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Psychosocial Aspects of Breast Cancer; a Review*

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INTRODUCTION

FOR MOST of us a cancer diagnosis is a dreadful prospect. For the sufferer, that is half the trouble. It is not that cancer does not have a dreadful reality but that, after diagnosis, life does go on. On discovering she had cancer, Alice Trillin [1] wrote

> "I felt immediately I had entered a special place, a place I came to call 'The Land of the Sick People'. The most disconcerting thing, however, was not that I found that place so terrifying, but that I found it so ordinary ... I didn't feel different ... What had changed was other people's perceptions of me ... everyone regarded me as someone who had been altered irrevocably".

A fascinating new study [2] has explored these differences in perception. One finding throws much light on controversy about breast cancer; and, in the psychological sphere, does much to explain the peculiar blend of overconcern and inaction which afflicts us. While 59% of healthy men and 26% of healthy women think breast cancer is "the worst thing that can happen to a woman" only 6% of *patients* think this. It is without question men who determine the treatments available to women with breast cancer. It may therefore be these very differences in perception, between sufferer and non-sufferer, between men and women, which make for those controversies. There is still much ignorance of what *women* feel and many assumptions are made on their behalf by the clinicians treating them [3]. Clinicians dealing with breast cancer do not escape the cultural stereotypes that surround them; and, in the case of any cancer diagnosis, we all feel a mixture of horror and pity which may colour our judgement in our dealings with patients with that diagnosis.

SCREENING

In the matter of screening for breast cancer, perceptions are paramount. Publicity has succeeded in making breast cancer the most feared disease [4], but every clinician has the distressing experience of up to 30% of his patients presenting with inoperable disease. Yet a recent *Lancet* editorial [5] noted that screening clinics were full of overanxious women seeking reassurance. Although they are more anxious about breast cancer [6], there is evidence [7] that, far from being overanxious, these women have a "legitimate if unspecified concern with their breasts" [8]. Studies of the social and psychological aspects of early detection have consistently shown that where facilities, whether for screening an asymptomatic population, self-referral or breast self-examination instruction, are provided, there is a tendency among women under 60 for those at greater risk of breast cancer to take them up [9–13]. Women who accept invitations to screening clinics are more likely to have a family or personal history of breast disease [12–14], self-referred women in addition are more likely to be middle class [12], and those who practise breast self-examination are more likely to be white, better educated and health-conscious [6, 15]. Epidemiologically such women are at greater risk of breast cancer than are those who reject screening invitations [14, 16]. There is evidence that no more than a small proportion of women have their anxieties increased by the screening procedure [17]. Chamberlain [18] has indeed suggested that screening clinics could with benefit emphasize their reassurance rather than their detection role.

What is the role of self-examination? Women who practise breast self-examination (BSE) are

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capable of detecting lumps as small as one centimetre [19]. Although recent studies [15, 20] have demonstrated the efficacy of BSE, there is little point in promoting it if women then feel they are bothering their doctors when there may be nothing wrong, as suggested in another distinguished editorial [21]. Women are more likely both to practise breast self-examination and to attend screening clinics if they have an optimistic view of early detection [6]; they must therefore be assured of a warm reception when they are worried.

Little of what I have said so far applies to the older woman, particularly the older single woman, most at risk of the disease and most likely to be asymptomatic [8] and to delay consulting a doctor [22, 23]. Older women are also less likely to accept screening invitations [12] or to practise BSE [6]. A more active role for the primary care physician has been suggested [23], especially when patients come with symptoms not matched by the degree of anxiety displayed.

We cannot ignore the anxiety engendered by fear of breast cancer. Results from the wide range of studies of early detection suggest that the most effective way forward might be a combination of promotion of BSE and the provision of clinics keeping women at high risk under regular surveillance and also freely accepting those who refer themselves. As long as late presentation is a major problem, the anxieties which trigger women should be harnessed and welcomed rather than lightly dismissed.

