

Addressing the psychological needs of the conservatively treated breast cancer patient: discussion paper

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Introduction

The psychological problems experienced by women who undergo mastectomy for breast cancer have been well-documented^{1,2}, but there is little evidence that breast conservation with radiotherapy prevents psychiatric morbidity. Studies using standardized psychological measures comparing the psychological outcome of lumpectomy with that found in mastectomy³⁻⁷ reveal little or no difference between treatment groups. In two studies, however, there was a less negative body image reaction amongst conservatively treated women^{4,5}, and another study provided some evidence that women given a choice of operation adjusted more readily to their treatment⁶. In the CRC Breast Conservation Trial⁷, patients randomized to either mastectomy or lumpectomy were interviewed using a modified Present State Examination (PSE)⁸. Diagnoses of anxiety and depression were made using DSM III criteria⁹. Levels of psychiatric morbidity and sexual dysfunction were high, but not significantly different between treatment groups. Patients also completed a questionnaire, the Rotterdam Symptom Checklist¹⁰, and Figure 1 shows that the lumpectomy patients appeared more anxious than the mastectomy patients.

These data challenge the assumption that breast loss is the primary cause of psychosocial problems post-mastectomy. Many factors contribute to psychiatric morbidity, especially the fear of cancer and its possible recurrence. These fears are shared by all

patients irrespective of treatment. This paper will focus on the problems of the breast conservation patients and discuss the implication of these findings for clinicians and counsellors.

An inability to predict the outcome of events is a psychonoxious experience for anyone, but for the anxious lumpectomy patients in our study⁷ this centred on uncertainty related to: (a) treatments and disease outcome; and (b) interpersonal relationships and emotions.

Anxiety related to treatments

Information about treatments and disease outcome

The debate about fully informed consent has received widespread publicity, but sparse systematic study^{11,12}. There is scanty evidence to show that giving patients detailed information either creates anxiety or destroys their ability to utilize denial as a coping strategy. On the contrary, the benefits of being well-informed appear to outweigh the anxiety provoked by uncertainty and unrealistic fears. Although clear information does not prevent the sustenance of a hopeful attitude¹³, clinicians are somewhat guarded about providing prognostic information for cancer patients¹⁴ and this often communicates itself to the patient as something serious. Patients themselves often feel inhibited about seeking information from doctors¹⁵ and thus invest much time in worrying.

A poorly informed patient is more likely to be an anxious patient^{14,15}, and our study patients often asked the interviewer very basic questions about their disease and treatments. Of the 26 (54%) women in the lumpectomy group who felt that information from their doctors had been inadequate, 12 (46%) were anxious a year postoperatively⁷. In contrast, amongst the 22 (46%) patients who perceived information as good, only 3 (14%) were anxious a year later ($P=0.03$, chi-square). These are retrospective data so we do not know whether anxious patients are less satisfied with their information or well-informed patients are less anxious. A current prospective study addressing this question suggests that our original hypothesis is correct.

One difficulty for both clinician and breast cancer patient is that there are consultations when the surgeon has little clear information to impart. This can be misinterpreted as evasive or unsatisfactory by the patient. The problem is exacerbated by the fact that at each outpatient visit, women often see a different doctor, who may assume that important aspects of diagnosis and treatment have already been discussed. Over 70% of the lumpectomy patients commented that after hearing the word 'cancer', they were too

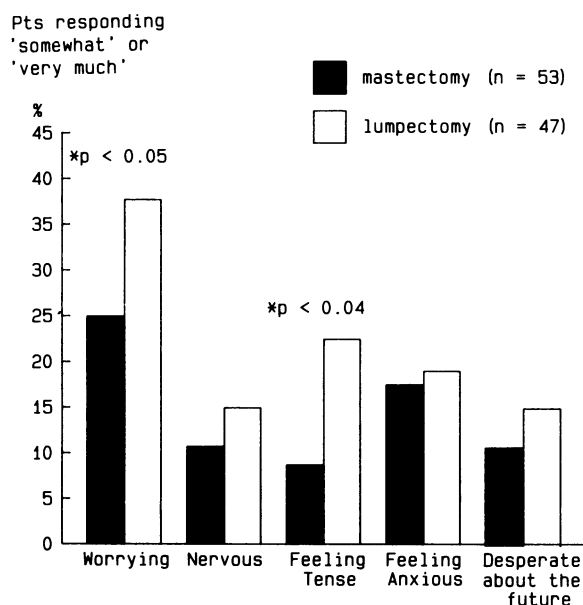


Figure 1. Single-item responses on the Rotterdam Symptom Checklist in the CRC Breast Conservation Trial⁷

shocked to take in what was said thereafter: 'After he said cancer, he might just as well have not bothered. It just went in one ear and out the other.' As this preoperative or 'bad news' consultation is also the time that most surgeons explain treatment options, we hypothesized that the presence of a close relative or friend would increase perception of information as good. This appears to be so; although the figures are not significantly different, over half the patients who had a companion present (14 of 25: 56%) felt well-informed, whereas 15 of 23 (65%) unaccompanied patients felt the information to be inadequate.

