from breast cancer. It seems likely that residual concerns about recurrence and fear of checkups may last for many years after the original diagnosis (NHMRC, 1999). However, most research suggests that both husbands and wives generally experience a gradual, steady improvement in emotional adjustment over time (Hannum et al, 1991, Zahlis & Shands, 1991; Carter & Carter, 1993).

Recurrence

The psychological impact of the diagnosis of recurrence may be much greater than that experienced at the time of the initial diagnosis (Jenkins et al, 1991; Hall et al, 1996). Some studies report that up to 40% of patients with progressive disease and in palliative care are clinically depressed (Bukberg et al, 1984; Hopwood et al, 1991; Hall et al, 1996) and for many women, distress increases as the

cancer progresses (Mahon et al, 1990). Silberfarb and colleagues (1980) compared the psychological status of 146 breast cancer patients who were in the initial, recurrent or terminal phases of illness. Women in the recurrent phase of illness reported significantly more psychological distress. They also had more problems with social isolation, role disruption and sexual difficulties. The participants in another study by Mahon and colleagues indicated that recurrence was more upsetting than the initial diagnosis as the threat of death was more real, treatment decisions more difficult, side effects of treatment more severe, and the fear of uncontrollable pain greater (1990).

Recurrence challenges women to confront their mortality more than at any other stage (Mahon et al, 1990; Northouse et al, 1995). It is seen as a particularly difficult phase for patients because it shatters hopes of a complete recovery or ensured survival. It also means more treatments that may be even more difficult than before. Fear of death is a theme that occurs with increasing intensity during this phase (NHMRC, 1999).

The impact of coping strategies and communication between partners

Women's coping mechanisms and disclosure patterns

There is a considerable amount of research that has been undertaken investigating how individuals cope with illness and the stress caused. It is important to recognise that individuals not only have very different ways of coping but that these may also vary over time. The woman's method of coping will normally exert a major influence on the level of psychological distress she experiences. This in turn may have a subsequent impact on the partner relationship.

In general, the more efficacious coping mechanisms are those that are focused on solving problems, confronting real life issues, actively searching for information (Weisman & Worden, 1976) having emotional discharge, for example, through humour, sharing experiences, and by cultivating hope and optimism (Brissette et al, 2002). The least effective coping mechanisms are those focused on avoidance, passivity and apathy, pessimism, blaming, acting out, and past regrets (O'Malley et al, 1979).

Generally being able to disclose and talk about one's problems at moderate levels is related to better psychological adjustment and less anxiety and depression. However, extremely high or low levels of self disclosure may be maladaptive (Northouse & Northouse, 1987; Pennebaker et al, 1988; Figueiredo et al, 2004). Vachon (1986) found that breast cancer patients who did not freely express their feelings but kept up a brave front were often considerably distressed after surgery. Personal accounts testify to the importance of self disclosure in diminishing feelings of rage, despair and being alone (Fiore, 1979; Cooper, 1982) and Cordova and Andrykowski (1999) found that the degree to which a woman had talked with people about her breast cancer was a significant predictor of post-traumatic growth.

Silver and Wortman (1980) suggested that disclosing feelings plays a major role in helping individuals adjust. They suggest three possible reasons why disclosure and expression of feelings facilitates adjustment, well-being and coping. First, it relieves any build up of tensions and anxieties. Second, it allows the person to receive feedback from others that their reactions are both

normal and common, which is also tension reducing. Thirdly, disclosure enables greater problem solving as patients start to view their current circumstances from a wider ranging and more objective perspective. In addition to these reasons, Manne suggested that disclosing feelings may increase the individual's cognitive processing of the issues surrounding the experience of cancer, leading to a decrease in the distress felt (Manne, 1999)

Nevertheless, Mitchell and Glicksman's study of 50 patients undergoing radiation therapy found that most patients wished that they could discuss their situation more fully with someone else (1977). Similarly, Meyerowitz and colleagues (1983) in their study of breast cancer patients receiving chemotherapy found that 42% of patients did not discuss their feelings about their cancer with other family members. Instead of talking openly, they chose to maintain a strong front in order to try and protect their husbands and children.

Disclosure may also be important in the person's own search for meaning. People developing cancer are more likely to reassess what is meaningful in their lives.

Frankl (1963) suggested that the search for meaning is the main motivating force. He also believed that finding personal meaning and value enabled people to become stronger and better able to face their current situation. In addition, Cantor in 1978 believed that developing a disease such as cancer can have a significant effect on a person's feelings of self. "Unless each of us feels some potency, some ability to understand and have effect, we experience ourselves as the passive victims of outside forces, we know ourselves to be without significance".

Emotional support from the partner and how couples cope and interact

Disclosure is only possible between partners if one is willing to talk about their illness at the same time as the other is willing to listen and respond. The findings of most studies is that open communication between partners is related to higher ratings of emotional closeness and less marital conflict following the diagnosis (Vess et al, 1985a; Lichtman et al, 1987; Gotcher, 1992). Families that communicate openly have reported more positive family outcomes than those who do not; in addition failures in communication may contribute to feelings of isolation and misunderstanding, interfering with the adjustment for both spouses (Spiegel et al, 1983; Baider & Sarell, 1984; Sabo et al, 1986; Vess et al, 1988). Communication is also vital in negotiating role changes and new role expectations within the family and in developing patterns of support (Vess et al, 1985a).

One of the reasons for lack of communication is that family members try to conceal feelings in order to protect themselves and others from the pain and distress associated with these feelings (Bowen, 1976). Family members may collude with one another not to talk about what is worrying them most or show their emotional feelings. This has been termed mutual pretence (Glaser and Strauss, 1965). Unfortunately, although family members may regard this as one way of protecting each other, the end result is often the opposite with members bearing the emotional and psychological pain and suffering alone, sometimes not realising that their partner is similarly affected.

With breast cancer, there is some evidence that many wives have a need to discuss the experience and their concerns, whereas husbands often withdraw from such communications (Lichtman & Taylor, 1986; Sabo et al, 1986). In one study, 31% of the women expressed their dismay over their

husbands' failure to communicate about cancer related issues (Lichtman et al, 1987). Communication difficulties are common especially in couples who avoid discussion of the possibility of future recurrence and death (Vess et al, 1985a; Lichtman et al, 1987; Northouse & Northouse, 1987; Gotcher, 1992). While many patients wanted to express freely their fears and anxieties about recurrence and death, their partners were worried and fearful that talking about these matters would hamper the patients' adjustment and might even bring about a recurrence of the disease.

