

Original Article

Physical side-effects experienced by women with breast cancer: the women's perspective

Angela Cross, Peter Salmon*

*Lecturer, Radiotherapy Division, Department of Allied Health Professions, *Professor, Department of Clinical Psychology, University of Liverpool, Liverpool, UK*

Abstract

Patients who receive radiotherapy need to be informed about its effects. Available evidence is inadequate because it has focused on selected symptoms and has emphasized the objective characteristics of symptoms rather than the patients' own experience of them. This study therefore examined women's own accounts of physical side-effects during the first 12 months after treatment for early breast cancer. Semi-structured audio-taped interviews with 15 patients 1 week to 12 months after treatment were analysed qualitatively. The women described some symptoms that were consistent with what is already known, in particular fatigue and skin changes, but also others that have been previously neglected. The women's explanations for symptoms were an inextricable component of their experience of them. Surprisingly, many women blamed themselves for having caused their symptoms. These findings contribute to the evidence that is necessary to inform health care professionals' advice to patients. They can also guide future quantitative research into symptoms associated with treatment and ensure that this is grounded in patients' experience of symptoms rather than clinicians' assumptions about patients' experience.

Keywords

Breast cancer; radiotherapy; physical side-effects; attributions

INTRODUCTION

Cancer of the breast is the most common malignancy in Western women. In the UK, 1 woman in 14 will contract breast cancer and 1 in 21 (approximately 15,000) will die from the disease.¹ Affected women have to cope not only with the effects of disease, but also with the effects of treatment. There is a consensus that patients should be made aware of both acute and late toxicity of treatment, together with their likely incidence, duration and the appropriate management.² It is, therefore, important to know what the effects of treatment

are. For patients to be adequately informed, the information that they are given must reflect, not only the objective characteristics of treatment toxicity, but also patients' experience.

This study is concerned with those patients who receive radical radiotherapy to the affected breast and immediately surrounding area following conservative surgery (lumpectomy with or without axillary sampling/clearance). Radiotherapy is intended to reduce the risk of disease recurrence. Nevertheless, it can cause severe complications, including pneumonitis and arm oedema.³ Although these affect only a minority of patients, less severe physical reactions to the treatment are much more widespread. Objective evidence exists for a number of discrete reactions. These include changes in the feelings and movement of the associated shoulder

Address correspondence to: Angela Cross BSc(Hons), DCR(T), Radiotherapy Division, Department of Allied Health Professions, Thompson Yates Building, Quadrangle, Brownlow Hill, University of Liverpool, Liverpool L63 3GB, UK

and arm and changes in the size, shape and texture of the treated breast. An acute skin reaction, particularly tenderness, itching and tightness of the skin occurs.^{4,5} These acute symptoms persist for up to 6 weeks following treatment,^{4,6} although the chronic skin changes following the acute changes may last for months or years.^{6,7} Fatigue has also been documented during and immediately following the period of radiotherapy.⁸⁻¹² Little research has been conducted into other acute physical complaints which are observed clinically, including sleep disturbances, weight changes, nausea and chest problems.

In general, therefore, previous research has emphasised objective features of physical reactions; the women's subjective perspective has been neglected. Moreover, previous studies have tended to focus only on specific types of symptom and there is no evidence that surveys the range of symptoms. To produce such evidence, it has been argued that studies should extend after completion of therapy and should find out directly from patients what they experience.¹⁰ A quantitative approach to understanding women's symptom experience would be premature; it is first necessary to find out what should be quantified. Qualitative methods are suited to exploring patients' experience of treatment.^{13,14} A recent qualitative study¹² has illustrated how this approach can identify aspects of women's experience of radiotherapy that should inform clinicians' work. Whereas that study focused on the experience of treatment as a whole, the focus of the present study is on the experience of physical symptoms. Therefore, in this study, women who had received radical radiotherapy following conservative surgery for breast cancer during the previous 12 months were asked to describe, in their own words, any physical symptoms experienced. Their accounts were analysed to identify the components of their experience and to describe the diversity of reported symptoms.

METHOD

Patients

Participating patients met the following criteria:

- Female.
- Received conservative surgery and radical radiotherapy for breast cancer during the previous 12 months.

- Aware of the diagnosis.
- Able to speak and understand English sufficiently to take part.
- At least 21 years of age.
- Not receiving cytotoxic chemotherapy or further radiotherapy at the time of the study.
- Without evidence of metastases.

Patients were recruited consecutively at either of two outpatient clinics, one in a specialist regional oncology centre, the other in a peripheral outpatient clinic held in a district general hospital. They were under the care of a single clinical oncologist. Of 15 women approached, all agreed to be interviewed.