ADJUSTMENT TO PRIMARY SURGICAL TREATMENT

It has been suggested that both delay [24–26] in seeking treatment and subsequent psychiatric morbidity [27, 28] could be reduced if it were known that breast loss were not the inevitable consequence of breast cancer diagnosis. Three questions need consideration: (1) What proportion of patients fail to adjust to mastectomy? (2) What characterizes those who fail to adjust? Is there any evidence that some patients may be unable to adjust to breast loss? and (3) Is there any evidence of improved adjustment in patients who have had breast conservation?

(1) *What proportion of patients fail to adjust?*
The cancer patient has been described as "a person under a special and unusually severe form of stress" [29]. Observations of cancer patients around the time of and in the few months following diagnosis are similar to those made of persons experiencing other severe stresses and are characterized by a sequence of mood changes. These are: shock and disbelief, anxiety, anger, guilt and finally depression [30]. What has been called the "shifting balance between denial and the integration of reality" [31] occurs in a cyclic fashion with diminishing intensity until equilibrium is re-established; or perhaps the patient does not adjust. This pattern is common in all cancers. Some of the special features of breast cancer which may add to the burden of adjustment for the patient have already been described. Two major critical reviews on psychological aspects of breast cancer recently concluded that the enormous body of literature is so "disorganized, disjointed and confusing" [32] that the amount and nature of resulting morbidity "is still only hinted at rather than convincingly demonstrated" [30]. However, six studies [25, 33–37], albeit involving small numbers of patients, have produced sufficiently similar findings on mood disturbance and sexual problems 12–18 months following mastectomy to suggest that they may be representative. Between 15 and 25% of patients are sufficiently depressed for psychiatric treatment to be appropriate and about 30% of patients have sexual problems. With this latter figure, though, it is worth bearing in mind that Silberfarb *et al.* [36] found sexual problems largely correlated with physical morbidity (although both might have had a common cause) and that Morris *et al.* [34] found almost equal numbers of benign disease patients reporting deterioration in their sexual relationship over the 2-yr period following biopsy.

(2) (i) *What characterizes those who fail to adjust?*
Studies of variables which distinguish between good and poor adjusters have consistently shown that previous psychiatric treatment [38], evidence of depression at the time of diagnosis [34, 38, 39], general emotional lability [25, 34, 39], anticipated or actual lack of support [38, 40–42] and lack of employment [40, 41] significantly predict poor adjustment.

(ii) *Is there any evidence that some patients are unable to adjust to breast loss?* After a lifetime of observations on cancer patients, Sutherland [43] wrote "mastectomy is an intolerable insult to women whose self-esteem and expectation of esteem from others is predicated to a large extent on their beauty and shapeliness". The three studies [25, 44, 45] of the independent effect of breast loss on psychiatric morbidity all illustrate the interaction between general risk factors for adjustment and the meaning of the breast for the individual woman. Women who are evidently depressed at the time of surgery and clearly express dread of mastectomy and women whose 'prime concern' is breast loss are significantly more likely to need psychiatric referral following mastectomy than are those without these characteristics. Dean *et al.*'s [45] recent study found that women with poor marriages were more likely both to opt for and benefit from immediate breast reconstruction and this evidence, along with that of Hughes [25] and Denton [44], who also found that women searching for new sexual partners were more at risk, suggests that women whose self-esteem has been damaged by failed or lost sexual relationships suffer further damage from mastectomy. But as Dean *et al.* conclude, "the decision about reconstruction can safely be left to the patient who alone knows the importance of her own breast" [45].

(3) *Does breast conservation improve adjustment?*

The only study to date specifically concerning women who have had breast conserving treatment is a small one by Sanger and Reznikoff [46], using volunteer subjects. They found that women had less change in body satisfaction than women undergoing modified radical surgery but that there were no significant differences in marital or general psychological adjustment. However, in the Boston area, where women are routinely offered radiotherapy as a primary treatment alternative, almost 100% prefer it [26], although several authors [25, 27, 47–49] have noted the progressively de-energising and depressing effects of radiotherapy resulting in delayed return to usual activities, which may of itself increase vulnerability to depressive illness.