Appropriate support is also crucial for the emotional adjustment of the well spouse (Northouse, 1984). Before treatment, the spouse and partner are concerned about the illness and the spouse's main concerns are usually directed towards supporting the patient. After treatment, however, the well spouse may be reluctant to burden the patient with his own concerns (Sabo et al, 1986). This may also lead the spouse to feel isolated and unsupported (Oberst & James, 1985; Sabo et al, 1986).

Relationship focused coping

Couples not only have to deal with their own emotions and problems, they also have to cope with each others' problems, fears and emotions. This has been termed relationship focused coping (Coyne et al, 1990; Coyne and Smith, 1991). There is some evidence to suggest that couples may be at greater risk of experiencing psychological and marital distress when the wife is the ill spouse (Baider et al, 1989; Levenson et al, 1993) and research findings suggest that couples cope differently according to whether the husband or the wife is ill.

In a recent study, Badr and colleagues collected data from 182 married couples. In 90 couples both partners were healthy, in 50 couples the wife had a chronic illness and in 42 couples, the husband was ill (2004). They found that the mechanisms of coping with illness in a couple was very much associated with whether it is the husband who is ill or the wife.

They found out that when the husband was ill, the husband and wife were more likely to react by active engagement whereby both partners became actively involved in decision making and other problem solving activities, obtaining the resources they need to cope. However, if the wife was ill, the husband was more likely to engage in protective buffering. This includes denying anxieties and concerns, putting on a brave front, or deferring to his partner to avoid any disagreements or difficulties. This behaviour was also more likely to be elicited in the wife, who was more likely to engage in avoidance coping and protective buffering, and less likely to solicit network support.

In most situations, the use of protective buffering and avoidance coping has been associated with more psychological and marital distress while active engagement, disclosure and open communication has been associated with less distress. In addition, Badr found that the more congruent the couples were in their use of active engagement and open communication about the illness, the more satisfied they were with their partnership.

However, the results of their study also suggest that some couples use compensatory measures. There is less psychological distress in a situation where one spouse copes by protective buffering and avoidance and the other spouse compensates by engaging in fewer of these behaviours. Thus some couples take turns in whether they disclose or hide concerns and worries, thus reducing the

overall emotional and psychological impact of the chronic illness. In general, they found that couples experienced the most problems when both spouses responded with avoidance or protective buffering. However, in a minority of couples, avoidance and protective buffering worked best for their psychological health and their relationship. Thorne (1985) found a similar effect with some families indicating that never discussing the illness was the secret to their success. Avoiding discussion of illness, recurrence or death may be an effective coping mechanism for some couples.

Other studies on relationship coping after physical illness in one of the partners have found different results. However, the findings of most studies suggest that the wife commonly adopts the coping mechanisms favoured by the partner whether this was active engagement or protective buffering. While this may support the husband in his coping, it often meant that the women's needs for open discussion were often unmet (Badr, 2004).

Thus, relationship difficulties and dissatisfaction seem most likely to occur where couples are divergent in the coping patterns and their need to communicate or when one member of the couple adopts the coping mechanisms that suit their partner's needs rather than their own. Hilton (1993) found that couples that differed most in how they preferred to communicate showed more dissatisfaction with their marriages after breast cancer, whereas couples who agreed on their communication patterns appeared to show less distress. Couples who hold a similar view to the importance of verbal communication are more satisfied, feel more supported and have better adjustment to diagnosis and treatment.

Quality of the relationship, however, is another important factor. Manne found that wives engaging in protective buffering in less satisfying marriage were more distressed than wives who used protective buffering in marriages that were more satisfying (Manne et al, 1997). In addition, spouses with good prior relationships may be more adaptive in their coping and intuitively respond according to their partners' needs.

Unwillingness to talk about the future

Another important and related factor is being able to talk about the future and providing continued emotional support. Some women may find that the partner is supportive but only in the short term. Silver and Wortman (1980) note that patients commonly view adjustment as a long term process, they regard the disease as an ongoing threat; and still need to express their fears several months or years after the cancer episode. Their partner is more likely to see the illness as a crisis that has been resolved with the completion of treatment and no further discussion is required. This difference was indicated by one woman in Silver and Wortman's study (1980) who had recently been treated for breast cancer. She said:

“Its five years before they consider you are cured. Well, for his peace of mind as far as he's concerned, it's over and done with. The issue is closed. He doesn't want to talk about it”.

Silver and Wortman (1980) suggested several reasons why significant others might expect their partner to recover from the crisis sooner. Partners may believe that it is important to be positive and not to dwell on the cancer as this in turn creates more fears and worries. Being positive may help

them feel more positive and convincing the patient that they are cured makes it easier to maintain these beliefs themselves.

This difference in response may lead to relationship dissatisfaction and distress in that the spouse's silence or unwillingness to discuss these issues may be interpreted by the patient as a lack of concern or caring. However, in reality, this is not usually the case. In their study, Silver and Wortman (1980) found that partners expressed more concern about recurrence than the patients did. Although many partners indicated that they still had many fears about their partners' illness and death, they never disclosed or talked about them.

These results suggest that couples who express their realistic concerns, such as the possibility of recurrence and death, and appear to be sensitive to each other's emotions and concerns, will generally show better marital adjustment than couples who do not.

5) Predictors of couple adjustment after breast cancer- demographic factors, illness and treatment factors

Age

Generally the evidence of the impact of age is conflicting. Some studies suggest that couples under 50 experience more distress and marital conflict than older couples (Jamison et al, 1978; Wellisch et al, 1978; Wellisch et al, 1983; Hughson et al, 1988) including more anger and resentment (Wellisch et al, 1983). Other studies either show no effect for age (Baider & De Nour, 1988b; O'Mahoney, 1997) or find that younger couples report less disruption (Lichtman et al, 1987). These differences in findings could be due to age being closely related to other important factors, such as stage of disease or length of the couple relationship. The finding by some investigators of less disruption in younger women could be due, in part, to younger women having less advanced illness and be undergoing more conservative treatment. The finding by others of less disruption in older couples could be due to most of the older couples having been in relationships for longer periods of time; generally, the longer the couple has been together and the more established their relationship, the less they are affected (Lichtman et al, 1987; Northouse and Swain, 1987).

