

# Psychological support for patients undergoing breast cancer surgery: a randomised study

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## Abstract

**Objective**—To evaluate the effect of support from a nurse specialising in breast care and a voluntary support organisation on prevalence of psychological morbidity after surgery for breast cancer.

**Design**—Prospective randomised study.

**Setting**—Three teaching hospitals in Glasgow with established breast clinics.

**Subjects**—272 women aged less than 70 years undergoing surgery for breast cancer.

**Interventions**—Patients were randomly allocated to receive routine care from ward staff, routine care plus support from breast care nurse, routine care plus support from voluntary organisation, or routine care plus support from nurse and organisation.

**Main outcome measures**—Prevalence of psychological morbidity as assessed by self rating scales: 28 item general health questionnaire and its subscales, and hospital anxiety and depression scale. Measurements were made at first postoperative clinic visit and at three, six, and 12 months after surgery.

**Results**—On each self rating scale, psychological morbidity tended to fall over the 12 month period. For each scale, scores were consistently lower in patients offered support from breast care nurse alone compared with the other groups, which were similar to each other. Differences were significant or nearly so: P values were 0.015 (28 item general health questionnaire), 0.027 (anxiety and insomnia), 0.072 (severe depression), 0.053 (somatic symptoms), 0.031 (social dysfunction), 0.093 (hospital anxiety), and 0.003 (hospital depression).

**Conclusion**—Support from breast care nurse can significantly reduce psychological morbidity, as measured by self rating scales, in women undergoing breast cancer surgery.

## Introduction

The high prevalence of psychological morbidity after surgery for breast cancer is well documented.<sup>1-4</sup> Most centres undertaking the primary management of patients with breast cancer now have specifically designated nurses who provide practical advice and support. An alternative approach has been pioneered by various support groups. Volunteers, who are not medically qualified but who may be cancer sufferers themselves or the relatives of cancer sufferers, offer counselling and support. Studies of the effectiveness of breast care nurses have given variable results,<sup>5-8</sup> while the effect of voluntary support organisations has not been fully evaluated.<sup>8</sup>

The aim of the present study was to assess the impact of a breast care nurse and a support organisation on the prevalence of psychological morbidity in patients undergoing surgery for breast cancer.

## Patients and methods

Consecutive patients aged less than 70 who were undergoing breast cancer surgery in three Glasgow teaching hospitals over a two year period were considered eligible for the study. All patients were under the

care of three consultant surgeons with a strong interest in the management of breast cancer. The extent of surgery and the choice of adjuvant treatment were defined by a standard joint protocol. Before surgery, patients were randomised by telephone to one of four groups: (a) routine support from ward staff and an information booklet (Understanding Cancer of the Breast: BACUP), (b) routine ward care as above and support from a specialist breast care nurse, (c) routine ward care as above and support from a voluntary organisation (Tak Tent), and (d) routine ward care as above and support from both the breast care nurse and the voluntary organisation.

## SUPPORT FROM BREAST CARE NURSE

The nurse (JMCA) had previous ward experience in managing breast cancer patients after surgery. In addition she had extensive experience of documenting the prevalence of psychological morbidity in breast cancer patients with self rating scales and talking to breast cancer patients as part of a study comparing psychological morbidity in patients undergoing either mastectomy or breast conservation.<sup>9</sup>

The nurse adopted an informal approach and did not wear a uniform. Before surgery, she explained the preoperative and postoperative routine and provided information about the type of surgery, the likely appearance of the wound, and symptoms such as numbness in the arm. She ensured that those patients who needed a prosthesis received one promptly. She encouraged patients to use their arm freely after surgery and to return to all normal activities. If further treatment (radiotherapy, chemotherapy, or tamoxifen) was prescribed she informed the patients of its nature, duration, and possible side effects.

She offered patients the option of a joint interview with their husband or other relatives. She avoided giving false reassurance about the prognosis but intervened if a patient was unduly pessimistic. She corrected misconceptions such as the belief that the cancer arose from erroneous behaviour by the patient. She allowed patients to express emotions such as grief freely and listened sympathetically to sexual problems such as feeling undesirable. She gave reassurance that such feelings were understandable.

She emphasised that the patients would be seen again at their subsequent clinic visits and that they could make an appointment to see her at any time. The patients were given a contact telephone number. The initial interview lasted 20-30 minutes; the length of subsequent interviews was dictated by need and unavoidable external pressures on time.