PROCEDURE

Recruitment and interview

The researcher attended outpatient clinics, selecting patients consecutively. She introduced herself to the patient as a researcher independent of the hospital and assured her of confidentiality and anonymity. Interviews took place in a private room and were semi-structured. Patients were asked to describe physical symptoms and experiences that had arisen, intensified or changed since before treatment. The patient was prompted, as necessary, to consider at least the following areas:

- General health and physical activity.
- Digestion, appetite and weight.
- Strength, energy and sleep.
- Breathing.
- The treated area.

The pace and sequencing of the interview depended on the patient: the interviewer encouraged patients to talk in their own way and avoided closed questions. Twelve patients were interviewed alone; 3 asked for their partners to be present. The duration of interview ranged from 25–45 minutes. Interviews were audiotape-recorded and transcribed.

Analysis

This followed established conventions for ensuring that the findings are 'grounded' in the data rather than reflecting pre-existing ideas.^{13,14} First, all statements concerning physical symptoms and experiences were extracted from the first 13 transcripts and grouped by one author. For most patients, explanations for physical experiences

were inextricably part of patients' accounts. Therefore these attributions, although not originally intended to be part of the study, were included in the data set for analysis. The resulting categorisation of syndromes and attributions was 'tested' by the second author and modified in light of this. When 'cycling' between data and the emerging categorisation was complete, two further interviews were conducted and the categorisation was found to accommodate the results without further modification. In the results that follow, the range and commonality of content of each category is illustrated by patients' statements, numbered to indicate the patient by whom they were made. Silverman¹⁵ has argued that, although quantification of patients' experience in terms of categories decided by experts is often misleading, counting patients in terms of the categories that emerge from the analysis can show the completeness of a qualitative analysis. This procedure was adopted here.

RESULTS

Sample

Of the 15 women, 12 were married and living with their partner, 1 was a widow, 1 was divorced and 1 was single. Ages ranged from 43–64 years (mean 57). Thirteen of the women had cancer of the left breast. All but one took Tamoxifen. All had received radiotherapy during the previous 12 months (Table 1).

Table 1. Details of patients recruited. All subjects except number 12 received Tamoxifen

Number	Age	Marital status	Number of months post therapy at interview
1	62	Married	4
2	64	Separated	7
3	61	Married	4
4	58	Married	10
5	52	Single	5
6	49	Married	7
7	58	Married	7
8	62	Married	12
9	55	Married	3
10	64	Widow	12
11	59	Married	4
12	43	Married	12
13	55	Married	0.5
14	56	Married	9
15	60	Married	10
Mean = 57			

SYMPTOM THEMES

The initial analysis separated symptoms into two groups according to whether they affected the irradiated area or the whole of the body. Subsequently a third category included 'positive' changes and a fourth included localised changes unrelated to the irradiated area. Explanations for symptoms fell into two groups: attributions to treatment or to other medical, personal and social factors. These are illustrated for each symptom category.

SYMPTOMS AFFECTING THE WHOLE BODY

Eating and drinking

All patients volunteered changes in weight, all but one describing an increase: 'I put 10lbs on in weight but I'm hoping to lose it [4]'. A few women were mystified by this change: 'I've put weight on, I don't know why but I can't get it off [8]', but most could explain it. Although weight-gain is a side-effect of Tamoxifen, only two women suggested this explanation and, of those, one had not initially appreciated it: 'I asked about the side-effects [of Tamoxifen]. The weight business wasn't explained to me but the night sweats were [10]'.

Instead, 10 women gave explanations other than treatment. Some of these were positive, attributing weight-gain to a more positive attitude: 'Having got this [cancer] gives you a bit of a shock and I think I've put some weight on because my attitude has changed and I'm a bit more content [12]', or to a separate achievement: 'I have put on 2 stone since the surgery but I have given up smoking [12]'. By contrast, other explanations indicated the woman felt culpable for her weight change: 'I'm a comfort eater [7]. I'm piling the weight on but I do put it on very easily [6]'.

Change in appetite included reports of both improvement and loss: 'I lost my appetite a bit. . . I think it's because when you are on your own you can't be bothered cooking [2]', or alternatively: 'I feel as though I want to eat all the time – I'm hungry [1]'. Thirst, often in association with a dry throat, was a frequent complaint. In most cases, patients who described this side-effect felt unable to explain the cause although one patient suggested that she was drinking more 'due to the hot flushes [5]'.

