Specialist nurse counsellor interventions at the time of diagnosis of breast cancer: comparing ‘advocacy’ with a conventional approach

Nicholas Ambler  Bsc(hons) MSc CPsychol  
Clinical Psychologist, Frenchay Healthcare Trust, Bristol

Nichola Rumsey  BA(hons) MSc PhD CPsychol  
Principal Lecturer, Department of Psychology, University of the West of England, Bristol

Diana Harcourt  BSc(hons)  
Research Psychologist, Frenchay Healthcare Trust, Bristol

Fawzia Khan  BSc(hons)  
Research Associate, General Practice and Primary Care Research Unit, University of Cambridge, Cambridge

Simon Cawthorn  BSc MS FRCS  
Consultant Surgeon, Frenchay Healthcare Trust, Bristol

and Jane Barker RGN  
Breast Care Nurse, Frenchay Healthcare Trust, Bristol, England

Accepted for publication 11 February 1998

Specialist nurse counsellor interventions at the time of diagnosis of breast cancer: comparing ‘advocacy’ with a conventional approach

Over recent years, specialist breast care nurses have become increasingly recognized as core members of any breast care team within the UK. Part of the role is to support patients at the highly stressful stage of receiving a diagnosis. This paper describes an ‘advocacy’ style of nurse counsellor intervention which aims to improve patients’ preparation for, and involvement in, the diagnostic consultation and provides a framework for future counselling support. One hundred and three women undergoing surgery following diagnosis of breast cancer or a benign breast lump were supported using either this advocacy intervention or a more conventional model of care. The aim was to identify the most effective and appropriate method of intervening at this important stage. Assessment took place before surgery, with 2-week and 6-month follow-ups, and included the Hospital Anxiety and Depression Scale, Rotterdam Symptom Check List and semi-structured interviews addressing perceived quality of care, involvement in decision-making and psycho-social functioning. Whilst the
results of many measures were similar for women in the two intervention groups, qualitative data support the implementation of the advocacy method by the breast care nurse.

Keywords: breast cancer, specialist nurses, diagnosis, intervention, advocacy

INTRODUCTION

The personal impact of breast cancer is considerable. During the past 20 years, studies of psychological reactions have repeatedly drawn attention to persistent and serious levels of distress which continue to disrupt the everyday lives of women long after treatment for the illness has been successfully completed. Anxious and depressive reactions, relationship and sexual difficulties, and concerns about altered appearance following mastectomy are all prevalent (Maguire et al. 1978, Hughson et al. 1986, Dean 1987). Such reactions often complicate continuing treatments such as chemotherapy and radiotherapy. More importantly, this distress is in itself both disabling and indicative of poorer overall recovery.

The increased awareness of women’s psycho-social needs has resulted in the development of a new specialist role for nurses in many breast surgery services in the UK. The remit of the breast care nurse now often includes counselling from the time of diagnosis, through the time of hospital treatments and follow-up after the surgical and adjuvant treatments have been completed.

The role of the breast care nurse counsellor has been gaining credence rapidly in the British National Health Service (NHS) and this service now appears universally available across the UK. Indeed, 226 of 229 Healthcare Trusts listed in the 1996 Macmillan Directory of Breast Cancer Services in the UK (Macmillan Cancer Relief Fund 1996) reported having a named breast care nurse specialist in post.

Recent guidelines have recommended that specialist breast care nurses should complete the English Nursing Board ENB A11 Advanced Breast Care Nursing course, have training in counselling and communication skills and be a core feature of any breast care team (NHS Executive 1996). However, there is still a lack of clarity concerning the most appropriate method for delivering counselling support. Many breast care nurses have come into a counselling role without preparatory training. Many lack ongoing support and supervision in their role, a concern highlighted by Fallowfield and Roberts (1992). Their survey revealed that only 25% of respondents had any formally recognized counselling qualifications, that less than half used a particular framework or approach to the counselling they offered, and that more than a third received no form of supervision. This does not necessarily suggest that the counselling being provided is ineffective.

Indeed, there is evidence to the contrary (Maguire et al. 1980, Watson et al. 1988, McArdle et al. 1996). It does, however, highlight the need for research to more clearly define the kind of support that should be offered, and to compare the relative effectiveness of different approaches.