## SUPPORT FROM VOLUNTARY ORGANISATION

Tak Tent ("Take care" in Old Scots) was founded in Glasgow in the late 1970s to help people affected by cancer.<sup>10</sup> Trained and accredited counsellors started seeing clients in 1986. Training in counselling was based on the transactional analysis theory developed in the 1950s by the American psychotherapist Eric Berne.<sup>11</sup> Counsellors underwent 200 hours of training, some of which was residential. The programme of training and counselling was supervised by an

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accreditation committee. After accreditation, regular meetings of the counsellors for the purpose of supervision were held to ensure that standards were maintained.

Tak Tent offered three types of support: information, counselling, and regular group meetings with fellow cancer sufferers. Usually cancer patients self refer to Tak Tent and seek help from the counselling service or participate in the regular group meetings. For the purpose of this study, Tak Tent agreed to function in an atypical fashion: patients allocated to receive support from Tak Tent were given an introductory leaflet and subsequently contacted by one of the counsellors after discharge from hospital. All contacts between the patient and the counsellors were through the association's office.

It was up to individual counsellors to decide the level of support required. There were no restrictions on the methods the organisation might use. These might include maintaining contact by telephone or post, arranging one to one meetings for counselling, and encouraging attendance at Tak Tent group meetings. Reports were prepared at regular intervals and subjected to peer review and scrutiny by the director of training and counselling. One of the surgeons (DCS) was also chairman of Tak Tent at the start of the study.

#### ASSESSMENT OF PSYCHOLOGICAL MORBIDITY

Psychological morbidity was measured with self rating scales: the 28 item general health questionnaire and the hospital anxiety and depression scale.<sup>12,13</sup> Scores on the general health questionnaire range from 0 to 28 and measure non-specific psychological morbidity. The questionnaire also contains four subscales: somatic symptoms, anxiety and insomnia, social dysfunction, and severe depression. Scores on each subscale range from 0 to 21. The hospital anxiety and depression scale was designed specifically for hospital patients, and scores range from 0 to 21 for both anxiety and depression. We had previously shown a close relation between scores on the general health questionnaire and observer ratings used by Maguire.<sup>3,4,14</sup> Measurements were made at the first postoperative clinic visit and at three, six, and 12 months after surgery.

The study was approved by the hospital ethics committee. Because it was accepted that informed consent would introduce bias and therefore invalidate the findings, informed consent was not sought.

#### DATA ANALYSIS

The data on the self rating scales were summarised as means and standard deviations. This was done in spite of the distributions being skewed because, with a large number of tied observations, the medians were unhelpful. The data were analysed by calculating a simple summary measure for each woman, namely the average value over her four assessments (postoperative clinic visit and follow up at three, six, and 12 months).<sup>15</sup> These summary measures were then compared among the four groups by means of the Kruskal-Wallis test, with a correction for ties. The analysis was performed on an intention to treat basis. The Kruskal-Wallis tests were followed with pairwise multiple comparisons among the four treatment groups by means of Mann-Whitney tests. The results of these comparisons are reported as unadjusted P values. A Bonferroni correction to allow for the six pairwise comparisons would require the unadjusted P value to be  $\leq 0.008$  before one could claim significance at the 5% level.

#### Results

Three hundred and eleven patients were considered eligible for the study. Of these, 39 were excluded: two did not speak English, two were deaf, nine were of low intellect, four had presenile dementia or were in psychiatric care, and 14 lived in remote areas and were unable to attend follow up. In the remaining eight cases the surgeon requested counselling because he thought that the patient had high levels of anxiety.

The remaining 272 patients were randomised to one of the four groups, and table 1 gives their background details. The overall number of patients and the number in each institution were similar in each group, and the groups were well matched for the various baseline characteristics recorded. One hundred and twenty two patients underwent mastectomy while 144 underwent lumpectomy, 124 received no adjuvant treatment or tamoxifen alone, 103 received radiotherapy, and 41 received chemotherapy. Within the first year after surgery 14 patients developed local recurrence, 12 developed disseminated disease, and nine died.