Strength, energy and sleep pattern

Comments such as 'always very tired [11]' and 'little energy [5]' were common. For several women, tiredness dictated what they could or could not do: 'If I felt a bit tired. I thought that's it I'm having a rest and didn't do anything [4]'. Few women related their tiredness to the radiotherapy, blaming other factors, for example hot weather, high blood pressure, the skin reaction or other extraneous demands such as being 'tired of travelling [for treatment] every day [13]', or 'I look after my parents so that could possibly be why I am more tired. . . I'm trying to cope with a full-time job as well [5]'. In a further attempt to counteract the tiredness two women had bought vitamin supplements [2,4].

Most women (9) reported disruptions to sleep, including difficulty getting to sleep, waking during the night and waking early in the morning. Frequently, 'night sweats' and 'hot flushes [1-4,7,12,14]', were identified as causes. For others, thoughts and worries were to blame: 'I don't sleep well. I think sometimes it's on your mind - it's going all the time [12]', or difficulty in lying comfortably: 'Initially I was not sleeping well because I sleep on my front and my arm restricted me [1]'.

Breathing

Of the 6 women who had complained of a cough, 2 [3,6] said they had undergone diagnostic tests (at 3 and 6 months post treatment respectively) which had shown the problem was likely to be radiation damage to the lung. Of the remaining 4, 1 suggested her cough was due to treatment she was receiving for an unrelated medical problem [12]. The others could not explain their cough.

SYMPTOMS LOCALISED TO THE TREATED AREA

Changes in size and shape of the breast

Most women described their breast as changed, i.e. as 'solid [2]', 'swollen [3,7]', 'smaller [5,14]', 'bigger [6]' or 'lighter [8,11]', but these changes were sources of inconvenience rather than concern: 'There is a difference between the two which doesn't bother me but when it comes to a swimsuit or a tight bodysuit, I don't think I would wear one now [12]'.

Changes in skin

Similarly, changes to the colour, texture or feel of the skin, e.g. being 'pink and a bit sore [7]', although common (8 patients) were generally described dispassionately. Indeed, one patient spontaneously reported being 'surprised that I had no skin reaction [4]'. However, a few reports that the skin was 'badly burned [1]', had 'peeled [2]' or had 'broken down [1]', were more emotive. Changes to the irradiated nipple were occasionally reported. The lumpectomy scar was a source of discomfort for 3 women, although 2 of these women attributed this to strain imposed by daily activities rather than the radiotherapy.

Breast pain and discomfort

Most women experienced breast pain and described it graphically as: 'sharp and shooting [2]', 'tender [7]', 'sore [8]', or 'throbbing [13]'. In addition, an 'irritating [7]' and 'sore [4]' nipple was described by 2 patients. Although most of these women blamed the radiotherapy, 3 reported falls, causing injuries to the treated area, and blamed subsequent breast discomfort on these falls: 'When I touch [the breast] it's sore but I had a fall and the breast became sore about 3 days after it happened [5]'.

Changes to the shoulder and arm

Reduced mobility and soreness were common: 'At first my shoulder was stiff [2]' and 'it aches under the arm where I had the lymph glands done [3]'. In general, patients blamed the surgery but some, although informed about the possibility of side-effects, were alarmed or confused: 'After surgery I got a lot of swelling [under the arm] which by watching TV and talking to the other patients I know what it was now. I was not prepared for that although I was told in hospital if you have your lymph glands done you do get some fluid, but you see that didn't mean a thing [1]'.

LOCALISED SYMPTOMS UNRELATED TO THE TREATED AREA

Two patients described highly localised symptoms that they attributed to treatment. One reported: 'I've had a cyst on my eye, also my face is covered in spots which I think is because of the Tamoxifen [5]'. The second complained of frequent

headaches since completion of the radiotherapy and a temporary loss of voice requiring speech therapy [14].

POSITIVE CHANGES

Positive aspects of the treatment were only rarely recounted. There were, however, two notable instances. One woman stated: 'I sleep like a log – no problem. I think I'm sleeping better [since the breast cancer was diagnosed] [4]'. Another commented: 'My husband thinks I look much better since the treatment. I feel as fit as a fiddle. I'm made up to feel so well [9]'.

DISCUSSION

Specific symptoms associated with treatment for breast cancer, such as fatigue, have been investigated extensively during the period of active treatment. This study is the first in which the accounts of women who have been treated for breast cancer are used to describe how physical symptoms are experienced during the year after completion of radiotherapy. As might be anticipated, many of the women's experiences were consistent with existing evidence but others were discrepant. Moreover, the women's experience of their symptoms included important components that were not related to their objective characteristics.

