

Breast cancer: causes of patients' distress identified by qualitative analysis

R V H JONES

BERNARD GREENWOOD

SUMMARY

Background. Previous investigations of the psychological consequences of having breast cancer have usually involved quantitative analysis within medical models.

Aim. This qualitative study set out to identify key events which had caused distress to women with breast cancer and to compare the frequency of these events with doctors' beliefs about their relative frequency.

Method. The causes of distress in 26 women with breast cancer were identified by qualitative analysis of unstructured interviews. Subsequently, all hospital doctors and general practitioners in the Exeter health district were sent a list in random order of the eight events which had most commonly caused distress and were asked to rank them in order of frequency for patients with breast cancer.

Results. The responses suggest a mismatch between the doctors' expectations and the experience of the patients.

Conclusion. Patients may suffer distress in areas of management doctors do not suspect are important; qualitative analysis can identify these areas.

Keywords: breast cancer; patient personal experiences; patient concerns; psychological morbidity; doctor-patient relationship.

Introduction

THE physical and psychological morbidity associated with having breast cancer and with its treatment have been the subjects of much research. The emphasis however has been on medical models.¹⁻⁵ The aims of this study were to identify key events which had caused distress to women with breast cancer by a method uninfluenced by medical preconceptions, and to compare the frequency of these events with doctors' beliefs about their relative frequency. The study had approval from the local medical ethics committee.

Method

Over the period 1988-91 patients with a history of breast cancer from two general practices in Devon were asked by their general practitioner in person to tell the story of their illness to a medical anthropologist (B G) who visited them at home. The interviews were minimally structured. With strict confidentiality safeguards and with the patients' permission each interview was recorded and transcribed on to a word processor. For each patient the situations, actions and events which gave rise to negative and positive emotions were identified by a form of grounded theory.^{6,7} The text of each transcribed interview was searched sentence by sentence for words and phrases which indicated negative or positive emotions (markers), for example 'it was just awful', or 'I

came home and cried and cried' or 'they explain everything to you — they're marvellous'. The event or aspect of the situation (category) which had given rise to the emotion was then linked to each marker. A list of all the categories identified in the interviews was made and the number of patients in whom each category had occurred was noted.

As a follow up to the identification of causes of distress among patients, all hospital doctors and general practitioners in the Exeter health district were circulated in 1991 with a list containing in random order the eight numerically most frequently reported distressing events as defined in the study. They were asked to rank them in the order of frequency with which they judged them to occur. The overall rankings were calculated separately for the replies received from junior hospital doctors, from hospital specialists and from general practitioners.

Results

Of the 39 women with a history of breast cancer identified six did not wish to be interviewed, seven were considered by their general practitioner to be too ill to be asked, and 26 were interviewed. Eighteen of the 26 women had received radiotherapy; 16 had had a full mastectomy.

Analysis provided 22 spontaneously generated categories, of which 13 had caused distress in five or more women (Table 1).

Accounts of problems following radiotherapy included:

'Your whole personality seems to change. I never had the same energy. Even now most days I have to sleep in the afternoon — for someone of my age that's awful isn't it? It had left me depressed and tired.'

'They didn't warn me about all this. When I went to see them again I was greeted with: "How did you like your Christmas present?" I didn't think that was funny. They never said anything about after effects.'

Table 1. Causes of distress in women with breast cancer.

Category	No. of patients experiencing distress
<i>All patients (n=26)</i>	
Worry, shock at first symptom	13
Fear of recurrence	12
Being told the diagnosis	11
Problem with doctor (eg attitude, delayed referral)	11
Waiting for appointment at the hospital	9
<i>Radiotherapy treatment (n=18)</i>	
Depressed, weak, tired	15
Burns	12
Sickness	11
<i>Mastectomy (n=16)</i>	
Problems with prosthesis	13
Affected by loss of breast	11
Residual problems with arm	8
Immediate post-operative problems (eg drainage tube)	7
Poor service related to prosthesis	5

n = total number of women in group.

R V H Jones, MA, FRCGP, senior lecturer and B Greenwood, MB, PhD, research fellow, Institute of General Practice, University of Exeter. Submitted: 15 February 1993; accepted: 22 November 1993.

© British Journal of General Practice, 1994, 44, 370-371.

With regard to prostheses, in addition to problems with the prosthesis itself five women reported poor advice and poor service.

'One burst, which wasn't very nice. I went to the doctor and being male he didn't think it was very important, and to me it was the most important thing in my life. He didn't understand. I think some older male doctors don't understand.'

'They were horrible then. It used to rise up — it was terrible it really was. It used to be dreadful — that makes you feel bad and it's only this last three years that I've had a decent one. Now it's more natural, like a breast proper.'

'There was only a little shop with a cold back room. They showed you one or two, one of which fitted. They were discussing your breast in the shop with men coming in. I found the thing repulsive.'

From 105 junior hospital doctors 24 completed replies were received, from 62 hospital specialists 18 replies were received and from 100 general practitioners 77 replies were received. The doctors' estimates of the order of frequency of the events causing distress in women is shown in Table 2.

