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Psychological Aspects of Breast Cancer; Workshop Report

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INTRODUCTION

THE USE of parallel sessions prevented many surgeons and oncologists from contributing to the workshop on psychosocial aspects. This led some participants to express concern that insufficient attention was still being paid to these aspects. Others argued that much progress had been made in recent years. They cited the growing willingness of surgeons to use lumpectomy rather than mastectomy in early breast cancer and the increasing awareness that some adjuvant chemotherapy regimes were extremely unpleasant for the patient. The workshop itself also confirmed that progress had been made, since one of the best papers was given by a surgeon, Simpson, of Wellington, New Zealand, rather than a psychologist or psychiatrist.

Three main questions were considered: (1) What studies have recently been completed or are still underway that will help improve the care of women with breast cancer? (2) What areas have been neglected? (3) How might any deficiencies be remedied?

PROBLEMS BEFORE OR AT THE TIME OF DIAGNOSIS

Kushner, herself a patient who had been treated for breast cancer, highlighted the emotional turmoil experienced by most women in the period after discovery of a lump, discharge or retraction of a nipple. She called this emotional response the 'anxiety tree' since the uncertainty about whether the symptoms were due to cancer or benign disease coupled with waiting for a diagnosis fuelled much anxiety. This prompted her to set up a 24-hr advisory service manned by paid helpers who were carefully selected and trained, since she felt insufficient help was available from the patient's own doctor or hospital. They provide factual information about the diagnosis and treatment of cancer to any woman who requests it as well as explanatory booklets. They also advise them how they might speed up the diagnosis or verify its accuracy.

In an attempt to reduce uncertainty, many clinicians have adopted a 2-stage diagnostic procedure. A biopsy is first performed and the diagnosis made. The woman is then told she has a cancer which will need to be removed in a few days time and the treatment discussed. This means that when she proceeds to lumpectomy or mastectomy she already knows what is wrong and will have had an opportunity to discuss it with her doctor and family. Other clinicians still prefer to do a biopsy under general anaesthetic and proceed immediately to further surgery if the frozen section confirms a malignancy.

Psychologically, the 2-stage procedure might be expected to cause greater short-term upset because it confirms the diagnosis and the woman has a period of waiting, but better long-term adjustment because of the opportunity to face and discuss what is to happen. The one-stage procedure may minimise distress early on because the women may still hope that the disease is benign, but it could cause greater distress later on when they suddenly realise they have had a cancer and a breast is removed. As yet there has been no systematic comparison of a 1- vs 2-stage procedure to test whether the latter leads to a better long-term psychological and social adjustment.

Nor has there been any rigorous study of the relationship between what patients are told about their disease or how their questions are answered and their later adjustment. Is it better to be honest ("I'm afraid you have a cancer there. The good news is we should be able to remove it completely") than try to protect the patient ("There are a few cells which could turn cancerous if we do not remove them")?

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SCREENING

No papers were proferred on the psychological effects of screening and breast self-examination, but certain women would appear to be at risk psychologically.

Most go because they feel fit and well and are confident that they will be confirmed as free of cancer. If they turn out to have cancer this is likely to come as a terrible shock because of the absence of warning signs and symptoms and the abruptness of the transition from being well to seriously ill.

The fact that the cancer was asymptomatic is also likely to pose other problems. If it was there without her knowing how will she know if it has recurred? What confidence can she ever have that she is free of disease?

While breast self-examination may lead to early diagnosis, it could, in some women at least, promote anxiety about breast cancer. There have already been reports of women developing obsessional rituals of examining their breasts many times a day and seeking very frequent medical reassurance that they are clear.

It is therefore important that current studies of screening include adequate psychological measures and pay particular attention to these sub-groups.

ROLE OF FOLLOW-UP

Regular follow-up is mandatory if clinical trials are to be conducted, but it has not been established that it materially improves survival. Are recurrences or metastatic disease picked up any sooner than they would have been if the women had been discharged back to the care of their own doctors? What has been established is that follow-up visits usually remind women of their disease and activate worry that it may have recurred. They also learn of the fate of other women who have been treated for the same disease. Some women, however, gain confidence from the knowledge that they are being followed up regularly, and the relative merits of regular follow-up vs little follow-up have still to be determined.