Stage of illness

In the early stages of breast cancer, the stage of the illness is not predictive of marital adjustment (Lichtman et al, 1987; Baider & De Nour, 1988b; O'Mahoney, 1997). However, a poor prognosis, illness progression and recurrence can result in more distress and increased marital conflict (Krant & Johnson, 1978; Northouse, 1981; 1984; Wellisch et al, 1983; Lichtman et al, 1987). Prolonged treatment is also more disruptive than short treatments (Meyerowitz et al, 1979). While the threat and fear of death creates a significant anxiety throughout the illness (Gotay, 1984), this is likely to intensify with recurrence or illness progression.

While both patient and partner may fear recurrence, this may be more pronounced for the spouse than for the patient (Lichtman & Taylor, 1986). This fear may be exacerbated by any unexplained

symptoms, thus affecting the couple relationship as well as individual adjustment (Oberst & James, 1985; Zahlis & Shands, 1991; Hilton, 1996).

Hinton (1981) observed couples coping with terminal cancer and three patterns of restricted communication. Some couples avoided any discussion about the illness as a self protection mechanism, preventing an increase in their own distress. Others wanted to maintain a positive attitude to maintain hope, and avoiding discussing the illness. A third group of patients did not normally talk about their emotions and feelings, so this was a continuation of their usual style of communication.

Type of surgery: Mastectomy versus breast conserving surgery

There have been a considerable number of studies in this area in order to determine the impact of the different treatment options. Efforts to improve quality of life have increased the use of breast conserving surgery (Fallowfield et al, 1986). Patients of all ages with stage 1 and 11 disease (this includes tumours up to 5cm with or without axillary node metastases and no distant metastases) are now considered appropriate to receive either breast conserving surgery with radiation or mastectomy (Coon, 1988; Kennedy, 1989). Although women in this category are now usually offered a choice, it is still important to ascertain the impact on quality of life of the two types of treatment.

Body image

There is clear evidence that body image is much more likely to be affected with mastectomy or mastectomy with reconstruction rather than conservative surgery (Mock, 1993). Moyer (1997) conducted a recent meta-analysis of studies comparing the psychosocial effects of breast conserving surgery with mastectomy. She identified 40 appropriate investigations and mean weighted effect sizes were calculated for six psychosocial outcomes. Modest advantages were found for breast conserving surgery for psychological, marital-sexual, social adjustment, body/self image, cancer related fears and concerns. However, the largest effect size between treatments was for body/ self image. This is consistent with other findings (Lasry et al, 1987; Kemeny et al, 1988; Margolis et al, 1990; Ganz et al, 1992). This evidence is consistent even though body image has been operationalised in a variety of ways in these studies, including feelings about appearance, comfort with nudity, use of bathing suits, sexual desirability, shame and embarrassment. Breast conserving treatment can also mean that there are less problems getting clothes to fit, needing a prosthesis, or getting undressed (Schain et al, 1983, Steinberg et al, 1985; Aaronson et al, 1988).

However, the evidence suggests that concerns over body image decrease over time for most women. Ganz assessed women at one, seven and 13 months post-operatively and found that the differences between treatment groups reduced over time with both groups of women showing some improvement in body image between post treatment assessments (1992). Dorval and colleagues (1998) assessed women on average of eight years post treatment and found no differences between women treated with mastectomy or lumpectomy according to sexual satisfaction; satisfaction with surgery; or ratings of appearance of the scars.

Body image can impact on psychological functioning. However, some women may prefer an impaired body image if they have a greater chance of survival and this will depend on whether worries over survival are greater than concerns over appearance. Women vary according to what concerns them. Factors such as the age of the woman, whether they are currently in a relationship, the stability of this relationship, and the presence of children, will all have a bearing on what worries them most (Peters-Golden, 1982; Fallowfield et al, 1987; Pozo et al, 1992).

Differences in sexual satisfaction and dysfunction

Apart from body image, the evidence for the psychosocial outcomes of the different types of treatment is equivocal. These equivocal results are probably related to the methodological difficulties found in many of the studies and their lack of comparability according to what is being measured and how, the timing of the measurement, how treatment was assigned as well as small sample sizes. There are also difficulties in comparing the outcome of different groups of women who have opted for a specific treatment as those choosing breast conservation are more likely to be more concerned with their body image than those deciding upon a mastectomy. In addition, most studies have relied on women's accounts or self report measures which may not always be reliable; women receiving surgery may be so grateful for the treatment received and their life being saved, that they under-report subsequent problems (Fallowfield et al, 1987).

The meta-analysis conducted by Moyer found only a very small but significant effect size favouring breast conserving surgery rather than mastectomy according to sexual adjustment (Moyer, 1997). However, Kiebert and colleagues's review on the subject (1991) showed no differences in sexual functioning between women treated with lumpectomy compared with those treated with a mastectomy in seven out of 11 studies. They suggested that there is little solid evidence of differences in sexual satisfaction and dysfunction according to type of operation (Taylor et al, 1985; Baider et al, 1986; Kemeny et al, 1988; Hall and Fallowfield, 1989; Schover, 1991; Kiebert et al, 1991; Fallowfield & Clark, 1991; Schain & Fetting, 1992).

Schover has suggested that one of the reasons for the different findings is the methodology and outcome measures used. He suggests that studies using more subjective measures are more likely to show better outcomes for the women with breast conservation. When more objective measures are used, there are usually no differences between groups (Schover, 1991).

Differences found between treatments might not only be due to the type of operation performed but due to other accompanying therapies. Schover has suggested that the radiation or chemotherapy which is more often given with breast conservation may contribute to sexual difficulties as it has an impact on fatigue, loss of libido and premature menopause (1991). The impact of these other treatments will be considered later.

Marital satisfaction

The evidence for differences between treatments according to their impact on marital satisfaction is even more equivocal. While some have found that couples had better marital satisfaction following breast conserving surgery than mastectomy, others have found the reverse or no differences. For example, Lichtman and colleagues (1987) found better marital outcomes in those receiving breast

conserving surgery and postulated that this could be due to the sexual relationship being better in the breast conserving group. Schover examined the results of 12 studies comparing women having breast conservation with those who have had a mastectomy (1991). Women who have breast conservation had more positive feelings about their bodies than those having a mastectomy but there were less differences in other areas such as distress, quality of marital relationship, frequency of sex and sexual dissatisfaction. Pozo and colleagues (1992) found that conservatively treated patients reported better sexual adjustment at six and 12 months, but otherwise there were no differences in mood, perceptions of social support, marital and life satisfaction, quality of life or life adjustment. However, the studies of Baider and colleagues (1986) and O'Mahoney (1997) found that mastectomy patients reported higher levels of relationship satisfaction. O'Mahoney reported that mastectomy patients had higher levels of time shared together and relationship satisfaction than lumpectomy patients (1997).