Comparison of Tables 1 and 2 shows that although the first three items on the doctors' list had been distressing events for up to half the women interviewed, a greater proportion of the women had been distressed by the side effects of treatment. The most frequent distressing situation had been depression, weakness and tiredness after radiotherapy. Moreover 13 out of the 16 women who had had a mastectomy had problems with their prostheses and this was the last or last but one item on the doctors' lists.

The doctor's ranking order which most nearly accorded with the experience related by patients was provided by a junior hospital doctor who added the comment 'Have you considered sorting replies according to whether family members have suffered from this disease? One of mine has.'

Discussion

Papers published recently⁸⁻¹⁰ suggest that medical interest in qualitative methodology is increasing. Grounded theory is a qualitative method which is in extensive use in operational research. It has been described as 'the discovery of theory from data'.^{6,7} Results are expressed in terms of observation and questions which can form the basis of hypotheses. These hypotheses

can then be tested by further research, either qualitative or quantitative.

In this study the original observation culled from the narration by 26 women with a history of breast cancer of their experiences was the identification of events which frequently caused distress. Questions which arose included how accurate were the patients' accounts: to what extent had their memories faded or had earlier anxieties been obliterated with time? Other questions centred round what had actually happened: do similar events still happen, do they happen in illnesses other than cancer? A third set of questions concerned the extent to which doctors are aware of the events which frequently distress women with breast cancer, or more broadly: how aware are doctors of patients' problems and priorities? From among these questions it was decided to test the hypothesis that doctors are unaware of the frequency with which certain events had caused distress to a group of women with a history of breast cancer. This hypothesis was then tested by a questionnaire.

It is clear from the results of this study that the doctors who answered the questionnaire would be likely to underestimate the frequency with which women with breast cancer suffered from side effects of radiotherapy or from problems with their prostheses. This in turn could lead to a lack of consideration of these areas. The hypothesis which emerges is that assessment of patient need is strongly influenced by doctors' preconceptions.

Qualitative research is not an easy option. The conditions to be observed are as rigorous as those needed in quantitative research although very different in nature. For general practice, however, qualitative research can have major practical advantages. It does not require large populations to acquire significance or validity. Based on observation without prejudice it may, as in this study, raise new and challenging questions. The great potential for research which exists within general practice will not be realized until qualitative methods are more widely understood, taught and used.

References

1. Maguire GP, Lee EG, Bevington DJ, *et al.* Psychiatric problems in the first year after mastectomy. *BMJ* 1978; 1: 963-965.
2. Greer S, Morris T, Pettingale KW. Psychological response to breast cancer: effect on outcome. *Lancet* 1979; 2: 785-787.
3. Fallowfield LJ, Baum M, Maguire GP. Effects of breast conservation on psychological morbidity associated with diagnosis and treatment of early breast cancer. *BMJ* 1986; 293: 1331-1334.
4. Hughson AVM, Cooper AF, McArdle CS, Smith DC. Psychosocial effects of radiotherapy after mastectomy. *BMJ* 1987; 294: 1515-1518.
5. Fallowfield LJ, Hall A, Maguire GP, Baum M. Psychological outcomes of different treatment policies in women with early breast cancer outside a clinical trial. *BMJ* 1990; 301: 575-580.
6. Glaser B, Strauss A. *The discovery of grounded theory: strategies for qualitative research*. London: Weidenfield and Nicolson, 1968.
7. Turner B. A. The use of grounded theory for the qualitative analysis of organizational behaviour. *J Management Stud* 1983; 20: 333-348.
8. Anonymous. Medicine and culture [editorial]. *Lancet* 1991; 337: 1012.
9. Gantley M, Davies DP, Murcott A. Sudden infant death syndrome: links with infant care practices. *BMJ* 1993; 306: 16-20.
10. Pope C, Mays N. Opening the black box: an encounter in the corridors of health services research. *BMJ* 1993; 306: 315-318.

Acknowledgements

The authors thank David Knowles, Derrick Sims, Colin Knowles, David Batty and Peter Lee, administrators in Exeter University who ran a marathon to raise money in support of this research. We are also grateful to the trustees of the Howe Green Trust, to Heather Hutchinson, and to the women who were so generous in their interviews.

Address for correspondence

Dr R V H Jones, Foxenholes, Couchill Lane, Seaton, Devon EX12 2JH.

Table 2. Estimate by doctors of order of frequency of causes of distress in women with breast cancer.

Category	Ranking order of frequency		
	Junior hospital doctors (n = 24)	Hospital specialists (n = 18)	General practitioners (n = 77)
Worry, shock at first symptom	1	1	1
Being told the diagnosis	2	2	2
Fear of recurrence	3	3	3
Affected by loss of breast	4	4	4
Depressed, weak, tired after radiotherapy	5	5	5
Sickness with radiotherapy	6	6	6
Problems with prosthesis	7	7	8
Burns with radiotherapy	8	8	7

n = number of respondents in group.