What can be concluded from this diverse information? A proportion of women fail to come to terms with a breast cancer diagnosis. The factors which are associated with poor adjustment are general risk factors for poor psychosocial functioning under stress. Women who will be particularly at risk of poor adjustment from breast loss are those in whom one or more of these factors interact with a factor which predicts poor adjustment to breast loss, such as lack of social support and looking for a new sexual partner; or women whose breasts are a crucial element of their self-respect. It appears that these latter women are likely to indicate that they dread mastectomy. Women who undergo intensive radiotherapy may, however, need support to enable them to return to their normal activities.

INFORMING WOMEN ABOUT AVAILABLE TREATMENTS

This brings us naturally to discussion of women's participation in choice of treatment, which must, in turn, depend on their being fully informed of the available treatment options and of the criteria for selecting among them.

In articles on communicating a diagnosis of cancer and its treatment options, medical academics desert their seats of learning, clinicians step out boldly from behind their cases and the typical article on the subject polarizes two patients [50, 51], one better not being told, and the other thriving "on a diet rich in information" [50]. The evidence on which these impressions are based is entirely lacking. The doctor usually ends the article by telling the reader what *he* feels *he* would want. Lewis [52] postulates the case of a young leukaemic, innocent of his diagnosis, who is asked to sign a consent form before entering a treatment trial. "Thus, at a stroke", Lewis writes "the patient is asked to sign a consent form with some very disturbing information on it. He does not have "serious anaemia" ... he has leukaemia. Treatment for his condition is unsatisfactory... the ultimate outcome will not be cure". The language used here suggests that the patient is a child. Even so, evidence suggesting that patients, even children [53], make a better adjustment as equal partners in the gravity of their situation is largely ignored. Despite protestations that patients vary in their responses, studies [27, 54, 55] indicate that doctors adopt consistent policies of telling or not telling patients the diagnosis, based on personal solutions to the problem rather than logic or research findings. Haan's [56] detailed analysis of the participants—doctor and patient—exchanging what she calls "an unfavourable medical forecast" suggests two key influences on the doctor's behaviour: first, that doctors are not immune from the general air of pessimism with which the public continues to regard any cancer diagnosis, though recent surveys [55, 57, 58] suggest some changes may be taking place; constant dealings with cancer sufferers lead the doctor to adopt the detached position fostered by medical training. Secondly, traditional models of medical care place the patient in the position of passive recipient, and this position is reinforced when the diagnosis is cancer, an illness over which patients feel they can exercise little, if any, influence. In this position of unilateral responsibility "the doctor must do all and be all ..."; he is "in the impossible position of always needing to succeed" [56]. It is not surprising that he is reluctant to disclose that he cannot recommend any one best treatment.

Whether or not they are told the diagnosis, between 80 and 90% of patients in studies [48, 54, 59–61] stretching over the last 20 yr correctly tell research workers what it is. In avoiding frank discussion doctors indicate either that the facts are too dreadful to communicate or that they are reluctant to provide emotional support. Since defensiveness breeds defensiveness, patients in units where the policy is to tell little do not wish to know for fear of losing hope [54]. Conversely, a study [61] in a university clinic showed that patients who were fully informed about their diagnosis were more hopeful and wished to be involved in treatment decisions. Involving the patient in decisions about her care is one way for doctors to reduce the burden of unilateral responsibility.

Several authors [31, 62–65] have noted that the psychological processes through which patients pass as they adjust to the course of cancer mean that they have different requirements for information at different times. Denial is unlikely to be sustained, and one problem in labelling a patient as a 'denier' is that staff may limit communication with her so that she becomes isolated [65]. Telling the diagnosis is not a once-for-all action on the part of the clinician, but should be the hallmark of openness, a climate in which trust flourishes, anxieties can be voiced and support offered. Since in a recent American study [66] of recruitment to a randomized clinical trial, 86% of patients gave "trust in their doctor" as their main reason for participation, maintaining trust in the medical profession is clearly pragmatic for its research interests.