MORBIDITY OF TREATMENT

The psychological and social sequelae of breast cancer, mastectomy and adjuvant chemotherapy have already been documented. It is clear that at least 1 in 4 patients will develop an anxiety state, depression, sexual problem or combination of these. Knopf reported a study in which she interviewed 28 women who had completed treatment with CMF (cyclophosphamide, methotrexate and 5-fluorouracil) and 50 women who were still on treatment. While on CMF, 48% had experienced a reduction in libido and the physical toxicity had been considerable. Once treatment was completed women began to worry much more about their breast loss and survival. Knopf's findings suggest that women may need emotional support after completion of CMF to help them resolve these concerns.

This question of when to provide support was also raised by Simpson and his colleagues. They had used linear analogue scales to measure the quality of life in four groups of patients: those treated by mastectomy; or by mastectomy and chemotherapy; those given chemotherapy for advanced disease; or women who had had a chole cystectomy (controls). They noted a sharp and marked decline in quality of life in the breast cancer patients 3 months after surgery, especially in those on chemotherapy, even though most had seemed to recover well initially. They concluded that prolonged support by a specially trained nurse was necessary, that women should be encouraged to return to work as soon as possible and that early referral to a psychiatrist should be considered when problems were noted.

This concern about the failure of some women to return to work even when well enough to do so was echoed by Lober and his colleagues. In a multicentre trial based on simple questionnaires, over one-third failed to return to work or took a much less demanding job.

DETECTION OF PROBLEMS

A major question concerns the ability of clinicians to detect which women have developed problems and the willingness of women to disclose them. Simpson and his colleagues made a valuable contribution to this debate. In their quality of life study they had asked the doctors, specialist nurse and relatives to complete identical linear analogue scales at the same time as the patient. This allowed them to determine how well these raters agreed with the patient. There was good agreement between the doctors and patient on chemotherapy on only 4 out of 20 items. The nurse only agreed on 5 items. Thus there were serious discrepancies, and these were equally evident on items measuring toxicity, physical adjustment, psychological adjustment and social activity. This confirms previous claims that much morbidity remains hidden because clinicians are inadequately trained to detect it, and patients do not want to burden the doctor with such problems [1, 2]. It also raises serious doubts about the reliability and validity of performance indices like the Karnofsky scale.

TRAINING IN ASSESSMENT SKILLS

Studies which have observed doctors and nurses directly while interacting with patients have confirmed that they are often lacking in the relevant skills [3]. This should not be surprising since few will have received any explicit training in interviewing skills, or ever seen or heard directly how they relate to patients. Even if they possess the skills they may be reluctant to use them. For it could be like opening Pandora's box and they might be swamped with problems, some of which they might not be able to handle. It could also take up much time and jeopardise their own emotional survival. Do I really want to know that the chemotherapy which is essential for any chance of survival is having such drastic psychological effects? Consequently, many clinicians prefer to work on the basis that any patients who develop such problems will disclose them. Bransfield, in reporting a study of nurses, suggested they actually became worse at detecting problems the longer they were in training, the more specialised they became, the longer the treatment and the worse the prognosis.

The study reported by Faulkner and Maguire offered some hope that doctors and nurses could learn the relevant skills. In a previous study a specialist nurse was asked to practise assessing mastectomy patients. She recorded each interview on audiotape and was then given feedback. Feedback included discussion of the questions which need to be asked to elicit any problems (for example, "How have you been feeling in your spirits since surgery? Have you felt low or miserable?"). It focused on the use of techniques like detecting and clarifying cues ("You say you felt devastated by the breast loss; would you like to tell me about it?") and control (keeping the patient to the point). The indications for psychiatric referral were also discussed. The specialist nurse subsequently recognised and referred 76% of those of her patients who were independently judged to have psychological problems. The doctors and nurses concerned with a control group recognised and referred only 15%. Consequently there was over 3 times less psychiatric morbidity in the specialist nurse's group at 12–18-month follow-up [4].

