Health visitor support for patients with breast cancer – 2


In the second of two articles, the author’s report on research indicates that health visitors (HVs) with preparation and education for the role, can provide effective support for patients having treatment for breast cancer in the community. A sample of 35 patients with breast cancer was interviewed at home soon after referral from hospital following treatment and again three months later. They had many medical and psychosocial problems relating to their disease and its treatment, indicating need for professional support. Support from HVs consisted of preparing patients for treatments, assessing how they were coping and liaising with staff from the breast unit. The HVs encouraged patients to express their feelings about altered body image, sexuality and depression, as well as offering information and medical advice when this was requested. The HVs also helped patients with social problems, mainly difficulties with family relationships, finance and work. The first article appeared on May 7 1997

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KEY WORDS

- HEALTH VISITING EDUCATION
- BREAST CANCER
- LIAISON NURSES

RESEARCH HAS REVEALED a high incidence of physical and psychiatric morbidity among patients with breast cancer. After mastectomy, many patients develop psychological problems, such as severe anxiety or clinical depression, requiring psychiatric treatment (Maguire et al 1978, Morris et al 1977). Advanced surgical techniques, designed to conserve breast tissue, have been combined with adjuvant therapy to try to reduce the incidence of psychiatric morbidity.

However, while studies comparing the psycho- social outcome of mastectomy with lumpectomy and radiotherapy revealed some advantage to women treated by breast conservation in terms of body image, there was little difference in terms of psychiatric morbidity or
sexual dysfunction (Fallowfield 1991).

Tait (1988) noted that, regardless of treatment, 20-40 per cent of patients with breast cancer developed depression, anxiety or sexual problems within a year of surgery, although such problems were rarely recognised by their carers. Failure to adapt to changed body image, compounded by problems with a prosthesis and anxiety about possible recurrence of the cancer, are persistent research findings.

Ongoing stress affecting patients with breast cancer was noted by Burish and Lyles (1983) who found that patients may take a year to regain normal function after suffering depression, anxiety and reduced self-esteem. Other problems were disturbed marital relationships and physical complications of surgery, such as lymphoedema and frozen shoulder.

AIMS OF RESEARCH
As described in the previous article, the aims of the research were to evaluate health visitors’ (HVs) support of patients undergoing treatment for breast cancer. Evidence of morbidity accompanying the diagnosis and treatment of breast cancer was noted early in the research at a follow-up breast clinic where eight of the 20 patients seen by one doctor had problems including:

- Possible recurrent breast lumps
- Lymphoedema of the arm
- Frozen shoulder
- Vaginal thrush
- Depression
- Dissatisfaction with a prosthesis.

An interview with a patient who had had breast surgery three years previously showed clearly that such problems could persist over several years. However, she now thought about her breast cancer only fleetingly, whereas formerly she had been preoccupied with it ‘23 hours a day’.

METHOD
An initial survey of patients attending the breast unit was necessary in order to identify patients’ main concerns and sources of support. This would be followed by planned health visiting support for patients with breast cancer in the community. An initial survey of patients consisted of:

- A small pilot study of 29 patients interviewed in the outpatient department
- Two tape-recorded interviews with each of a further 18 patients at home.

Results of initial survey Patients’ main anxieties related to the diagnosis of cancer and fear of recurrence and problems or anxieties over treatment. Fear of recurrence was mentioned most frequently as difficult for patients. Patients were often anxious about the forms of treatment they were receiving or had received (chemotherapy, radiotherapy, surgery). Six of 13 patients who had had surgery had problems with their new body image. The main problems of seven patients with advanced cancer were maintaining hope, fighting off depression and coping with the physical symptoms of their illness.
EVALUATION OF PLANNED HEALTH VISITING SUPPORT

A sample of 35 patients, consisting of 32 women with a variety of treatments for primary breast cancer and three women with recurrence of the disease, was recruited during an eight-month period. Figure 1 shows the age range of respondents.

Two semi-structured, tape-recorded interviews were conducted with each patient at her home. Patients were interviewed soon after their referral from hospital and again three months later when HVs would have had time to visit. Patients were asked whether they had any problems, how they were coping and what professional and informal support they were receiving. At the second interview, each patient was asked to draw a diagram of her social contacts (professional and informal) and to describe in the diagram the helpful or unhelpful behaviour shown by each person since the cancer diagnosis. The HV’s position within the diagram was noted as were the patient’s perceptions of her role and support.

RESULTS

Patients with breast cancer having treatment in the community had many problems and anxieties in relation to their disease and its treatment, indicating need for professional support.