Cancer related fears

Moyer investigated cancer related fears and concerns and found that these were slightly less in women with breast conserving surgery, especially in longer term assessments (1997). It is possible that the disfigurement resulting from mastectomy may remind some women of the threat of cancer (Aaronson et al, 1988). On the other hand, some women may worry more about the cancer recurring as less breast has been removed (Fallowfield et al, 1986; Massie & Holland, 1991). However recent medical evidence, that indicates that both treatments are comparable in terms of survival rates, may contribute to women becoming less worried over breast conserving surgery (Jacobson et al, 1995; Early Breast Cancer Trialists' Collaborative Group, 1995).

Type of surgery may also have some influence on the type of psychological distress expressed. There is some evidence that those receiving mastectomy may be more prone to depression (Deadman et al, 1989), while those receiving breast conserving treatments may be more prone to anxiety (Moyer, 1997). However, these findings need confirmation.

Adjuvant therapy

Radiation and chemotherapy can be physically and psychologically draining. There are the side effects of fatigue, skin burns, nausea and hair loss. Chemotherapy can result in severely reduced oestrogen levels which can initiate a premature menopause which can be permanent. This may result in vaginal drying, soreness, pain and atrophy, making intercourse painful or sometimes impossible. In addition, women may experience a change in pallor, weight, sleep disturbance, hot flushes, and emotional lability. While these symptoms can create behavioural disruption and emotional distress when the woman is actually being treated, these problems often reduce later (Baider and De-Nour, 1988a, Northouse, 1989; O'Mahoney 1997). Baider and De-Nour (1988b) suggest that although adjuvant treatment may be disruptive and distressing at the time, it can reduce distress one to three years following surgery, because the patient is less concerned about recurrence. However, other researchers indicate that some of these difficulties may become chronic in some women (Ganz et al, 1996).

Treatment with chemotherapy has been shown to contribute to psychosocial maladjustment, sexual dysfunction and poorer body image (Schover et al, 1995). The use of chemotherapy for breast cancer has increased considerably since the 1980s (Ganz et al, 1998). A study by Ganz and colleagues (1998), that investigated women one to five years post treatment found that sexual problems were more common in those receiving chemotherapy. The evidence is mixed according to whether this effect lessens over time. One study comparing women seven years post-treatment found that women given chemotherapy have substantially increased symptoms including vaginal dryness, decreased libido, painful intercourse and more difficulty reaching orgasm (Young-McCaughan, 1996). However, another study with participants that averaged 10 years post treatment (Joly et al, 2000) showed no differences according to chemotherapy status.

Tamoxifen, a commonly used drug in both the treatment and prevention of breast cancer, has been considered to have a negative impact on sexual functioning (Ganz et al, 1998). However, three recent studies on breast cancer survivors have shown no effect (Young-McCaughan, 1996; Ganz et al, 1998; Mortimer et al, 1999). These studies have investigated women at various stages post-treatment from two to 24 months (Mortimer et al, 1999) to seven years (Young McCaughan, 1996). In Mortimer and colleagues' study, sexual dysfunction was comparable to a normative sample of healthy women.

Age and phase of life may be important factors in assessing the impact of chemotherapy. Lindley and colleagues (1998) found the greatest negative change in sexual functioning occurred in premenopausal women who experienced chemotherapy-induced amenorrhea (absence of menstruation).

Reconstruction

Breast reconstruction can result in a cosmetic outcome superior to breast conservation (Taylor et al, 1985; Cady & Stone, 1990). Generally levels of body image and body satisfaction in those receiving reconstruction fall between those treated with mastectomy without reconstruction and those receiving breast conserving treatment (Mock, 1993).

Two investigations have compared women treated with breast conserving surgery with those undergoing mastectomy then reconstruction. They both suggest slightly better outcomes for the former. In one study, body image and satisfaction with surgery was superior in the breast conserving group, but there were no differences in sexual adjustment or fear of cancer recurrence (Noguchi et al, 1993). In another study, there was evidence that women were less affected sexually after a partial mastectomy including a higher incidence of breast caressing during sexual activity (Schover et al, 1995).

Opportunity to choose

Allowing patients to choose may improve psychological well being regardless of what procedure was done as usually having some kind of personal control over treatment results in less distress (Maguire, 1989; Fallowfield et al, 1990; Pozo et al, 1992). However, this is not true for all women, some may prefer the surgeon to choose for them. Being able to choose may also lead patients to feel responsible if treatment is unsuccessful (Morris and Ingham, 1988).

What treatment is chosen does depend on the woman's personal concerns. If they are concerned about body image and disfigurement or are currently not in a long term relationship, breast conserving therapy may be the more appropriate option. Other factors which may affect the choice made include tolerance to radiation, beliefs about treatment efficacy and the concerns of significant others. However, adequate preparation prior to treatment and long term support for all breast cancer patients is important regardless of surgery received (Fallowfield et al, 1986; Maunsell et al, 1989).

Age and type of surgery

The findings of the impact of type of surgery according to age of the women are mixed. Maunsell and colleagues (1989) found that women under 40 who had breast conserving treatment were less distressed than those having had a mastectomy. However, women aged between 50-59 were more distressed with breast conserving treatment, while those over 70 did not differ. However, this finding was not replicated by Maraste et al (1992).

Overall, the evidence is very mixed, but suggests that a woman's overall psychological health, relationship satisfaction and pre-morbid sexual life are far stronger predictors of post-cancer sexual and marital satisfaction than the actual type of surgery done to the breast.

6) The role of the health professional

It is crucial that health care professionals provide patients with avenues for dealing with intrapersonal issues such as their emotional well-being, sexuality and self image; and interpersonal issues, such as their relationship with their partner. However, existential issues, such as the meaning of life or confronting one's own mortality, are also important. Northouse and Northouse (1987) examined over 200 clinical papers and research studies between 1996 and 1986 that focused on communication dimensions of the cancer experience. They concluded that patients need to be assisted in the following personal tasks: maintaining a sense of control; seeking information; disclosing feelings; and a search for meaning.

The way in which the diagnosis is delivered affects not only the women's understanding of the illness but also can have an impact on her psychological adjustment in the long term (Sardell & Trierweiler, 1993; Roberts et al, 1994). Both communicating hope and imparting information have been found to be important (Northouse & Northouse, 1987) and research suggests that up to 66% of women prefer key information to come from a hospital doctor (Meredith et al, 1996).