This was encouraging and suggested that non-specialist nurses might also be able to learn these skills.

A group of 8 nurses who worked on a ward predominantly concerned with the surgical care of breast cancer patients were given similar feedback training and also taught to use a standardised assessment form [5]. This required them to rate the presence and severity of any problems found and the action taken. Assessment of interviews before and after training showed that considerable gains had been made. They were much more likely to have asked about key areas and to have detected any problems compared with before training.

Follow-up confirmed that they continued to use these skills, integrated their assessments into their daily work and used them with other patients. A key feature of this scheme was that the nurses had direct access to a psychiatrist if they wanted advice or wanted to refer a patient who had become very anxious or depressed. Thus it might be possible for a specially trained nurse to enlist the help of non-specialist nurses in ensuring that the progress of each patient with breast cancer is carefully monitored. This would minimise the risk of her accumulating a load that she could not cope with, allow her to be more of a resource person and act as a consultant to nurses already concerned with care.

Much concern was expressed about the need to provide emotional support for specialist nurses and the risks to their emotional well-being if they were not properly trained and supported. Examples were given of nurses who had failed to cope with this role. The willingness and ability of psychiatrists to provide support was questioned and this could prove to be a major limiting factor in the development of better aftercare schemes. Studies are required to determine the best means of providing support to specialist nurses.

PREDICTING THOSE AT RISK

The task of a specialist breast cancer nurse might be eased considerably if she could restrict her attention to those most likely to develop problems. Maguire and his colleagues reported a study of 152 patients who underwent mastectomy that sought to determine which pre-operative and post-operative factors were associated with the development of morbid anxiety, depression and sexual problems. Menopausal status, the woman's statement about the value of her figure, level of anxiety and prior experience of cancer in others had no predictive value. Dread of mastectomy and depression of moderate or marked severity proved good predictors of later problems. Previous psychiatric illness predicted a change from no symptoms of anxiety or depression to some, rather than from no symptoms to sufficient to constitute psychiatric illness!

The presence or absence of a confiding tie (that is, someone in whom the patient can confide how she really feels) was a powerful predictor before and after surgery. Logistic regression and log-linear modelling confirmed that it had a considerable protective effect against the development of problems, especially depressive illness and sexual problems.

After surgery, the development of moderately severe or severe pain or swelling in the affected arm, experiencing of moderately severe or severe toxicity on chemotherapy and failure to adapt to the loss of a breast were strongly predictive of psychiatric problems.

If these findings are replicated in other studies, it would be justifiable to focus attention on those women who are already depressed before surgery, dread the idea of losing a breast, have a history of previous psychiatric illness and have no confiding tie, and be alert to those who do not accept the breast loss, develop physical complications or experience toxicity when on chemotherapy.

What is not clear is how the presence of a confiding tie has such an effect, and studies are needed to clarify this. Nor has it been shown that a non-confiding tie can be converted with help into a confiding one. If it could, it might well prevent problems. The data also suggest that breast conservation, adoption of axillary sampling rather than clearance and reduction of the adverse effects of chemotherapy ought to reduce psychosocial morbidity substantially.

BREAST CONSERVATION

While the incidence of problems should be less if the breast is conserved than if it is removed, it is possible that this could be offset by increased worry that not all the cancer has been removed and adverse effects of increased radiotherapy. Some studies comparing women who had a mastectomy with those who had not were discussed, but it seemed likely that only controlled studies which included adequate psychological measures would satisfactorily answer this question. Very preliminary data from studies reported by Jonkers and by Beckmann suggested that conservation might lead to a marked reduction in problems. For example, only 9% treated with lumpectomy experienced a loss of libido, compared with 40% of those undergoing mastectomy. Opinion was firmly divided about the feasibility of such controlled trials. Most agreed that informed consent should be obtained, but some thought that this would lead too many women to refuse to participate. Even if they entered a trial they might reject the treatment option to which they were assigned. The trials might also be subject to considerable bias. Those most likely to cope well with any treatment might be more likely to enter the trial and those less able to cope more likely to refuse. This would minimise the chance of finding any differences. If such trials are conducted the demographic and psychological characteristics of those who participate must be compared with those who refuse. An alternative strategy which has been adopted in some centres is to do the randomisation and then present the option so drawn as the best treatment for them. At present there are no data about the psychological impact of informed consent vs the 'best option' policy.