Surgery

The lumpectomy patients often expressed concern that they had received the 'wrong' treatment and that the cancer would return – a fear reinforced by the knowledge of fellow patients who developed local recurrence and subsequently had to have a mastectomy. 'I'm just frightened now in case I find another lump. It's preying on my mind all the time that there's been one and I might get another one, you know'.

Some lumpectomy patients developed obsessional checking of their affected breast; 5 of 48 (10%) admitted to self-examination at least daily: 'When I was lying in bed I was spending hours just lying there feeling. When I touch I feel as if I've got lumps all over'. Others treated it as an alien part and avoided touching it or looking at it: 'I'm scared to do it in case I find another'.

Some women (13%) felt that they had been misled about the cosmetic advantages of having 'just a little lump' removed, as the following quote reveals: 'When he said they'd just remove a little lump, I felt relieved. I mean no one really wants to lose a breast do they? But when I look at what's left I wonder if it was worth it. I mean, I'm still a freak aren't I? I don't like touching it or looking at it and I'm scared to death it's going to come back again'.

Radiotherapy

Most breast conservation patients receive radiotherapy and this produced considerable anxiety for some, due to the paradox that although radiation 'cures' cancer, it is also linked to causing cancer. Side effects of radiotherapy such as anorexia and fatigue are cumulative, making some patients feel worse at the end of treatment; indeed, 32% of the breast conservation group were still complaining of tiredness a year postoperatively. For some women this was depressing and anxiety-provoking, awakening fears that irradiation is harmful. The knowledge that one is having radiotherapy is sufficient in itself to produce side effects; one study found that 75% of patients who received sham radiotherapy reported nausea and fatigue¹⁶.

Denial is an important coping strategy for certain cancer patients. Regular radiotherapy sessions and contact with others being treated for more advanced cancers make it difficult to sustain such a strategy. Facing the reality of diagnosis during radiotherapy made some women more anxious.

Anxiety related to interpersonal relationships and emotions

Social comparison groups

An important coping strategy employed by people under stress is the use of social comparison groups¹⁷. It is usually possible, no matter how dire one's prob-

lems, to find someone worse off with whom one can compare oneself favourably and thus dissipate some anxiety. The study patients were asked if they had any close friends or relatives who had received treatment for breast cancer. Amongst the lumpectomy patients, 24 of 48 (50%) had personal experience of someone with the disease (the overwhelming majority of whom had been treated by mastectomy). These patients therefore had an opportunity to make favourable comparisons, e.g. 'I had an aunt who died, but she had to have a mastectomy'; 'My mother died 5 years ago, but she'd had both off. At least they caught mine early'. The other 24 lumpectomy patients with no experience of breast cancer in someone close had less chance of utilizing the favourable comparison coping strategy, and 13 (54%) were found to be suffering from an affective disorder one year postoperatively. Of the 24 patients with previous experience of the disease, 5 (21%) were anxious or depressed ($P < 0.05$, chi-square). Another explanation for these findings could be that patients with experience of the disease had in some way already accomplished the work of worrying vicariously through their involvement with someone close. Rehearsal of what is to come through a third party's own experience or adequate preoperative information, might well be a prerequisite for good postoperative adjustment.

Cancer carries with it a stigma that makes certain patients painfully isolated¹⁸. Fear that friends will abandon them often has a self-fulfilling element about it, as the apprehensive and depressed patient frequently does become socially ostracized. The seminal work of Brown and Harris¹⁹ showed that the presence of a close confiding relationship with a partner significantly reduced the development of affective disorders in women who had experienced a major loss or traumatic problem. Other studies have shown that good social support prevents anxiety and depression during acute crisis²⁰ and that social support is *negatively* related to the incidence of psychiatric symptoms²¹. People who regard family relationships as very good report fewer symptoms of depressive neurosis or anxiety and have fewer general psychiatric disorders²².

Only 9 of 48 (19%) lumpectomy patients claimed to have no one to talk to about problems and 4 of those patients were anxious. Even with a confiding tie, 15 of 39 (38%) were anxious, so it appears that good social supports are in themselves not sufficient. A survey about the acceptability of the study questionnaires and interview²³ produced this comment from a patient which illustrates the problem: 'I felt that the interview was very beneficial as it allowed me to talk freely about a subject which family and friends seem to avoid'.