Feelings of powerlessness and helplessness are very common in patients with breast cancer, often relating from the patient's inability to predict or have an impact on events surrounding their illness. Many patients perceive a loss of independence and autonomy and this in turn, is likely to be associated with increased anxiety and depression (Derogatis, 1983 ; Northouse & Northouse, 1987).

Many cancer patients have been shown to have a strong need to discuss what life means for them and to be able to talk about issues relating to living with their illness. This may be an important step towards developing the individual's level of acceptance of the illness which in term has been

significantly linked to lower levels of distress in women with early stage breast cancer (Carver et al, 1993). There is some limited evidence that patients who have the opportunity to communicate about the meaning of their illness adjust better to the cancer experience, although the strength of this need is likely to vary between different individuals and at different stages of the illness (Northouse & Northouse, 1987).

The evidence presented here suggests that health professionals have to be constantly aware that there are not only individual differences between patients on the coping skills they adopt but these may vary within individuals at different times. This requires considerable sensitivity and Harker (1972) emphasises the importance of allowing patients to set the pace for what and how much they want to disclose about their experience and what the health professional needs to tell them. In general, needs for disclosure and information are greatest at the time of diagnosis and initial treatment and much less at terminal stages (Abrams, 1966).

Effective communication requires individually tailored explanations from the health professional, plus appropriate problem solving and acknowledgment of the women's feelings. Health professionals need to convey support, empathy and listen actively (Roter, 1977; Roberts et al, 1994). Studies have shown that the way a clinician and the treatment team relate to women patients and their partners can have a significant effect. These benefits include improvement in psychological adjustment, decision making, treatment compliance and satisfaction with care. However, interventions not only have the potential to reduce the psychological distress of patients and their families but also to enhance their potential for growth and transformation from the experience (Andrykowski et al, 1993).

Involving the spouse and the family

A major difficulty is that many doctors see patients as the main focus of their care rather than the family. They may talk to the patient but not always ensure that the spouse or other important family members are involved in the process.

This may mean that the patient's husband does not have the opportunity to ventilate his private concerns (Wellisch et al, 1978.). Harrison and colleagues suggest that men traditionally do not talk about emotional issues outside the home and cannot do so even in crisis situations (1995). Women are more used to sharing emotions with close friends and family and continue to do this in crisis. In many cases, therefore, the wife is usually the husband's chief confidante and he relies exclusively on her for affective support (Antonucci and Akiyama, 1987; Harrison et al, 1995). Thus not being able to talk to his wife, because of her own distress and worries, may deprive him of his usual outlet for dealing with problems.

Other studies have similar findings. Maguire (1981) reported that only a few husbands of mastectomy patients had discussed their worries with anyone. Many would appreciate having been able to talk to someone about their worries. Welch (1981) also found that family members perceived that their anxieties would have been lessened if someone had sat down to talk to them.

Moreover, there is some suggestion that health professionals are not always perceived as helpful in terms of providing support. Spouses of cancer patient perceived that they received little support from health professionals (Oberst & James, 1985). Northouse (1985) similarly found that husband of mastectomy patients perceived significantly less support than patients although they exhibited as much distress.

Studies have suggested that husbands find it helpful to receive support from health professionals and others. Husbands of mastectomy patients who received high levels of support reported less distress than those who had received lower levels (Northouse, 1985). Gates undertook counselling with husbands of mastectomy patients and considered that the husband were less distressed and more prepared to help their wives cope with the illness and psychological consequences (1980). Husbands may not only benefit from supportive communication with health professionals and others but may also be enabled to give better support to their wives in the process. It is important therefore that health professionals and others attend to the concerns, worries and distress of the husband not only for his well being but also that of his wife.

Body image and sexual adjustment

Doctors and health professionals also need to talk about body image concerns. They should not make the assumption that this is not an important issue for older women, although evidence suggests that body image is particularly important for women under 55 years of age (NHMRC,1999)

After treatment, it is important to explore sensitively about how the woman is coping with her altered appearance. Support and education from a specialist breast nurse may help with adjustment difficulties or in more severe instances, the woman may be referred to a psychologist or psychiatrist for cognitive behavioural, support or crisis therapy.

Asking about sexual adjustment is also important. Many women may find it difficult to talk about these issues, and it is therefore important that the health professional is proactive but sensitive in their approach. Those at risk for sexual problems including women who do not have a committed partner, those in unhappy relationships, those who are younger, those who still wish to have more children, and those who have a history of sexual difficulties in their relationship.

A joint session with the woman's partner may be crucial in facilitating the couple's future communication about sexual issues. In addition, the men may benefit from individual counselling or a support group. As with body image, it is important not to stereotype older women as asexual or unconcerned with sexual relationships.

Being sensitive to the way the couple cope, both individually as a pair

It is important for the health professional to identify the unique responses of each partner as well as the shared meaning and the way of coping developed by the couple together. The practice of telling each spouse different information may increase poor communication between partners. Maguire considered that these types of communication practices may send a message to families that open

discussion of feelings is too stressful and needs to be avoided (1981). If the husband realises by talking to a health professional that he should not guide the patient away from her fears, this may allow more open communication (NHMRC, 1999)

Asking about the relationship

It is important that clinicians routinely but sensitively ask about the quality of the relationship as part of their initial assessment as this has been shown to be one of the most important predictors of their marital adjustment post diagnosis and treatment. One sensitive way to approach this is to ask the patient about their support network: who can assist with practical issues; how her family and partner are dealing with the illness; and if she can openly discuss her thoughts and feelings and with whom (NHMRC, 1999).

Support group

It is also important for health professionals to assess level of support available to the individual and their family. While level of support from friends and family may be good initially, studies suggest that there can be significant decreases over time. Northouse and colleagues (1998) found that husbands of cancer patients at 60 days received much less support than shortly after diagnosis, however, this increased back to normal at one year (see table 3). This is consistent with the findings of Oberst and Scott (1988). They also found that 60 days post-diagnosis is difficult time for many patients and their spouses as the level of support from others was at its lowest level then.

Support groups may be valuable for both patients and partners, not only in reducing their own levels of distress but also in improving the couple relationship. There is some evidence to suggest that self help groups and peer support can be effective in reducing feelings of social isolation, depression and anxiety (Van den Borne et al, 1992). In addition, in Walker's study (1997), wives belonging to a support group reported more communication with their husbands about the illness and their husbands reported more satisfaction with communication

Referral and treatment

Although the evidence suggests that most couples will not experience major difficulties, it is important that medical staff are trained to recognise and identify psycho-social problems and referral on, if appropriate, to other more specialised help.