THE ROLE OF VOLUNTEERS

The workshop was taken to task by a participant who belonged to a self-help organisation because there had been no mention of the role of volunteers in helping women adapt to mastectomy. Some participants had misgivings about their use. They recounted experiences of volunteers who had been treated for breast cancer getting over-involved and rejecting advice. Some tended to impose their own experience on the patient rather than listening to her and allowing her to express her own concerns. The reluctance of many volunteer organisations to implement proper selection and training procedures was also seen as a major barrier to acceptance of their role by the medical and nursing profession. While there have been descriptive studies of the selection, training and impact of volunteers there seem to have been no controlled studies of their value or the effect of such work on their own psychological adjustment. Such studies are needed if the potential value of volunteers is to be properly realised.

OTHER AREAS REQUIRING ATTENTION

There have been very few studies of the impact of breast cancer and its treatment on the woman's partner or children. Nor has much been established about the way women from different countries and different cultures respond to breast cancer and mastectomy. Wide differences in reported psychosocial morbidity may reflect the influence of culture as much as different treatment policies.

Much more work is needed to determine how best to help women once problems have been discovered. Persistent depressed mood accompanied by symptoms like early-morning waking, diurnal variation of mood, loss of energy, impaired concentration and ideas of hopelessness responds well to antidepressant medication. However, it is not yet clear if depression which is still at a mild or moderate level of severity might respond equally well to more recently developed psychological methods of treating depression [6]. These have the potential advantage of both alleviating the depression and teaching the patients to cope more effectively with their predicament. Alternatively, the combination of antidepressants and psychological methods might prove optimal.

Anxiety usually responds to anxiolytics like Diazepam®. Concern about the risk of dependence and longer-term adverse effects on the brain has prompted the greater use of behavioural therapies like relaxation and anxiety management techniques. Their precise role and efficacy in the short and longer term have still to be determined. They may prove to have a special place in the treatment of those who become very anxious before each chemotherapy treatment. They might also prove of prophylactic value if taught to all patients shortly after diagnosis. It is possible that specialist nurses could be taught to give these treatments and prove as effective as psychiatrists or clinical psychologists, even when taught to groups of patients rather than individually. Indeed, it might prove as beneficial to treat those who are to have behavioural therapy for anxiety or depression in groups as it would be to treat them individually. It would be more cost-effective, but any positive effects might be outweighed by the disadvantages of putting cancer patients together.

Problems might be preventable if those coping strategies which predicted a poor outcome could be identified and changed to strategies predicting a good psychological outcome. Some workers such as Morris have already begun to determine if such behaviours can be reliably specified and measured. If they can be, their relationship to outcome and susceptibility to intervention could be properly assessed.

There was no discussion in the workshop about the relationship between patients' attitudes, coping styles and outcome of their cancer, but it was accepted that it is an important area for study. The most stringent test would be to take patients whose attitudes predicted non-survival, help them change these views and show that this improved their survival compared with similar patients who were not so helped. Such help could be given on an individual or group basis.

Concern was expressed that while much was known about the impact of diagnosis and treatment there had been little study of the consequences of recurrence, especially in patients who had been given a course of adjuvant chemotherapy or had been unable to complete it. It was also suggested that there was still a need for in-depth studies of how women treated for breast cancer perceived their predicament at different points of their illness career and how they tried to find a meaning for it.

PROBLEMS OF MEASUREMENT

Problems of measurement were highlighted by the range of measures adopted by members of the workshop. Some relied on simple self-ratings completed by the patient, which usually consisted of linear analogue or 4-point scales. Others preferred observer ratings or standardised and structured interview methods administered by trained raters. The use of more qualitative techniques such as relatively unstructured interviews and projective tests was also advocated.