**Medical problems** Patients’ medical problems were usually related to their treatments but in cases of patients with advanced breast cancer, also to their disease (Fig. 2). Problems relating to treatment extended over several months. Medical problems consisted of the effects of the disease or, more commonly, the side effects of treatment. Some patients had no significant problems while others had several. As patients’ adjuvant treatments were ongoing, new problems emerged in the second interviews.

There was close agreement between the researcher’s and HVs’ identification of the patients’ medical problems, based on patients’ comments. The HVs noted 86 per cent of medical problems noted by the researcher.

Support given by the HVs consisted mainly of preparing patients for treatments by telling them what to expect, assessing how they were coping with treatments and side effects, and liaising with staff from the breast unit to provide better advice for patients about treatments. For example, when patients experienced side effects from hormone therapy, HVs explained how nausea could be reduced by the timing of medication or, in consultation with the doctor, by splitting the dose. The HVs also encouraged patients to report severe hot flushes to the doctor as this symptom could be eased by the drug Dixarit. In two instances, the HVs gave patients leaflets explaining the effects of hormone therapy and possible problems associated with it.

The HVs’ role with patients who had arm stiffness, numbness or swelling was to reinforce instructions relating to arm exercises and the care of the arm after axillary node clearance. The HVs were not involved in dressing wounds. However, in one case, the HV noted that a patient’s wound had become infected and advised her to see her GP who prescribed antibiotics.

**Psychological problems** Most patients mentioned more than one psychological problem, with the total number of such problems reported by 35 respondents being 70 (Fig. 3). The main psychological problem identified was anxiety about the diagnosis of cancer and its possible...
implications for the future. This anxiety was particularly acute for five respondents who felt that there had been a delay in making a diagnosis. Additionally, some patients had concerns about their body image and sexuality following surgery. Eleven patients mentioned having periods of depression. Seven patients experienced a bereavement, five of these occurring just before or during the research period.

When patients had psychological problems associated with their breast disease or its treatment, the HVs' role was mainly psychotherapeutic. They encouraged patients to express their feelings and attitudes about their situation as well as offering information and medical advice when this was requested. The domiciliary assessment forms (DAFs) given to the HVs, had guidelines on how to assess for anxiety state or depressive illness as well as evidence of anxious or depressed mood. To rate as an anxiety state or depressive illness, certain symptoms need to have been present for at least 50 per cent of a four-week period.

There was close agreement about patients' psychological problems between the researcher and HVs.

The HVs helped patients with psychological problems in a number of ways. They assessed levels of anxiety in all patients they visited. They alleviated patients' anxiety by encouraging them to express their feelings about their situations and by discussing specific problems with them. Fear of cancer, recurrence and worry about prognosis were the most common causes of anxiety, expressed overtly by 25 patients. This supports a finding by Fallowfield et al (1990) that survival is a more salient concern than breast loss. One patient described sharing her feelings about her diagnosis with fellow patients: 'We had a good laugh at the breakfast table [in hospital]. I was recounting how when you hear you’ve got it, you immediately think this is the end, you are finished. I was thinking who I would leave my earrings to! Immediately, the rest of them said the same thing.'

While not being able to free the women from what Weisman and Worden (1976) called the 'existential plight' of their uncertain future, the HVs listened to women as they expressed the anxieties they kept from their families and friends for fear of upsetting them. Seven patients mentioned the advantages of talking to the HV because she was an 'outsider', 'not emotionally involved' and had a 'more detached view than immediate family or hospital doctors'. One young woman said: 'It's nice to speak to someone totally outside. People that you know well can be frightened to say the wrong thing.'

Among the 24 patients who had had surgery, six expressed concerns about their body image and sexuality. In most cases these anxieties diminished with time. Five patients awaiting surgery expressed anxieties about how they would look and feel afterwards. Three patients with advanced breast disease were concerned about effects of the disease on their appearance and one spoke of taking foam baths to avoid looking at herself. Patients who had hair loss due to chemotherapy were also concerned about sexuality.

The HVs assessed whether patients were able to look at their scars and how they felt when doing so. They also explored women's feelings about tissue expanders or breast implants. Where patients had prostheses, the HVs discussed the extent of their satisfaction with these. Enquiring about patients' sexual relationships since breast surgery was a sensitive topic and unless the patient raised it the HVs, with three exceptions, did not comment. One patient appreciated the opportunity to confide in her HV: 'It's safe to talk about private things. She wouldn't be shocked.'
Social problems Social problems were defined as difficulties relating to family relationships, finance, work and so on (Fig. 4). Twenty one (60 per cent) of the respondents mentioned such problems. The HVs are family visitors and it seemed likely that patients might confide some of these problems to them.