Perhaps this is a reflection of cultural conditioning, where we expect stoicism in the face of both physical and emotional pain. The anxious patient does not want to 'break the rules' that require her to confront cancer with fortitude and cheerfulness. The sick role is legitimate for the period of hospitalization, but by the time that a year has passed with no overt signs of physical problems, our lumpectomy patient is socially obliged to be functioning normally. Undeniably the mutilation of mastectomy induces emotional trauma, but it is possible to argue that the flat chest wall 'legitimizes' a maintenance of the sick role, whereas having 'just a little lump removed' creates the feeling that as treatment was comparatively 'trivial' the

woman should be grateful at retaining her breast and quickly return to normal psychosocial functioning. When she fails to do so, guilt ensues. She may try to repress these unacceptable emotions of misery and anxiety, which then increase the feelings of worthlessness, as the following extract from a taped interview illustrates:

Patient: 'I feel so guilty about feeling so lifeless and miserable. After all, it's not as though I had to have my breast off and they say they caught it early.'

Interviewer: 'Have you told anyone that you feel this way?'

Patient: 'Oh, no - I mean the family have got enough to worry about. They think that I'm marvellous, but as soon as no one's here I just cry. They expect me to be all right now.'

Interviewer: 'Have you mentioned this to the doctor at all?'

Patient: 'No - it wouldn't be right, would it? He's done his best. I should be grateful. Anyway, he's always so busy.'

What then can the busy yet compassionate clinician do to help prevent or ameliorate any of these problems? Simple awareness that patients might be experiencing some of the difficulties that have been outlined in this paper might assist the clinician in recognition of symptoms.

Ameliorating preoperative problems

In common with other studies²⁴, patients reported that the most anxiety-provoking period was that between finding the lump and the first outpatient appointment. Most had been unable to sleep, due to worrying thoughts ricocheting around their heads all day and night. They had been tense and unable to relax or concentrate and had felt extremely irritable. In such a highly charged emotional state, it is hardly surprising that so many patients reported that the information regarding diagnosis and treatment was inadequate. We have provided some evidence that the use of a patient advocate or close companion may facilitate assimilation of the information given, and other workers have described the benefits of providing written information²⁵.

Giving reassurance

All cancer patients suffer uncertainty about their disease and are fearful of recurrence or metastatic disease. As breast conservation is a relatively new treatment for breast cancer, many patients so treated harbour anxieties that they may not have had the most effective treatment. Some will have these anxieties further exacerbated by the knowledge that radiotherapy is required to 'clear up any remaining cells'. The surgeon can do a great deal by reassuring patients that for early breast cancer there is no difference in survival for patients treated by mastectomy or lumpectomy²⁶. False reassurance destroys trust if things go wrong, but there is much that the surgeon can say that will permit patients to maintain hope and a positive attitude.

Ameliorating postoperative problems

Giving permission to talk about emotions

Few surgeons fit the callous, insensitive stereotype portrayed of them by some journalists^{27,28}. One reason for the failure of surgeons to detect psychiatric morbidity is the reluctance of some patients to disclose their emotional experiences. We have shown how these women often feel guilty about their

reactions to treatment and so rarely volunteer their feelings to surgeons. The busy clinician does tend to focus on enquiries concerning physical problems in follow-up clinics, thus reinforcing the patient's feeling that she should not mention psychosocial problems and reinforcing the surgeon's assumption that psychiatric morbidity does not exist. Giving permission, by encouraging the patient to talk about her attitude towards her cancer and treatment, would help remove this impasse. If the surgeon lacks the time, appropriate communication skills and emotional resources to cope with these important aspects of care, then assistance from *properly* trained counsellors might be invaluable.

Giving appropriate treatment

Even when patients are recognized as clinically anxious or depressed, there is often a surprising reluctance to treat them effectively with appropriate anxiolytic or antidepressant therapy. The assumption that affective disorders are natural reactions to a diagnosis of cancer, and therefore not worthy of treatment, is a nonsense.

Effective relief of depression in cancer has been achieved with drugs such as mianserin, one of the new generation antidepressants with few side effects²⁹. Anxiety can be controlled with short courses of benzodiazepines such as lorazepam, and anxiety-related insomnia is often eased by a hypnotic such as temazepam. When the more acute psychiatric symptoms are under control, referral on to a clinical psychologist or psychiatrist for anxiety management training or cognitive behaviour therapy is recommended.

Utilizing other sources of help

The specialist nurse counsellor: Some hospitals employ specialist nurses who can be trained to recognize psychosocial dysfunction. If these nurses are then able to refer patients on for appropriate treatment at an early stage, then rates of psychiatric morbidity decline³⁰. Such nurses can also be trained in counselling skills which may ameliorate mild or borderline cases of anxiety that might not require other pharmacological or psychiatric intervention. The involvement of specialist nurses at the beginning of treatment may also exercise a prophylactic effect.