Localised symptoms commonly included changes to the appearance or feel of the skin which are consistent with the known effects of radiation in radiotherapy.^{4,5} In addition, however, women described other localised changes, including swelling or shrinking of the breast or changes in solidity that, although not previously documented, are likely to be consequences of surgery and radiotherapy rather than radiotherapy alone. Women described these changes relatively objectively, bearing out previous evidence that, although common, these symptoms are not experienced as a serious concern. However, the occurrence of breast pain was reported more emotively. References to the skin being 'burned' or 'breaking down' probably reflect erythema and moist desquamation.⁴ However, they also reveal negative, destructive views of radiation, even in the context of radiotherapy, which might intensify the distress associated with these symptoms.

Most symptoms, however, were not localised but were systemic or concerned physiological systems remote from the site of irradiation. The most extensive reports concerned tiredness and fatigue. Fatigue emerged as an important symptom in a similar study,¹² in which it was proposed that fatigue was particularly troubling because it interfered with gender-related roles. However, the present results suggest a different reason for the particular difficulty associated with fatigue. Unlike skin reactions, which were readily attributed to the destructive effects of radiation, fatigue was not reliably attributed in this way. Perhaps, whereas the lay view of radiation as 'burning' provides a plausible way of linking it with skin problems, there is no similar model to link radiation or other aspects of treatment to fatigue. Therefore many patients attributed fatigue to other factors in their lives, such as caring for parents or working. The absence of a plausible explanation for fatigue, or making sense of it by attributing it to aspects of one's way of life, might well increase patients' concern with this symptom.

Patients also indicated that normal sleep patterns were disrupted, consistent with evidence that sleep is more frequently and more severely disturbed in cancer patients than in the general population.¹⁶ It is not clear why several patients reported coughing; radiation pneumonitis is considered to be a rare complication of treatment for these patients.¹⁷ Thirst and changes in appetite (both increases and decreases) were common.

Our interviews explicitly sought information about symptoms that had been experienced since treatment, irrespective of the patients' or interviewer's belief that they were side-effects of treatment. A striking feature of patients' reports of symptoms was the diversity of attributions that were made for them. Some symptoms were attributed to treatment in ways that clinicians would expect e.g. night sweats being blamed on Tamoxifen. However, many patients' attributions were discordant with clinicians' understanding. For instance, a variety of reasons were given for the almost universal weight gain. Few, however, attributed it to Tamoxifen despite weight gain being known by clinicians to be a side-effect.¹⁸

Sometimes treatment was blamed for changes that were unlikely to be related, such as a cyst on

the eye. Conversely symptoms that were likely to have been side-effects of treatment were attributed to extraneous factors or concurrent medical disorders, such as weather, domestic responsibilities or trauma to the breast. Each kind of misattribution might have harmful consequences. Incorrect attribution of a new symptom to treatment is likely to deter the patient from seeking medical attention for it. Conversely, attribution to a separate medical problem or trauma may increase concern about a problem that is, in reality, innocuous. Furthermore, some patients blamed themselves for changes experienced, for example putting on weight due to 'comfort eating'. Finally, patients described several attempts at self-management of symptoms. However, attributions of symptoms to irrelevant factors may lead to ineffective or counter-productive attempts at self-management.

The diversity of attributions for symptoms indicates a patients' need to make sense of bodily experiences, combined with a search for plausible ways of doing so. This search is clearly dependent on the sources of information that are available. The patients' exposure to information about their symptoms was not a focus of the study. Nevertheless, some patients' statements about their symptoms contain important clues about how different sources of information are used. In particular, it was clear that explanation by a clinician that was technically accurate (for example, that the ipsilateral arm might become lymphoedematous) could be experienced as completely uninformative. Even where such an explanation had been received to no effect, information from other patients and the media was received in such a way that it was able to help patients to make sense of their symptoms. Patients are therefore open to more accessible forms of explanation and the health care professionals should provide this authoritatively. Such explanations might prevent attributions that are potentially harmful. For example, although an extreme reaction, moist desquamation is not rare and patients should be warned in clearer terms than skin 'breaking down'. An opportunity arises to change clinical practice by developing information transfer to patients while also improving the content of that information.

The importance of the evidence reported here is that it will allow the design of information in

terms, which correspond, to patients' experience rather than clinicians' assumptions. In this way, inaccuracies that were apparent in this group of patients can be avoided. In addition the evidence may be used to increase the awareness of the difficulties encountered by these women. Although the present study is preliminary, some important observations, which could be used to inform patients, are already apparent. More detailed information could be based on quantitative studies of patients' symptoms. To achieve this, the present study could be used to identify the items for a questionnaire survey. We shall, in due course, report the findings of such a study.

Acknowledgement

The authors are indebted to Dr R.D. Errington for his enthusiastic support.

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