For someone with breast cancer, the most critical stage of psychological care is likely to occur towards the beginning of the whole experience. A retrospective study by Benedict et al. (1994) reported extremely high anxiety levels in the period from discovery of a breast problem to receiving a definite diagnosis. Following the discovery of a breast lump, the consultation involving the disclosure of diagnosis, the moment of confirming many women’s worst fear, is an overwhelming experience. In the midst of this, there are often decisions to be made about surgery, and arrangements to be made for an early admission to hospital. The experience will for many, remain a vivid and distressing memory (see for example a survey by the National Cancer Alliance 1996). Hence, the way this consultation is handled may have considerable influence on longer term psychological reactions. In view of the importance of the diagnostic phase for later adjustment, the lack of studies investigating this stage is surprising (Poole 1997).

Although practice varies, the nurse counsellor typically becomes involved immediately after the patient has received the diagnosis, allowing time for additional questions and to discuss any necessary preparations for treatment. The nurse counsellor will also be concerned with the early emotional impact of diagnosis and will want to gauge how best to provide ongoing support.

Whilst a regime of providing support after receiving bad news is valuable, there is scope to begin this process sooner. Whilst in some clinics the specialist nurse is present during the diagnostic consultation, establishing the nurse/patient relationship prior to this stage offers potential benefit. Providing patients with a knowledgeable advocate may prove a buffer of emotional and practical support against the extreme stress of this consultation (Cooper & Watson 1991). An advocate in the context of breast cancer has been defined by Ganz (1995 p. 115) as ‘a helper, counsellor, or supporter, who defends the best interests of the patient’. Partners or close relatives often try to fulfil this role, but they too can be distressed by bad news and in many respects may be unable to help reduce the shock and loss of control which many patients experience at this time (Pistrang & Barker 1992).
The study

In summary, a protocol was set out which aimed to reduce the stress of the diagnostic consultation by directing it more towards the patient's own agenda of needs at this time. It was intended that this would improve long-term psychological outcomes. Hence, the ‘advocacy’ style of intervention begins prior to diagnosis in contrast to the more conventional approach in which the patient meets the breast care nurse only after the diagnostic consultation has taken place.

The main aims of this advocacy method are:

- to promote better understanding of treatment options, process and outcomes;
- to increase patients’ sense of personal composure and involvement, both in the consultation and in any decisions that are made; and
- to provide emotional support at the time of diagnosis.

The potential benefits of this advocacy approach were explored in the piece of action research which is the focus of this paper.

The expectation of the study was that the advocacy method would produce more favourable ratings on measures of psychological distress, involvement in the decision-making process, and patients’ perceptions about the quality of care. It was expected that these differences would be evident soon after diagnosis, and that they would be sustained at follow-up.

The study also aimed to assess whether or not the advocacy method was logistically viable within a busy clinic and compared the two approaches in terms of the time-commitment needed by the breast care nurse.

The study compared the reactions of women diagnosed as having breast cancer with those of women with a benign breast lump. All women in the current study underwent surgery following their diagnosis and had no previous diagnosis of cancer.

METHODOLOGY

Subjects

A consecutive series of 110 women attending the Breast Care Centre, Frenchay Hospital, Bristol, England, and whose treatment involved surgery for a benign or malignant condition were recruited into the study. Of the 110 women recruited into the study, one died prior to the 6-month follow-up interview and another six failed to attend one of the assessment stages. These cases were therefore removed from the analysis. Three of the sample were lost from the conventional treatment group and four from the advocacy condition. For the remaining 103 subjects, 66 were recruited during the conventional nurse counselling phase and 37 in the advocacy phase. A diagnosis of malignancy was made in 67 (65%) of the patients, the remaining 36 (35%) had a benign lump.

Ethical procedures

Ethical approval for the current project was obtained from the Trust’s Research Ethics Committee. After each woman had received her diagnosis, the breast care nurse described the research project and explained that participation would involve being interviewed on two occasions (2 weeks and 6 months following surgery) and completing questionnaires pre- and post-surgery and at each interview. All the women who were approached about the study agreed to participate and each completed a consent form at the time of the first interview.