Much research suggests that psychological distress is frequently under-recognised and under treated (McDaniel et al, 1995) and this may be because women with serious physical illness are reluctant to mention their psychological distress or professionals hold back from identifying it. Similarly, distress in their partners needs to be assessed.

The majority of findings suggest that psychological interventions improve the emotional adjustment and social functioning of women with cancer. These interventions can include cognitive behaviour therapy, psychotherapy, psycho-educational therapy, group therapy and family therapy. In a meta analysis of 45 randomized controlled trials in cancer patients, those receiving psychological therapies had made a significant improvement in emotional adjustment (12%), social functioning (10%), in treatment and disease related symptoms (14%), and in overall improvement in their

quality of life (14%) when compared to those not receiving psychological therapies (Meyer & Mark, 1995). Another meta analysis of 116 intervention studies showed that cancer patients receiving psycho-education or psychosocial interventions had lower rates of anxiety, depression, mood disturbances, nausea, vomiting and pain, as well as greater knowledge about the disease and treatment, than the control group (Devine & Westlake, 1995). Additional improvement was found in a meta-analysis of trials of supportive therapy and CBT in the treatment of depressive disorders in women with breast cancer (Sheard & Maguire, 1996)

Generally studies have shown improvements regardless of the type of intervention or whether patients are seen individually or in groups. In most trials, the therapy has been provided by a specially trained counsellor, breast cancer nurse, social worker or psychologist. However there is some suggestion that therapies conducted by more highly trained therapists over longer periods of time can be even more effective (Sheard & Maguire, 1996).

Individual therapy may improve the individual's psychological well-being and functioning and this in turn can have an impact on the couple relationship. However, there is also considerable evidence that couple therapy can be beneficial. Couples with difficulties can also be taught to recognise their coping and communication styles, teaching them conflict resolution, problem solving, and communication skills and by helping partners to clarify each others expectations (Hilton, 1993; Carter & Carter, 1994,). Couple therapy has been shown to reduce emotional distress in couples with breast cancer, increase sexual satisfaction in both partners and reduce depression in the woman (Christensen, 1983). Psychosocial interventions, such as conjoint therapy, including facilitating the couples' understanding of each others' coping styles and working through feelings, can also be helpful (Pistrang & Barker, 1995; Lewis & Deal, 1995).

Group work with couples may also be helpful. Shields and Rousseau found that a two session format improved mental health functioning and cancer related stress in participants. They considered that the experiences of couples were normalised within the group and that both patients and partners found that talking about their worries was helpful with an improvement in both their perspective and their problem solving abilities (2004). Further studies need to be undertaken to replicate these findings.

Discussion

The discussion section will be in four parts. First, a consideration of methodological issues; second what factors would make couples most at risk of relationship deterioration and breakdown; third a discussion regarding the discrepancy between research findings and lay beliefs; and fourth, what can be done to help.

Methodological issues

There is still much more work that needs to be done in terms of refining research methodology in this area. Many of the studies did not use very sophisticated measurements and there is some concern regarding whether the widespread use of questionnaires will lead to an underestimate of difficulties reported as couples may find it hard to admit to these problems on a questionnaire. In

addition, couples with difficulties or who might have separated (many might move location) are less likely to take part in follow up assessments.

In addition, there is a lack of studies that focus on separation and relationship breakdown. Only one study has been conducted that has specifically concentrated on relationship breakdowns and this was undertaken in Canada. Further studies, particularly within the UK, are needed to confirm these findings.

One difficulty when comparing studies is that there is no clear agreement on how to define and measure marital or sexual adjustment. Researchers use different definitions and concepts have been operationalised in a number of different ways. For example, there is a difference between marital satisfaction and marital disharmony, thus couples can report high satisfaction even though they may go through periods of intense conflict.

It is also important to use comparison groups as marital breakdown, disharmony, conflict, and sexual problems are common in couples without the additional stress of breast cancer. It is therefore difficult to evaluate the specific risk of breast cancer compared with other forms of cancer or life stresses.

Additional qualitative studies are also necessary to explore in more detail the experience of breast cancer on the couple relationship. However, as individual differences are very important, the sample sizes may need to be large, or a series of studies be conducted on specific patient groups or on couples at varying levels of risk.

There is also a need for more longitudinal studies that cover long term adjustment. Some couples may take some time to adapt to the illness and treatment but show an improvement over time. Others with difficulties may find these exacerbate over time, as the quality of their relationship is gradually eroded. Currently, long term studies are few.

Given these methodological issues, and the equivocal findings, it is not possible to be conclusive about the impact of the breast cancer on the couple relationship. However, there are some tentative and important findings regarding which couples might be most at risk and how these couples might be helped.

Who is most at risk?

There is little evidence of an overall increase in marital breakdown and marital dissatisfaction among couples with breast cancer, with scores being similar to norms for well adjusted couples (Northouse et al, 1998). However, there is evidence that some couples will be more at risk of breakdown or relationship deterioration while others may find that they grow closer together and that relationship has been enriched as a result of surviving the illness. Still others may find no major change. There is also evidence suggesting that many couples will experience an increase in strain within their relationship, and that this occurs even in those that indicate that their relationship remains good.

It is therefore of value to ascertain which factors are important in determining how the relationship will fare and who is most at risk:-

1. Quality of the pre-existing relationship

The findings from this literature review and the opinions of clinicians and researchers all indicate that the quality of the pre-existing relationship is the most important factor. Couples in good relationships who communicate and support one other (or who have found an alternative way of coping that suits them) are much less likely to be at risk of relationship deterioration and breakdown. Indeed, there is considerable evidence to suggest that certain couples grow even closer together as a result of enduring the trauma together.

Couples with pre-existing problems, however, may find that the experience drives them further apart. The clinicians and therapists suggest that for some couples, the diagnosis may be the last straw that leads to divorce (Carter & Carter, 1994; Taylor-Brown et al, 2000). Couples with poor quality unfulfilling relationships may be able to carry on living together as long as they are not presented with additional stresses. When they are faced with a major stressor, such as breast cancer, they do not have the emotional resources to support each other and survive the trauma, thus leading to dissatisfaction, disappointment and distress on both sides (Carter & Carter, 1994; Taylor-Brown et al, 2000).