It seems intuitively reasonable that counselling is valuable. Indeed, the recent King's Fund Consensus stated that: 'It is essential that counselling should be available'³¹, but there is little empirical evidence demonstrating that it has a beneficial effect³². Research is necessary to tease out the specific from the nonspecific effects of counselling; and to identify the characteristics that put certain patients at greater risk than others of developing psychiatric morbidity. Not all women require help; some might even find that it provokes anxiety or prevents them from utilizing their own coping strategies. The ability to act pragmatically and recognize which patients need counselling support and precisely what sort of help would be beneficial, is a prerequisite for any individual offering this service. It is unlikely that anyone without adequate training, no matter how sensitive and empathetic, could naturally possess all the appropriate skills and emotional resources necessary to be appointed as a specialist counsellor. Approved counselling courses are run by the British Association of Counselling, which publishes a useful *Counselling Resources Directory*³³.

Psychologists and social workers: In the past 20 years some powerful psychological interventions have been developed from the theoretical basis of behavioural and cognitive psychology. These interventions provide effective treatment options for stress-induced and phobic anxieties^{34,35}. Other professionals with a training in psychology might therefore be able to provide more than the nurse-counsellor, especially if they can offer patients help with relaxation therapy. Several studies have demonstrated the usefulness of this approach^{36,37}. Anxiety management training initially teaches patients how to identify their own internal cues for anxiety. They can then learn to induce anxiety through mental imagery and bring it back under control through muscular relaxation and imagery. This ability gives patients the confidence to exert self-control over symptoms of anxiety irrespective of the provoking stimulus. There is some evidence that relaxation therapy, together with cognitive therapy, can ameliorate fears of recurrent disease³⁸. In cognitive behaviour therapy, the patient is helped to shift perspective from a negative to a more positive viewpoint. The benefits of the psychological techniques of anxiety management and systematic desensitization have also been demonstrated in those patients receiving chemotherapy who experience anticipatory nausea and vomiting or become needle-phobic^{35,39}.

Sex therapists: Methodologically sound research about the effect of breast cancer on sexual functioning is sparse⁴⁰. Reports of the body image problems and loss of interest in sexual activity post-mastectomy considered breast loss to be the major cause of this dysfunction^{1,2}. However, women who have conservative surgery suffer a comparable deterioration in their sex lives to that experienced by mastectomy patients⁷. Some patients and their partners therefore might be helped by referral to a sex-therapist for conjoint therapy⁴¹, but not all would necessarily welcome this. One study reported that although desire for sexual intercourse declined for 87.5% of their breast cancer patients, half of these women reported an increased desire for other affectionate behaviour, such as kissing and physical closeness⁴². The surgeon can help by fostering open communication with the patient regarding sexuality.

Volunteer groups: In some hospitals, volunteers, many of whom have been treated for breast cancer by mastectomy, provide an advice/prosthesis-fitting service. There have been doubts raised about the potentially harmful effects of visits from a non-qualified person who might not have resolved all her own difficulties and could transmit these on to the patient⁴³. The victim/counsellor is not necessarily appropriate unless careful selection, training and supervision are given. As more women are treated conservatively, they may not meet up with the mastectomy counsellor if her primary role is one of prosthesis-fitting. This might well leave a large number of breast cancer patients with no counselling or support service at all.

Self-help groups: Some hospitals provide facilities or support for self-help groups. We have very little empirical information about the efficacy of these groups for breast cancer patients⁴⁴, but patients who do attend regularly attest to their supportive and

important informational role. Few of the lumpectomy patients in our study utilized such groups, as those available tended to be set up for mastectomy patients. Perhaps other self-help groups will evolve with the advent of more conservatively treated patients. This paper has highlighted the anxiety and consequent guilt and isolation many lumpectomy patients experience postoperatively, and the difficulty that many of them have in communicating these emotions to relatives and friends. Self-help groups run by someone with a sensitivity to these problems and skilled in group dynamics might be very useful. This could also be an appropriate time for teaching the group relaxation therapy⁴⁵. The charity CANCERLINK provides a directory of self-help groups and will assist with training and organizational help in setting up local groups through their Groups Support Service.

Conclusions

The patient treated conservatively for early breast cancer clearly has a plethora of emotional problems to face. We cannot assume that preserving a woman's breast will in itself protect her from anxiety and depression. She still has to cope with the knowledge of having a life-threatening disease with an uncertain prognosis. In addition, these patients often feel that they are inadequately informed about their disease and find difficulty in communicating their worries to health carers and family or friends. In order to design effective intervention programmes that may prevent or at least alleviate distress, we need much more basic research on the identification of the factors that contribute to the psychiatric morbidity associated with the diagnosis and treatment of early breast cancer. Until that time, clinicians can do much more to help their patients – by improving interpersonal communication skills; by utilizing other sources of help from other professionals; and by having the intellectual and emotional honesty to recognize that just because a patient fails to volunteer psychological distress that does not mean that it does not exist, or that it does not merit attention and treatment.

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