Procedure

During the current study period, women typically waited 1 week between the clinic appointment in which investigative procedures were carried out and the diagnostic consultation in which the results of these procedures and the diagnosis were made available. Both styles of nurse intervention took place at this second, diagnostic, appointment.

In the advocacy intervention, the breast care nurse tried to elicit the patient’s main concerns at their first meeting, immediately prior to the diagnostic consultation and helped her prepare for this meeting with the surgeon by developing a list of questions she would like to ask. This preparation was carried out for all patients attending the clinic and at this stage the breast care nurse was not aware of the diagnosis. She then accompanied the patient in the consultation, where if necessary, she could intervene to ensure that all the patient’s questions were dealt with. The counselling continued after the consultation with the surgeon had finished, but for a shorter time than would be the case with a conventional approach. After this, future contacts between the nurse counsellor and the patient continued on an ‘as needed’ basis in line with the conventional approach.

As a piece of action research aimed at developing service provision in one breast care centre, certain methodological limitations were imposed on the design of the study. It was impractical to ask the nurse to keep switching between one counselling method and another, as would be required by a randomized controlled trial. Equally, the involvement of two nurses in the study would have introduced potentially confounding variables. As alternative designs can be just as valid as a randomized controlled trial in psycho-social studies (Bottomley 1997), a time-sequential design was considered appropriate in this study.
Following a piloting phase, during which the normal intervention used by the breast care nurse was monitored, data collection began in the conventional phase. When this data collection was completed, the clinical psychologist trained the breast care nurse in using the advocacy method. Following piloting with the new, advocacy, method of working, data collection resumed in the second phase.

Assessment was by means of standardized scales and a semi-structured interview administered by an independent researcher 2 weeks post-surgery and at 6 months follow-up.

Visual analogue scales (VAS) were used to explore additional issues pertinent to the current study, including the extent to which women felt fully informed about their diagnosis, involvement in the decision to have surgery, satisfaction with treatment, psycho-social functioning, perceived levels of social support and feelings about their meetings with the breast care nurse.

In order to facilitate comparisons between the results of this study and those previously reported in the literature, anxiety, depression, and psychological distress, were measured using the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith 1983) and the Rotterdam Symptom Checklist (RSCL) (de Haes et al. 1990).

The HADS is a widely used self-administered measure of psychological well-being, independent of physical symptoms. The scale consists of 14 items, seven relating to anxiety and seven to depression. Potential scores range from 0 to 21 for each sub-scale, with a higher score suggesting a higher level of anxiety or depression. Scores of 11 or more on each sub-scale are considered to denote ‘caseness’, i.e. clinically meaningful degrees of anxiety or depression. Internal reliability of the scale has been found to range from 0.41 to 0.76 for anxiety ($P < 0.01$) and from 0.3 to 0.6 for depression ($P < 0.02$) and validity has been found to be high (anxiety $r = 0.74$; depression $r = 0.70$; $P < 0.001$) (Zigmond & Snaith 1983).

The Rotterdam Symptom Checklist requires respondents to indicate the extent to which they have been bothered by each of 34 symptoms during the past few days. These 34 symptoms create 2 sub-scales – a psychological scale which has shown high reliability (Cronbach’s alpha 0.88–0.94) and a physical scale with good reliability (0.71–0.88) (de Haes et al. 1990).

Analysis of data was carried out using the Statistical Package for the Social Sciences (SPSS) for Windows. Comparisons of data from the standardized scales were calculated using continuous scores and, in the case of the HADS and RSCL, the criteria for ‘caseness’ using a cut-off score of 11 (see Zigmond & Snaith 1983, Hopwood et al. 1991).

**RESULTS**

**Comparison of the timing of the two interventions**

The duration of initial counselling was monitored in each group. Those in the advocacy condition had a first meeting with the nurse which lasted a mean of 9 minutes ($SD = 3.6$; range = 5–15 minutes) before the consultation with the surgeon. The second meeting with the nurse, immediately after seeing the consultant, lasted a mean of 16 minutes ($SD = 6.5$; range = 5–30 minutes). This resulted in a total mean time of 25 minutes ($SD = 7.9$; range = 10–45 min). In the conventional group, the single meeting with the nurse counsellor immediately after consulting with the surgeon lasted a mean of 25 minutes outright ($SD = 12.7$; range = 5–60 minutes). Hence both conditions resulted in the same time commitment from the breast care nurse.