Although the studies reviewed here are mainly about communicating a diagnosis of cancer and not about recruitment to randomized trials, it seems that the problems which have arisen in this area may result more from the psychological discomfort which doctors feel in communicating with cancer patients than from the dilemmas of randomization, great though these are [67, 68]. The doctor can in fact reduce his awful burden of responsibility by encouraging his patient to participate in decisions about her treatment.

PROBLEMS OF ADJUVANT THERAPY

Nowhere has the patient been more conspicuous by her absence than in the literature on adjuvant cytotoxic therapy. The disease, not the patient, has been the province of oncologists; patients have not volunteered information on the psychological and social effects of the treatments either because they are ashamed of them, or because they do not think their experiences relevant [28, 69–73]. The conclusion of a recent distinguished gathering discussing adjuvant cytotoxic therapy was: "the benefits to *these women* were *deemed* to outweigh the disadvantages of short term toxicity" [74].

Three questions need answering: (1) What are the direct psychopharmacological effects of the drugs? (2) What evidence is there that the drugs cause or increase psychological morbidity from breast cancer? (3) What influences the response to side-effects?

(1) *What are the direct psychopharmacological effects of the drugs?*

There is definitive evidence [75] of cognitive impairment from chemotherapy regimes, whether steroid or non-steroid, even when effects of both metastatic disease and anxiety and depression are controlled for. Comparing patients on different regimes, Silberfarb and others [76] found those on regimes including vincristine significantly more depressed and fatigued, even though tumour response did not differ. Increased irritability and decreased libido may persist even after therapy has ended [70]. Patients can be warned of these effects, and clinicians should be alert for them [70].

(2) *What are the psychological effects of the regimes?*

Several studies [69, 71, 77, 78] have documented the psychological and social morbidity of patients on these regimes. All have had small numbers of patients and, except for that of Hughson *et al.* [78], have been poorly controlled. Even so, morbidity is clearly much higher than among patients having mastectomy alone; and, in view of the fact that we know that work outside the home offers protection against psychological morbidity, it is disturbing that two studies have reported patients giving up their jobs [71, 77].

(3) *What influences response to side-effects?*

Studies have suggested that these psychological effects are related either to the extent of physical toxicity [69] or to the extent of tumour response [79], but others [77, 80] have not found this. Our understanding of the underlying reasons for patients' tolerating or not tolerating particular side-effects has been greatly increased by personal accounts of therapy [72, 73], studies [28, 48, 60] of other adjuvant therapies and studies [80–84] which have attempted to understand the reasons for the distress using theoretical models. Several writers [71, 72, 77] have noted that the unpredictability of side-effects from treatment to treatment and unpreparedness for them made organizing their lives difficult for patients. Morris [80] found that, as in other cancer treatments, levels of distress are related to the degree of functional or symbolic disturbance which side-effects occasion; thus women who pride themselves on their cooking and sewing are likely to be more distressed by peripheral neuropathy than they are by total alopecia, which does not interfere with these activities. The 'peculiar malaise' experienced by a majority of patients in one study [71] is psychologically disturbing, to quote one patient, to "people who regard their level of energy as being as much a part of the body as arms, legs and senses" [72]. It is clear [47, 72] that many patients need help when they come to the end of a long period of concentrated adjuvant therapy of any type and must adjust from the state of chronically ill to well person at a time when they may still feel ill but medical support is dramatically reduced. Nerenz *et al.* [84] further suggest that patients whose symptoms rapidly disappear feel resentment at having to continue therapy which makes them feel ill, a result confirmed in studies of radiotherapy [47] and leukaemic patients [82].