#### SUPPORT SUPPLIED

Not all patients were willing to receive the support offered. No patient refused to see the nurse, but 12 stated that they did not want to be approached by Tak Tent. When approached by Tak Tent, a further 17 patients did not wish further contact. Twenty one patients felt they were coping and did not want to receive further support. Sixty four of the 135 patients

**Table 1**—Background characteristics of women undergoing surgery for breast cancer who were randomised to receive four different types of psychological support

	Support provided			
	Routine (n=67)	Breast care nurse (n=70)	Tak Tent (n=66)	Nurse and Tak Tent (n=69)
Median age (years)	59	55	56	57
Hospital:				
A	38	40	38	39
B	14	15	13	15
C	15	15	15	15
Surgery for breast cancer:				
Mastectomy	31	28	33	30
Lumpectomy	34	40	33	37
Other	2	2	0	2
Adjuvant treatment:				
Tamoxifen or none	34	29	30	31
Radiotherapy or tamoxifen, or both	22	29	23	29
Chemotherapy or radiotherapy, or both	10	11	11	9
Other	1	1	2	0
Nodal status:				
Negative	39	35	31	38
Positive	25	31	32	31
Unknown	3	4	3	0
Oestrogen receptor status:				
Negative	19	32	26	28
Positive	37	26	35	27
Unknown	11	12	5	14
Recurrence:				
Local	4	3	4	3
Distant	3	5	2	2
Deaths	3	1	3	2
Marital status:				
Married	39	50	45	53
Divorced	6	6	7	3
Widowed	14	6	8	10
Unmarried	8	8	6	3
Further education:				
None	50	51	51	51
College	15	18	15	17
University	2	1	0	1
Employment:				
None	42	40	38	38
Part time	15	19	16	16
Full time	10	11	12	15
Religion:				
Protestant	51	54	48	51
Catholic	14	15	16	13
Other or none	2	1	2	5
History of psychiatric treatment:				
None	49	48	50	50
By general practitioner	15	20	16	17
By psychiatrist	3	2	0	2

**Table 2—Numbers of breast cancer patients who missed one or more of their planned assessments and reasons for this**

Support provided	Months after surgery				Total
	1	3	6	12	
<b>Routine (n=20)*:</b>					
Terminally ill or dead		1	2	3	3
Intercurrent illness			1	1	1
Non-attender	3	4	4	3	4
Refusal to complete assessment	3	4	4	4	5
Unavailable	3	4	2	5	8
<b>Breast care nurse (n=7):</b>					
Terminally ill or dead			1	1	1
Intercurrent illness	1	2	2	1	3
Non-attender			1	1	1
Unavailable	1	1		1	2
<b>Tak Tent (n=8):</b>					
Terminally ill or dead				3	3
Non-attender	1	1		1	1
Unavailable	1	1	2	1	4
<b>Nurse and Tak Tent (n=11)*:</b>					
Terminally ill or dead		2	2	3	3
Intercurrent illness			1	2	2
Non-attender	1	1	2	2	2
Refusal to complete assessment	1	1	1	3	3
Unavailable		1		1	2

\*One patient appeared in more than one category.

**Table 3—Mean (SD) scores of psychological morbidity recorded by breast cancer patients on 28 item general health questionnaire and on its subscales by type of support provided**

Support provided	Months after surgery			
	1	3	6	12
No of observations	255	247	246	235
<b>General health questionnaire</b>				
Routine	5.2 (5.7)	5.2 (5.7)	4.2 (6.0)	3.7 (6.2)
Breast care nurse	3.4 (4.6)	2.7 (3.7)	2.7 (3.6)	1.9 (3.5)
Tak Tent	5.4 (5.4)	5.3 (5.5)	3.8 (4.5)	5.0 (6.5)
Nurse and Tak Tent	5.1 (5.6)	4.6 (5.0)	4.4 (5.7)	3.9 (4.9)
<b>Anxiety and insomnia subscale</b>				
Routine	5.8 (4.2)	5.4 (4.2)	4.4 (4.7)	4.7 (4.6)
Breast care nurse	4.9 (4.1)	4.3 (3.5)	4.0 (4.1)	3.5 (3.4)
Tak Tent	6.7 (4.3)	6.4 (4.7)	5.2 (4.1)	5.7 (5.1)
Nurse and Tak Tent	6.3 (4.5)	6.0 (4.3)	5.8 (4.8)	5.5 (4.4)
<b>Severe depression subscale</b>				
Routine	1.3 (3.0)	1.5 (3.0)	1.6 (3.8)	1.4 (3.9)
Breast care nurse	1.0 (1.9)	0.7 (1.6)	0.7 (1.3)	0.7 (1.4)
Tak Tent	1.7 (2.4)	1.8 (2.5)	1.2 (1.9)	1.3 (2.4)
Nurse and Tak Tent	1.5 (3.3)	1.4 (2.9)	1.7 (3.1)	1.3 (2.5)
<b>Somatic symptoms subscale</b>				
Routine	4.9 (3.6)	5.0 (3.6)	4.8 (4.1)	4.1 (3.4)
Breast care nurse	4.0 (3.1)	3.9 (3.2)	4.2 (3.3)	3.8 (3.4)
Tak Tent	5.2 (3.6)	5.9 (4.0)	5.2 (3.3)	5.4 (4.0)
Nurse and Tak Tent	5.0 (3.8)	5.4 (3.7)	5.1 (3.6)	4.9 (3.8)
<b>Social dysfunction subscale</b>				
Routine	8.6 (2.6)	8.7 (2.8)	8.0 (2.6)	7.8 (2.3)
Breast care nurse	8.0 (3.0)	7.3 (2.0)	7.3 (1.9)	7.1 (1.9)
Tak Tent	8.6 (2.7)	8.5 (2.4)	7.9 (2.3)	8.2 (2.9)
Nurse and Tak Tent	8.6 (3.0)	8.3 (2.7)	7.8 (2.1)	7.4 (2.6)