**Comparison of the demographic details of the two intervention groups**

The demographic details and treatments received by the women in each of the two groups are shown in Tables 1 and 2. The mean age of women taking part was 50 years (range 22–80 years); 83% lived with a partner and 60% were in employment. There was no statistically significant difference between the two study groups on any of these criteria.

All the women in the study underwent breast surgery following diagnosis. Twenty-three (34%) of the 67 patients diagnosed with cancer had a mastectomy, 44 (66%) underwent a wide local excision. Forty-eight per cent (10/21) of women with breast cancer in the advocacy group underwent mastectomy, compared with 28% (13/46) in the conventional group. This difference was not statistically significant.

Forty-three of the 67 patients with breast cancer went on to adjuvant treatment, five (7%) had chemotherapy, 31 (46%) had radiotherapy and 7 (10%) had both chemotherapy and radiotherapy. Significantly fewer patients in the advocacy condition underwent radiotherapy ($P = 0.04$), either with or without chemotherapy (38% vs. 65%). There was no notable difference between the groups for chemotherapy (19% compared with 17% – $P = 0.07$, not significant).

Of the 36 patients who had a benign breast lump, 34 (94%) underwent lumpectomy, one patient had Adair’s procedure (surgical removal of ducts) and one patient had a bilateral lumpectomy.

Contrary to the hypothesis that the advocacy counselling intervention would reduce psychological morbidity after diagnosis, many of the measurements were similar for women in the two intervention groups. Initially high levels of distress (as measured by the HADS and RSCL)
reduced following surgery (see Table 3). This reduction was significant ($P < 0.01$) and the reduction was maintained at 6 month follow-up.

In previous research, the needs of benign patients have often been ignored. The current results have therefore considered diagnosis in addition to the style of intervention received.

### Table 1
Demographic characteristics of the complete data group (percentages have been rounded to the nearest whole figure)

<table>
<thead>
<tr>
<th>Marital status</th>
<th>Conventional ($n = 66$)</th>
<th>Advocacy ($n = 37$)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$n$ (%)</td>
<td>$n$ (%)</td>
</tr>
<tr>
<td>Married/living with partner</td>
<td>58 (88)</td>
<td>28 (76)</td>
</tr>
<tr>
<td>Divorced</td>
<td>1 (2)</td>
<td>2 (5)</td>
</tr>
<tr>
<td>Widowed</td>
<td>1 (2)</td>
<td>3 (8)</td>
</tr>
<tr>
<td>Single</td>
<td>6 (9)</td>
<td>4 (11)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Employment</th>
<th>Conventional ($n = 66$)</th>
<th>Advocacy ($n = 37$)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$n$ (%)</td>
<td>$n$ (%)</td>
</tr>
<tr>
<td>Employed</td>
<td>42 (63)</td>
<td>20 (54)</td>
</tr>
<tr>
<td>Retired/Not working</td>
<td>23 (34)</td>
<td>17 (46)</td>
</tr>
<tr>
<td>Student</td>
<td>1 (2)</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age</th>
<th>Conventional ($n = 66$)</th>
<th>Advocacy ($n = 37$)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$n$ (%)</td>
<td>$n$ (%)</td>
</tr>
<tr>
<td>Mean</td>
<td>49</td>
<td>50</td>
</tr>
<tr>
<td>SD</td>
<td>11.88</td>
<td>12.77</td>
</tr>
<tr>
<td>Range</td>
<td>26–80</td>
<td>22–75</td>
</tr>
</tbody>
</table>

### Table 2
Treatment undergone by women for whom complete data are available, according to diagnosis (percentages have been rounded to the nearest whole figure)