Facing breast cancer (and the possibility of a shortened life), may also provoke a number of existential concerns in an individual or couple that have not been previously addressed. Qualitative research and clinical evidence suggests that many couples or individuals when faced with a cancer diagnosis will start to review their lives and carry out a resetting of priorities (Weisman & Worden, 1977; Viederman & Perry, 1980; Lichter et al, 1993;). For example, many people indicate that a cancer diagnosis has led them to recognise the importance of close intimate relationships. While this may consolidate very good or reasonably good relationships, those in poorer or difficult relationships may decide that they cannot carry on living together as before.

Similarly, a woman may believe that the stress of living in a difficult marriage was a major factor in the development of their cancer and that future stress might also affect its prognosis or progression. They may perceive that leaving a stressful or emotionally unsatisfying relationship may be one way of their improving their chance of survival or ensuring a more positive experience in the time that they have left (Taylor-Brown et al, 2000). Thus the diagnosis stimulates action in a previously unhappy relationship.

2. Degree of psychological distress.

Another possible predictor of couple adjustment after breast cancer may be the degree of psychological distress experienced by the patient as well as its chronicity. It is possible that the partner can cope with short term distress in the patient but that prolonged emotional distress may be difficult to endure. However, the evidence is not strong and there are few studies to date that have investigated this issue in detail. For example, the studies by Simpson and colleagues (2002) and Brady & Helgeson (1991) suggest that women who show continued distress elicit less social support from others. Interestingly, Bolger found that spouses increased the level of support they

gave when the physical symptoms in the women increased but they decreased support in response to increased psychological and emotional distress (Bolger et al, 1996). Continued distress in the male partner may also have a deleterious effect on the couple relationship (Wellisch et al, 1978). Thus the less distressed spouse (be they either patient or partner) may learn to cope with the distress by avoidance, distancing themselves, or directing their attentions elsewhere, all of which could have an impact on the couple relationship.

Although these findings are tentative, they do reinforce the need for interventions designed to reduce emotional distress in both patient and partner, not only for their own well-being but also for the long term well-being of the couple relationship. Help and support should not only be available at the initial diagnosis and treatment but at all stages. The findings suggest that recurrence and later stages of the disease may be a particularly difficult time for both patient and partner when much distress and anxiety is encountered. Additional support may be of particular importance at this time.

3. Presence of Sexual difficulties

There is evidence of sexual difficulties post diagnosis and treatment, in terms of desire, arousal and orgasm. However, these problems are not found in all individuals or couples and many problems will decrease over time as the couple learn to adapt and adjust.

Few studies have specifically examined the impact of sexual difficulties on the couple relationship with women with breast cancer. However, one would expect that the quality of the pre-existing relationship would be a major factor, not only in determining the quality of the sexual relationship but also the impact of sexual difficulties on the relationship. Other factors include prior sexual difficulties and psychological distress in either the patient, partner or both (Schover et al, 1989).

Body image is very commonly affected but generally these concerns reduce over time. However, body image and sexual difficulties are areas that can be improved by external help. It is important for health professionals to be both pro-active but also to be able to probe sensitively into these areas. Health professionals can either offer help themselves or refer on to other appropriate agencies. Talking about these issues to both patient and partner may also facilitate a more open discussion between them, thus leading them to talk about and find their own ways of coping, adapting and supporting one another.

4. Adverse reactions in either the patient or her partner

There is little in the current research literature on adverse reactions. This may be due in part to the methodologies employed as studies using questionnaires are unlikely to yield such examples. However, qualitative studies do suggest that although instances of rejection, withdrawal or blame are infrequent, adverse reactions do occur (Lichtman et al, 1987). Patients and their partners may feel ambivalent feelings and may withdraw in order to reduce the pain of separation that they fear may occur later. They may find it difficult to live with the uncertainty of the illness and this may lead them to avoid emotional or physical intimacy with their partner, or an open discussion of their feelings.

Further qualitative studies or the study of clinicians' accounts may be necessary to find out more about these adverse reactions. These findings may be valuable if they can be used to investigate whether outside interventions can be of help and if so, what type and from whom. It seems highly likely that early intervention would be necessary in these cases but that many of those with adverse reactions, including emotional withdrawal, might not be motivated to receive such help. However, the rejected partner (whether patient or their spouse) would certainly need ongoing support and care.

5. Disclosure, support and open communication

Pistrang and Barker (1995) found that the quality of the support received from the partner was a more important determinant of distress felt by the patient than general relationship satisfaction. However, communication is a two way process, both patient and partner need to be able to disclose and respond to each other.

Women vary according to their ability to disclose and their need to talk. Generally disclosure is related to better psychological and emotional adjustment. This may be due to a number of factors including the emotional relief found by the ventilation of feelings; being able to conduct more cognitive processing of the experience; and enabling the individual or couple in the task for the search for meaning. Disclosure also allows the woman and her partner to receive feedback and support from each other and from family and friends, and to undertake appropriate problem solving.

Nevertheless, women do not always disclose the painful feelings they are experiencing preferring to maintain a strong façade to protect those around them (Meyerowitz et al, 1983). Other family members may collude in this pretence, thus leading all the individuals involved to bear the distress alone. This can be particularly difficult for the partner who might not be receiving help from health professionals or from other family members and friends. They may feel reluctant to burden the patient with their own concerns and fears (Sabo et al, 1986) but may have no one else that they can turn to for support.

Many male partners cope with illness in their partner by protective buffering, including withdrawing from overt discussions about the illness (Badr, 2004). Women are more likely to have a need to talk about the experience and future concerns but find that their partners withdraw from all these discussions, preferring to put on a brave face, an optimistic cheerfulness or a total avoidance of the subject. This type of reaction has been generally associated with more psychological distress (with the individuals coping with the fears and anxieties alone) while active engagement, disclosure and open communication have all been associated with less distress. It has also been found to have an impact on the couple relationship, with avoidance and withdrawal being commonly misinterpreted by the other partner as a lack of feelings or caring.

While some male partners may be supportive and communicative in the short term, they may not perceive the need over a longer time period. Generally, patients see the recovery from the illness as a long term process, while their partner may prefer to regard the illness as a crisis that has been successfully resolved by treatment (Silver & Wortman, 1980). This can lead to dissatisfaction in the relationship, especially if the lack of long term response and discussion by the partner is interpreted by the woman as a sign that her partner's concern was short lived.

These results suggest that it is important for most couples to express their concerns and fears and be sensitive to each others' feelings. Men should be empathetic and low in withdrawal and avoidance. However, open communication is not helpful for all couples, some may cope better by putting on a brave face.