Two strikingly useful recent studies [83, 84] have demonstrated a relationship between distress from side-effects and patients' coping responses. Depressed patients appear more likely to experience vague and diffuse side-effects, such as malaise and pain, which are difficult to manage; anxious and depressed patients are also more likely to experience anticipatory vomiting. Both authors suggest that the reason for this is that such side-effects feed into the sense of helplessness which is often a central feature of the cognitions of depressed and anxious persons. Both also suggest programmes to increase patients' understanding of their disease with the aim of reducing their sense of helplessness in a specific area, that of managing their illness.

PSYCHOLOGICAL SUPPORT

The burgeoning literature, public concern and growth of alternative therapies reflect the sense of helplessness induced by a cancer diagnosis, often manifested as dissatisfaction with information [34, 85–88], in a world in which people are increasingly unprepared to be the passive recipients of medical care. Unfortunately, those setting up services for patients have often failed to distinguish between this more general problem, which affects all patients, and the need to help the 25% who find it difficult to cope. Although difficult to evaluate, this more general need is probably well served by the short-term information/rehabilitation group, along the lines of that run at Memorial Sloan-Kettering [88, 89], in larger centres; or by using oncology counsellors [37, 90] to reinforce medical guidance. Patient volunteers [89] and mutual help groups [91] may play their part in providing role models for patients, although they have not so far been evaluated.

But it is most unlikely that such groups, or counsellors using a general psychotherapeutic approach, will much benefit those patients who suffer psychological morbidity. Apart from those upset by breast loss, there are those who cope poorly with stress. As we have seen, they are vulnerable individuals for whom a cancer diagnosis is but one more difficulty. Thus the feature which may unify these patients in the early stages of recovery becomes progressively less important as physical recovery is achieved. Those studies which have attempted evaluation, whether of groups [92] or individual counselling [37, 90], have not distinguished the components of the help offered so that, where an effect has been demonstrated, it is impossible to know whether this results from better information, early referral or counselling. Maguire *et al.*'s study [37] of a nurse counsellor demonstrated a significant effect on the level of morbidity 18 months after surgery, but it seems likely that this was achieved by early referral to a psychiatrist and the use of psychotropic medication, a form of help which is not always acceptable to patients [93–96]. A recent randomized prospective clinical trial [97] of counselling for moderately depressed women under the care of a general physician—a group psychiatrically remarkably similar to Maguire's patients—could demonstrate no effect of the help after 1 yr of follow-up.

In the case of other problem groups, those having adjuvant therapy and those experiencing early recurrence, cancer and its treatments continue to be an important focus for the patient. Therapy is not therefore aimed at solving general problems but specifically at mastery of the problems of illness. Relaxation therapy is reported [98] to be helpful in the control of side-effects; improving patients' understanding of the relationship between cytotoxic therapy and their disease may reduce damaging fantasies and patients' sense of impotence [83]. Therapy of this type, known as cognitive therapy since it attempts to alter damaging cognitions, may be helpful with other cancer patients, but is not yet evaluated in this area [99].

Although generalized support groups have not been particularly successful with adjuvant patients [100, 101], there is no doubt that they are useful for some patients with recurrent disease [102–104]. Unlike the newly diagnosed, these patients are likely to have more, rather than less, in common as their disease progresses: the problems of isolation, relations with families and medical staff, treatment side-effects, declining health and the prospect of death. These groups differ from psychotherapeutic groups in that the majority of patients are psychiatrically normal people who are coping with a shared external stress [105].

Finally, to draw together some of this material. Three problems underlie many of the controversial issues in breast cancer. These are the public fear of cancer; our sense of helplessness, whether or not rational, when dealing with it; and the fact that, in breast cancer, men are treating women. These three factors make us afraid or embarrassed to look into the real concerns of its victims so that we prefer to 'deem' solutions for them. We do not wholeheartedly put these solutions into practice because, both as scientists and as human beings, we sense we might not be quite right. There is overkill in research, and little change in treatment or psychological care for the majority of patients. On the psychological side, there is sufficient evidence to suggest solutions, even for the smaller centres, but, to put in a final thought, perhaps these cannot begin until there is more support for staff.

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