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Conventional</th>
<th>Advocacy</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$n$</td>
<td>%</td>
</tr>
<tr>
<td><strong>Cancer</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgery</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patey mastectomy</td>
<td>13</td>
<td>(28)</td>
</tr>
<tr>
<td>Bi-lateral mastectomy</td>
<td>0</td>
<td>(0)</td>
</tr>
<tr>
<td>Wide local excision (WLE)</td>
<td>32</td>
<td>(70)</td>
</tr>
<tr>
<td>Bi-lateral WLE</td>
<td>1</td>
<td>(2)</td>
</tr>
<tr>
<td>Adjuvant therapy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemotherapy only</td>
<td>2</td>
<td>(4)</td>
</tr>
<tr>
<td>Radiotherapy only</td>
<td>24</td>
<td>(52)</td>
</tr>
<tr>
<td>Chemotherapy &amp; radiotherapy</td>
<td>6</td>
<td>(13)</td>
</tr>
<tr>
<td>No adjuvant treatment</td>
<td>14</td>
<td>(30)</td>
</tr>
<tr>
<td><strong>Benign</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgery</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lumpectomy</td>
<td>19</td>
<td>(95)</td>
</tr>
<tr>
<td>Bi-lateral lumpectomy</td>
<td>0</td>
<td>(0)</td>
</tr>
<tr>
<td>Adairs/microductectomy</td>
<td>1</td>
<td>(5)</td>
</tr>
</tbody>
</table>

### Comparison of advocacy and conventional interventions

An analysis of variance (ANOVA) with repeated measures examining the effect on anxiety of the type of intervention yielded a significant result, with anxiety significantly lower 2 weeks post-surgery in the advocacy condition compared with the conventional intervention ($F = 4.64; 1101; P = 0.034$). However, when diagnosis was considered, there were no significant differences in the anxiety scores (as measured by the HADS) of cancer patients between the two intervention groups at any of the assessment points. Pre-surgery, benign patients in the advocacy group showed significantly lower levels of anxiety than those in the conventional condition (one tailed $t = 1.81; d.f. = 29; P = 0.04$); however, there was no significant difference between the two intervention conditions at subsequent assessment points. Within the advocacy condition, pre-surgery anxiety levels reported by cancer patients were significantly higher than those reported by patients with benign lumps ($t = 2.32; d.f. = 34, P = 0.03$).

Levels of ‘caseness’ (using a cut-off of 11 on the HADS) were also significantly lower 2 weeks post-surgery in the advocacy condition as a whole ($\chi^2 = 3.85; d.f. = 1; P = 0.05$) (see Table 4).

Analysis of variance has shown style of intervention to have no significant effect on HADS depression scores ($F = 0.554; P = 0.646$).

In relation to the psychological scale of the RSCL, there were no statistically significant differences in scores or levels of caseness between the two counselling intervention conditions. However, women diagnosed with cancer in the advocacy condition reported a bigger drop in psychological distress between the pre-surgery and 2 weeks post-surgery assessment points. Using the physical sub-scale of the RSCL, at each assessment point, cancer patients in the advocacy condition reported lower physical symptom scores than those in the conventional intervention group; however, once again, these differences were not significant.

Ratings made by subjects in each group using the visual analogue scales illustrate that women in the study generally felt involved in the treatment decisions made about their surgery, that they were satisfied with the support provided by the nurse counsel who and with their overall care. Patients in the advocacy group tended to feel that the decision to undergo surgery was made jointly between themselves and the consultant, in contrast to patients in the conventional group who were more likely to report that the decision was made by the consultant alone. However, the only significant difference in this respect was for patients with benign lumps assessed at 6 month follow-up where women in the advocacy intervention group reported greater perceived involvement in the
decision-making process \(t = 2.20; \) d.f. = 34; \(P < 0.035\). The advocacy condition produced more favourable ratings for satisfaction with treatment, but the only comparison to approach significance was between patients with a benign lump 2 weeks post-surgery \(t = 1.85; \) d.f. = 33; \(P = 0.07\). No other significant differences were shown in the VAS ratings between the two groups. Women diagnosed with cancer were questioned in detail with regard to the role played by the breast care nurse. No statistical differences existed between the two
intervention groups, both of which rated the role played by the breast care nurse very positively. The results show that the breast care nurse did help women to think more clearly and to face the reality of the situation, and provided helpful information.