**Table 4—Mean (SD) scores of psychological morbidity recorded by breast cancer patients with hospital anxiety and depression scale by type of support provided**

Support provided	Months after surgery			
	1	3	6	12
<b>Anxiety</b>				
Routine	5.9 (4.2)	5.2 (3.9)	4.9 (4.5)	4.8 (4.7)
Breast care nurse	5.3 (3.8)	4.4 (3.1)	4.7 (3.6)	4.4 (3.6)
Tak Tent	7.1 (4.4)	6.4 (4.4)	6.0 (4.3)	6.3 (5.0)
Nurse and Tak Tent	6.4 (4.2)	6.2 (4.2)	6.1 (4.2)	5.8 (4.7)
<b>Depression</b>				
Routine	3.3 (3.3)	3.6 (4.3)	3.0 (3.5)	3.0 (4.0)
Breast care nurse	2.3 (2.7)	1.6 (1.7)	1.7 (1.7)	1.4 (1.8)
Tak Tent	3.4 (3.5)	3.2 (3.2)	3.0 (2.6)	3.2 (3.2)
Nurse and Tak Tent	3.0 (3.5)	2.7 (2.8)	3.0 (2.9)	3.0 (3.4)

randomised to the organisation were still in contact with Tak Tent at six months' follow up, and 46 remained in contact at one year. Within the first year after surgery, members of the Tak Tent organisation contacted patients by telephone on 456 occasions and by letter on 72 occasions. Counsellors received 14 telephone calls from patients and visited patients on 64 occasions. Patients attended 25 group meetings. Twenty six counsellors participated in the study.

During the course of the study the breast care nurse received 101 telephone calls either directly from patients or their immediate relatives. Seventeen patients were concerned about problems with the wound or swelling of the arm. Nine were concerned about their prosthesis or wanted information about breast reconstruction. Twenty four patients sought information or expressed concern about their treatment or its side effects, 10 expressed fears about their cancer, five wanted to know the results of investigations, and 16 requested general information. Ten patients contacted the nurse because they were unduly anxious or depressed, and one expressed suicidal thoughts. One patient who became aware of a further breast lump and nine patients who developed symptoms which they thought were suggestive of recurrence contacted the nurse directly without contacting their own general practitioner.

#### PSYCHOLOGICAL MORBIDITY

Forty seven of the 272 women missed one or more of their four planned assessments, and table 2 summarises the reasons. Ten patients were terminally ill or had died; six developed other serious illnesses; eight were chronic non-attenders; eight refused to fill in the questionnaires; and data were not available for 16 (in one case because the patient had moved out of the area and in 15 cases because time was not available for interview in a busy clinic or the nurse was on holiday).

Tables 3-5 show the results of the self rating scales and that there was a consistent trend in how the scores changed. On each self rating scale, psychological morbidity tended to fall over the 12 month period. For each scale, scores were consistently lower in the group of patients offered support from the breast care nurse alone compared with the other groups, which were similar to each other. In each case the Kruskal-Wallis test was either significant at the 5% level or nearly so: the P values were 0.015 (28 item general health questionnaire), 0.027 (anxiety and insomnia), 0.072 (severe depression), 0.053 (somatic symptoms), 0.031 (social dysfunction), 0.093 (hospital anxiety), and 0.003 (hospital depression).

It can be seen from the pairwise comparisons that the significant Kruskal-Wallis tests were predominately a result of differences between the group offered support from the nurse alone and the other three groups (table 6). In particular, there were clear differences between support offered by the breast care nurse alone and that offered by Tak Tent alone even when adjustment was made for the multiple comparisons involved.