Again, the quality of the pre-existing and continuing relationship is important here. Those in good relationships may have already developed a way of supporting and communicating with each other that suits their needs. However, the findings of Manne and colleagues (1997) suggest that wives engaging in protective buffering in less satisfying marriage were more distressed than wives who used protective buffering in marriages that were more satisfying. It is possible that couples in more satisfying marriages are less likely to interpret any non-communication as a lack of caring, but recognise that it is the way that the man or woman finds easiest to cope.

Other issues:-

Age

There is little evidence to suggest that age in itself is of major importance. Other factors such as length of the relationship (with less disruption in better established relationships) and stage of illness have more effect.

Adjustment over time and recurrence

Most studies report a reduction in dysfunction and distress over time. However, the evidence is mixed. Some couples may find that difficulties occur immediately post diagnosis and diminish over time as they learn to adjust to their new situation. However, some couples may cope in the short term but find difficulties later. For example, some women may find that their husband is supportive during the period of diagnosis and active treatment, but less so after this initial period has passed (Silver & Wortman, 1980).

Although this study has not specifically focused on recurrence or the terminal stages of the illness, these can be seen as particularly difficult times. There is some evidence to suggest that recurrence, for example, may have more of a psychological and emotional impact than the original diagnosis. Recurrence may shatter the couple's hopes for a complete recovery and ensured survival.

Type of treatment

There is little evidence that type of surgery has a major effect on marital functioning, although body image and sexual functioning is generally less affected by breast conserving surgery than mastectomy. Giving women the choice of treatment is usually the most appropriate action as women will vary according to what concerns them most, whether this is bodily appearance or worries over survival. There is some suggestion that chemotherapy and hormonal therapy can have an impact on sexual functioning. Therapies that bring about a premature menopause and physiological changes can be particularly problematic. In these cases, advice and relevant treatments from the health professionals are essential.

Discrepancy between research findings and lay beliefs

The literature presented here suggests that there is no strong evidence of an excess of relationship breakdown in couples with breast cancer nor a substantial decrease in marital dissatisfaction. What other factors could therefore account for the commonly held lay belief in the association?

First, it is possible that there is much more focus on couples who breakup or whose relationships deteriorate significantly than those couples whose relationship stays the same or improves after the diagnosis. Women or their partners do not always divulge their condition to others and others might not always be aware that they had had the illness unless it has some other major impact on the couples' life.

Secondly, the process of attribution may be important. Many couples may have been on the verge of splitting up prior to the diagnosis but their ongoing difficulties may have been covert so that others may have been unaware of the problems. Any subsequent breakup after the breast cancer is therefore likely to be attributed to the breast cancer rather than any longer term pre-existing difficulties.

Thirdly, a diagnosis of cancer may act as catalyst to discontinue living in an unsatisfactory relationship as before. Facing one's own mortality may prompt the individual or couple to review their past lives and what is most important to them. Those who have been living in difficult or stressful relationships may decide to part.

Finally, there is limited evidence that the diagnosis of cancer may bring about adverse reactions in small numbers of individuals, either the patient themselves or their spouse. This may also account for some of the lay beliefs. More research needs to be undertaken to find out not only which individuals might react in these ways but also how best to help them and their spouse.

What can be done to help?

The findings of this study indicate the great need to support both the patient and her partner at all stages of the illness. This should be seen as an integral part of the health care received by all patients. The patient needs to be supported during diagnosis, treatment, at follow-up and later stages (if appropriate). Support may reduce any psychological distress in the patient which can then have a subsequent impact not only on her physical health but also on her relationships with others, including her partner.

Support for the partners is also vital and they should be involved at all stages, if the patient agrees. Support for the partner is not only important for his own psychological and emotional health but may also have an impact on the quality of support he can give to the patient.

Supporting patients and partners is not always an easy task as their needs will vary over time. The needs of patients and their partners may also differ. Health professionals need to be sensitive and to be able to vary their approach according to the current needs of the patient and their partner.

Pre-existing difficulties

The evidence strongly suggests that pre-existing difficulties are the most important predictor of subsequent marital distress or separation. Some type of assessment by the health professional at an early stage can therefore be of value to determine whether the couple is at risk. The health professionals can then decide on whether a referral to a more specialised agency or counselling service may be valuable or whether continued support by the health care team is best. Initial research on interventions strongly supports that all types of therapy can be helpful, whether it is individual, couple or group therapy.

Support groups

Some individuals and their partners may also benefit from attending a support group for survivors as initial research indicates that individuals and couples may benefit from these. The type of support group can vary, some are aimed at patients, some at their partners and some at couples. Couples will differ according to the type of help they would like but attendance at a group may reduce levels of distress and improve the couple relationship. There is evidence that support and self help groups can be helpful in reducing feelings of isolation, depression and anxiety and can also improve communication between partners (Van den Borne et al, 1987).

Sexual difficulties

After treatment, it is important for the health professional to explore sensitively about body image, sexuality and the sexual relationship rather than wait for the woman (or her partner) to bring up these issues. Giving this information to couples gives them the permission to talk about the impact of the illness on their sexuality or the couple relationship. A joint session with the woman and her partner may be an important way of facilitating a more open communication between partners. However, this may not always be suitable for all patients. Referral elsewhere is another option that can be explored.

Encouraging open communication

Discussing issues with couples together can bring about an improvement in the way that the couples communicate with one another. Explaining the need to be open with each other's fears and concerns may facilitate these conversations. It may also be valuable to talk about the different ways that many people cope with breast cancer, with some preferring to talk while others put on a brave face and be cheerful. This can increase understanding between couples according to the different ways that they personally adopt. Thus, avoiding and not talking about the important issues is not always a signal that someone does not care.

It may also be important to indicate that psychological and emotional adjustment may take some time and that support and talking should not be limited to the treatment phase but should occur at later periods as well.

Future work

There is a continuing need to investigate this subject further but by using more detailed measures and interviews with couples over longer periods of time. Valuable information could be obtained by conducting interviews with couples who had found that surviving the experience had enriched their relationship as well as from those couples who report a deterioration or who had subsequently separated.

Interviewing patients and their partners can also be of value in determining how best to support and help couples through the traumatic experience. It would also be of value to find out what currently is being offered to couples by health professionals and oncology departments, including examples of good practice. By training health professionals and other relevant staff, and by the setting up a range of supportive measures, some of the difficulties commonly experienced by couples may be reduced.

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