Qualitative responses generated in the course of the semi-structured interview revealed that more than 70% of patients in the advocacy condition made positive comments about their pre-diagnosis meeting with the breast care nurse. The most common response related to the usefulness of this session in preparing and planning questions for the subsequent consultation. This level of favourable commentary was maintained at 6-month follow-up. Some women in the advocacy group (n = 10) expressed initial reservations about the pre-diagnostic meeting with the breast care nurse, feeling that she must have known the diagnosis and that this meeting must be indicative of ‘bad news’ to follow. However, eight of these women also highlighted positive aspects of this meeting.

Comparison between the cancer and benign lump diagnoses

The proportion of women with breast cancer or a benign lump showing ‘case’ levels of anxiety and depression (scores of 11 or more) are compared in Table 4. Both groups had a considerable proportion of patients suffering clinical levels of anxiety before surgery, which had dropped sharply by the 2-week stage. As mentioned previously, the greater incidence of anxiety ‘caseness’ amongst women in the conventional phase 2 weeks post-surgery was significant (chi² = 3:85, d.f. = 1, P = 0.049). There was a notable difference in the proportion of women in each group suffering from ‘case’ levels of depression, with higher numbers of women diagnosed with cancer producing these results; however, the small numbers in some cells have made further statistical analysis of this data inappropriate. At each assessment, women diagnosed with breast cancer reported significantly higher HADS depression scores than those with a benign lump (at clinic F = 6:16, P = 0·015; 2 weeks F = 4:23, P = 0·04; 6 months F = 6:96, P = 0·01), although, as stated above, the style of intervention was not significant.

The psychological distress scale of the RSCL showed a similar picture, with high levels of distress initially associated both with a diagnosis of cancer and with a benign lump. A significant reduction in distress was observed in each group 2 weeks following surgery (conventional cancer t = 3:38, P = 0·002; advocacy cancer t = 5:13, P = 0·001; conventional benign t = 5:25, P = 0·001; advocacy benign t = 2:99, P = 0·01). The reduction in mean scores between 2 weeks and 6 months post-surgery were not significant; however, distress was sustained at a higher level after surgery for those diagnosed with cancer.

There is evidence of psychological morbidity in women with benign breast lumps, (albeit to a smaller degree than in women with cancer) not just at the time of diagnosis, but also 2 weeks and 6 months after surgery.

Responses to the visual analogue scales indicated that women with benign lumps felt generally less well informed about their diagnosis and the need for surgery than women with cancerous lumps. They were also less happy about the way in which treatment decisions were handled, although this result was not significant.

Type of surgical intervention and adjuvant therapy

Patients with cancer undergo more extensive surgery and many have adjuvant therapy, both of which might be expected to cause persistent symptoms and concerns. Patients with a diagnosis of cancer exhibited less favourable scores on the physical distress sub-scale of the RSCL. However, despite a significantly higher incidence of radiotherapy amongst women in the advocacy condition, no specific effects of chemotherapy and radiotherapy were found. In relation to the HADS and the psychological scale of the RSCL, comparisons of cancer patients showed no significant differences at any assessment point between those undergoing mastectomy and those treated with more conservative surgery. There was no significant effect of chemotherapy or radiotherapy on anxiety or depression at 6-month follow-up.

DISCUSSION

It is evident from the initially high levels of distress reported by women in this study that the impact of the period leading up to breast surgery is considerable.