#### Discussion

In this pragmatic study we compared two treatment policies. Clearly the two approaches differed in that one was hospital based and the other community based. Furthermore, the timing of intervention differed in that the nurse saw the patients in the peri-operative period whereas the voluntary organisation saw them after discharge. These differences nevertheless reflect the reality of how breast care nurses and many self help organisations operate.

This study shows that a nurse specialist, working

### Key messages

- Psychological morbidity is common after surgery for breast cancer
- The value of different forms of psychological support for breast cancer patients is uncertain
- We compared effect of four different types of support for patients undergoing surgery for breast cancer: routine care from ward staff, routine care plus support from specialist breast care nurse, routine care plus support from voluntary organisation, or routine care plus support from nurse and organisation
- Scores of psychological morbidity were consistently lower in patients offered support from breast care nurse alone compared with the other groups, which were similar to each other
- Psychological support from an experienced breast care nurse can reduce psychological morbidity in patients undergoing surgery for breast cancer

closely with the medical and existing nursing staff, significantly reduced psychological morbidity as measured by self rating scales in women undergoing surgery for breast cancer. The nurse in this study, however, had extensive experience with breast cancer patients, not just in terms of caring for them but also in terms of interviewing them postoperatively for the purpose of research. Her pragmatic approach based on her experience seems to have been successful. Only two of the 139 patients allocated to support by the nurse were referred to a clinical psychologist for further treatment.

It is interesting that many patients turned to the nurse in times of perceived crisis. For example, several

patients used the telephone link to bypass their own general practitioner when they developed symptoms suggestive of recurrence. The nurse was usually able to arrange that they be assessed the next day and, if necessary, admitted promptly for further treatment.

The intervention strategy used by the support organisation in this study failed to reduce psychological morbidity. This was disappointing, but it is important to recognise that Tak Tent was not functioning in its usual fashion. A serious limitation faced by the voluntary counsellors was that they were unable to provide detailed information about the nature and extent of the disease, the rationale behind treatment, the potential side effects, and prognosis in individual patients. Furthermore, since they were unable, for practical reasons, to make contact until the patients had returned home after surgery, they could not establish rapport with patients during the initial crisis of diagnosis and treatment. These observations, however, do not preclude the possibility that individual patients may have benefited.

The failure to reduce morbidity in the combined group is difficult to explain. Consistency of approach may be important in these patients.

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**Table 5—Mean (SD) summary scores of psychological morbidity recorded by breast cancer patients by type of support provided**

Measurement scale	Support provided			
	Routine	Breast care nurse	Tak Tent	Nurse and Tak Tent
General health questionnaire:	4.6 (5.1)	2.8 (3.2)	4.9 (4.4)	4.6 (4.5)
Somatic symptoms	4.8 (2.9)	4.1 (2.8)	5.4 (3.1)	5.1 (3.2)
Anxiety and insomnia	5.3 (3.9)	4.3 (3.2)	5.9 (3.7)	6.0 (4.1)
Social dysfunction	8.3 (2.1)	7.4 (1.7)	8.3 (2.0)	8.1 (2.0)
Severe depression	1.4 (3.1)	0.8 (1.3)	1.5 (1.9)	1.5 (2.8)
Hospital anxiety and depression scale:				
Anxiety	5.5 (4.0)	4.8 (3.0)	6.5 (3.9)	6.0 (4.0)
Depression	3.3 (3.1)	1.8 (1.5)	3.3 (2.6)	3.0 (2.8)

**Table 6—Unadjusted P values for Mann-Whitney tests of pairwise comparisons of types of support provided for breast cancer patients by measure of psychological morbidity**

	Comparison of support provided					
	Routine v breast care nurse	Routine v Tak Tent	Routine v nurse and Tak Tent	Breast care nurse v Tak Tent	Breast care nurse and Tak Tent	Tak Tent v nurse and Tak Tent
General health questionnaire:	0.050	0.429	0.819	0.002	0.019	0.532
Somatic symptoms	0.184	0.235	0.612	0.006	0.053	0.536
Anxiety and insomnia	0.131	0.193	0.217	0.005	0.027	0.873
Social dysfunction	0.014	0.736	0.680	0.010	0.067	0.327
Severe depression	0.866	0.034	0.325	0.020	0.309	0.279
Hospital anxiety and depression scale:						
Anxiety	0.770	0.061	0.379	0.020	0.122	0.480
Depression	0.002	0.778	0.444	<0.001	0.052	0.313