There was close agreement between the researcher's and HVs' estimation of patients' social problems. Family relationship problems were mentioned by 17 women. Eight women had long-standing problems with adult children (four cases), partner (three cases), mother and siblings (one case). Four women seemed to lack support from certain family members since the breast cancer diagnosis. In five cases, school-age children seemed to be anxious about their mother's illness and this manifested itself in negative behaviour. One respondent described the reaction of her son: 'He went away when I was in hospital to stay with my cousin who he is fond of because he couldn't hack it any more. It's affected his school work.'

All the patients appreciated the interest shown by HVs in other family members. The HVs spoke to three of the children who appeared to have problems in accepting their mother's illness. For example, in the case of one child who was playing truant from school, the HV encouraged the patient to be more open with her daughter about her breast cancer.

Financial problems arose in ten cases because of the patient's or her partner's low income or unemployment. In all cases, the HV discussed the financial problems with patients and any benefits to which they might be entitled. In several cases, the HVs were able to obtain additional financial help for patients in the form of attendance allowances, clothing allowances, grants for furniture and funded holidays.

The HVs were aware of the ill-health of some patients' family members and of difficulties with work or unemployment and had discussed these with most of the women concerned. One young woman with recently diagnosed advanced breast cancer was successfully rehoused at the instigation of the HV who also applied for financial assistance for furnishings and clothing for her.

DISCUSSION
This research showed that patients with breast cancer needed support of the kind that HVs could provide because of the medical and psychosocial problems they experienced both after initial breast surgery and during the further treatments which took place on an outpatient basis. Women with large tumours having medical treatment before breast surgery needed support in the community from the beginning of their treatment and after breast surgery.

Patients with inoperable tumours were offered other forms of outpatient treatment and also needed support. Although there were only three patients with advanced cancer in the study sample, the severity of their symptoms indicated that they and other such patients had particular needs for support. An average of two medical problems per patient were noted, consisting mainly of the side-effects of treatment.

The main psychological problems identified were concerns about the cancer diagnosis and prognosis and about body image and sexuality. Many patients had had periods of depression. Social problems encountered included difficulties with family relationships, finance and work. Medical problems improved with time and treatment and the HVs assisted significantly in this improvement by preparing patients for
treatments, giving advice, assessing ability to cope, and liaising with GPs and breast unit staff over certain problems.

Psychological problems improved or were less salient in patients’ minds as their treatment progressed. Many patients reported that the availability of the HV to come and see them was important in allaying concerns and some mentioned the usefulness of the HVs as professional people who were more detached from their situations than were family and friends and to whom they could express their deeper anxieties. Patients were helped considerably with relationship difficulties and with financial and practical problems by the HVs.

In 13 cases (37 per cent), patients’ comments indicated that HVs’ support was important to their coping. The women in this group had severe problems and/or anxieties. The group contained all three women with advanced disease, two with inoperable disease, three with large tumours and two women who had severe side effects from treatment.

In 17 cases (49 per cent), patients’ comments indicated that HVs’ support had been important to their coping with their illness and treatment. The HVs had visited patients in this group less frequently than those in the first group, but in many cases had supported them through a particular crisis.

In four cases (11 per cent), patients indicated that although they were pleased to receive a visit, HVs’ support had not been important to their coping. One of these women was receiving visits from district nurses for wound dressings. In another case, there was a delay before the HV was able to visit. One young woman who had initially wanted the HV to call later, became upset and angry about her situation and refused help.

**CONCLUSION**

This research indicates that HVs with preparation and education for the role are in a unique position to provide effective support for patients having treatment for breast cancer in the community. Such support cannot be provided easily by informal carers who in any case need support themselves. It cannot often be given by other professionals, such as GPs, who usually lack the time for much home visiting. Specialist breast care nurse are often hospital based and carry a heavy workload. Managers and community nurses of the future must, therefore, recognise the needs of these patients for professional support in the community and be encouraged to provide it.

**IMPLICATIONS FOR PRACTICE**

1. Women with breast cancer may require support at home not only following treatment, but also during the preparatory phase before, for example, surgery.

2. Community nurses must be aware of the range of medical and psychosocial problems that can occur in patients undergoing, and following, treatment for breast cancer.

3. Following relevant training and with appropriate specialist support, health visitors can help patients to cope with psychosocial problems – for example, difficulties in family relationships – by providing an informed, objective perspective.
REFERENCES


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Fig 1. Age range of respondents

![Age range of respondents](http://nursingstandard.rcnpublishing.co.uk/resources/archive/GetArti...)

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Fig 2. Medical problems presented at first and second interviews
Fig 3. Psychological problems presented at first and second interviews (70 problems)

Fig 4. Social problems presented at first and second interviews (50 problems)