However, the reduction in distress post-diagnosis was marked, and considerably lower than comparable studies reported in the literature. At the 6-month post-surgery assessment point in this study, the levels of anxiety caseness were 12% in women with breast cancer and 5·5% in women with benign breast lumps. In previous research, Maguire (1985) and Burton et al. (1995) have reported enduring levels of anxiety and depression following breast surgery, with an incidence of ‘caseness’ in the region of 25%. Carroll et al. (1993) reported an incidence of 23% amongst a group of 930 mixed cancer patients, including 76 women with breast cancer. Dean (1987) used a combination of self-report assessment and a psychiatric interview to determine ‘caseness’, with the result that, 1 year post-surgery, rates varied from 5 to 26% according to diagnostic criteria employed. Goldberg et al. (1992) reported that 51% of a sample of 166 women diagnosed with breast cancer experienced severe anxiety pre-operatively, reducing to 29% at 6-month follow-up and 27% at 1 year post-operation. These were compared to a sample of patients with benign lumps in whom 37% experienced
high levels of anxiety post-operation, with 16% still highly anxious at 6-month follow-up and 18% with high anxiety levels 1 year post-operation. Routine post-diagnostic assessment of women diagnosed with cancer continued after this study was completed. This demonstrates similar levels of distress to those reported in the current study. The study sample is therefore considered representative in this clinic and reasons for the comparatively low levels of psychological distress amongst this population remain open to speculation.

In the previous literature, data relating to patient distress were often derived from clinics where there was no counsellor support or where this had only recently been introduced. The lower levels of enduring psychological distress observed in this study may have been an artefact arising from the local patient population or service provision. Alternatively it may reflect a wider shift resulting from the now more routine inclusion of a counsellor in breast cancer care. These generally lower levels of distress were not anticipated and have limited the opportunity to explore differences between the two types of intervention employed in this study.

No systematic differences emerged from the analysis of data from the standardized scales. However, responses to several of the visual analogue scales employed in the semi-structured interview were more favourable in the advocacy condition. Patients in this group rated themselves as better informed, having a greater understanding of the treatment options and feeling more involved in decision-making concerning their treatment. Advocacy was also rated more favourably by those women with a benign diagnosis.

The inclusion of women with benign lumps produced another interesting finding in that their pattern of distress was similar rather than different to that experienced by women with breast cancer. Northouse et al. (1995 p 200) has commented that 'breast biopsy is a stressful, emotionally charged event for many women. It is not a benign experience.' Certainly the results of this study highlight the psychological distress experienced by these women. One of the advantages of advocacy is that the counsellor sees all clinic attendees who have undergone biopsy. The provision of psychological care therefore has a broader perspective than focusing solely on cancer diagnosis.

The advocacy method was designed to follow a more explicit protocol than the conventional counselling method. The clinical staff were initially sceptical. Although advocacy takes no more time, it is more challenging both for the counsellor and the surgeon. It is interesting to note that on completion of this study, the staff have nevertheless adopted the method on a permanent basis and patients report it to be both satisfying and beneficial.

The role of the specialist breast care nurse counsellor has developed rapidly during the past decade. The provision of specialist training of nurses working with cancer patients has been recommended in the Calman-Hine Report (Expert Advisory Group on Cancer 1995). Whilst such training is now becoming available, there is rarely any specific guidance on how to best handle the support of patients at the time of diagnosis.

Since this study was initiated, the number of ‘one-stop’ clinics offering same-day diagnosis of symptomatic breast problems has increased considerably. Speedier diagnosis appears to be becoming the norm. Early indications from evaluations of the impact on patients of a one-stop system show benefits for those with benign lumps (Ubhi et al. 1996). However, there is no sign of speedier diagnosis in any sense moderating the psychological impact of a cancer diagnosis. In certain respects the stress is intensified when results are provided more quickly. Hence, psychological care at this time will continue to demand attention for the foreseeable future.

This advocacy intervention was developed to advance the role of specialist nurses who work with breast cancer patients. However, it can be more widely applied. Future research may wish to consider its application to any ‘bad news’ consultation in which the patient may benefit from having his/her individual concerns specifically addressed by an advocate nurse.

CONCLUSION

The surprisingly low level of prolonged psychological morbidity in this study prevented any firm conclusion being drawn about the relative effects of the advocacy method. However, there were some signs of its superiority over a conventional approach. Advocacy has become a permanent feature in the provision of care for women diagnosed with breast cancer in the clinic chosen for this study.

This project was driven by the need to find a framework for psychological support that could be employed by the growing number of specialist breast care nurses early in the process of diagnosis and treatment. The evolving changes to breast care services, in particular the move to same day diagnosis, are likely to intensify pressures on staff and patients. Further efforts are needed to develop and evaluate specific protocols of psychological support for women during this crucial stage of their care.

References