Discussion revealed that those involved in current studies had two quite different aims when using measurement. One aim was to try to develop measures of quality of life. The problem inherent in this approach was to agree on a concept of what constituted 'good quality' and on the dimensions to be measured. Measurement tended to focus on levels of activity, and satisfaction vs dissatisfaction. The other aim was to determine the number who developed physical toxicity, social problems or psychiatric morbidity of sufficient severity to warrant clinical intervention.

There was continued pressure on researchers from clinicians to devise a simple, short self-rating scale which could be used in clinical trials to allow quality of life to be measured. Such scales could probably determine if there were any differences between two treatments.

From the clinical viewpoint the best way forward would be to concentrate on measures of physical toxicity, social functioning and psychological adjustment, including anxiety, depression and sexual adjustment [7].

Comparative studies are required to see how acceptable self-rating scales are in different cultures within Europe (Anglo-Saxon, Teutonic, Nordic, Gallic and Latin). To be of any value they must be administered in a standard fashion by a trained nurse who explains the scale's purpose and checks that it has been completed correctly. Presentation at monthly intervals may be the optimal frequency of administration and estimates of change must take statistical account of the values before treatment.

These studies should attempt to validate the questionnaires by interviewing random samples of high, medium and low scorers using standardised and structured interview methods such as the Standardised Social Interview [8] and Present State Examination minus the psychotic items [9]. Interviewers would need to be rigorously trained beforehand using videotaped examples, practice and feedback. Tests of reliability and rating drift should be included and independent audit carried out by interviewers from one centre rating the audiotapes from another and comparing ratings made on those tapes. In this way, the feasibility, reliability, specificity and sensitivity of each contending scale could be determined in relation to breast cancer patients with early or advanced disease, or who are being given or not given particular forms of treatment. These studies cannot be done without adequate research funding.

Meanwhile, studies of psychosocial aspects should try to include: details of how the samples were obtained; how representative they were of the population from which they were drawn; whether diagnosis was a 1- or 2-stage procedure; what physical treatments (with what complications) were given since diagnosis; the incidence of recurrent disease; whether patients had a confiding tie, previous psychiatric illness or pre-operative depression; and the number and characteristics of those who refused to take part.

CONCLUSION

The workshop has confirmed that many important questions relevant to the care of women with breast cancer remain to be answered. If they are to be answered adequately, there needs to be greater cooperation between centres, and a willingness to test and validate different methods of measurement. This does not preclude descriptive and qualitative studies, which should continue to afford valuable insights into the experiences of women being treated for breast cancer.

REFERENCES

1. Palmer BV, Walsh GA, McKinna JA, Greening WP. Adjuvant chemotherapy for breast cancer: side-effects and quality of life. *Br Med J* 1980, **281**, 1594–1597.
2. Maguire P. Psychosocial aspects and rehabilitation. In: Baum M, ed. *Clinics in Oncology; Breast Cancer*. Philadelphia, PA, W. B. Saunders, 1980, Vol. 1, 833–852.
3. Sanson-Fisher R, Maguire P. Should communication skills be taught in medical schools? *Lancet* 1980, **ii**, 523–526.
4. Maguire P, Tait A, Brooke M, Thomas C, Sellwood R. Effect of counselling on the psychiatric morbidity associated with mastectomy. *Br Med J* 1980, **281**, 1454–1456.
5. Tait A, Maguire P, Faulkner A *et al.* Improving communication skills. *Nursing Times* 22 December 1982.
6. Blackburn I, Bishop S, Glenn A, Whalley L, Christie J. The efficacy of cognitive therapy in depression. *Br J Psychiat* 1981, **139**, 181–189.
7. Van Dam FSAM, Linsen ACG, Conzijn MA. Evaluating quality of life: behavioural measures in cancer clinical trials. In: Staquet M, Sylvester R, Bayste M: *The Practice of Clinical Trials in Cancer*. Oxford, Oxford University Press, 1983.
8. Clare AW, Cairns VE. Design, development and use of a standardised interview to assess social adjustment and dysfunction in community studies. *Psychol Med* 1978, **8**, 584–604.
9. Wing JK, Cooper JE, Sartorius N. *Measurement and Classification of Psychiatric Symptoms*. Cambridge, Cambridge University Press, 1974.