



Qualitative Analysis of delay in reporting of breast cancer in a tertiary care center

KEYWORDS

breast cancer; symptoms; consultation; delay

Hashmi SJ

Assistant professor, Department of community medicine, Government medical college Aurangabad

Gaikwad AV

Associate professor, Department of community medicine, Government medical college Aurangabad

ABSTRACT

Background: Delayed presentation of symptomatic breast cancer of six months or more is associated with lower survival rates from the disease, yet 36.8% of women wait at least six months before consulting their general practitioner (GP) with breast symptoms. **Aim:** To explore the factors that influence physician consultation by women with breast cancer symptoms. **Design of study:** Qualitative analysis of semi-structured inter-views. **Setting:** 210 women with newly diagnosed breast cancer, registered in Aurangabad cancer registry. **Method:** Interviews were conducted, comparing two groups of women divided according to the extent of delay between onset of symptoms and seeking medical care. 134 women had sought advice from their GP within 6 months of symptom discovery ('non-delayers') and 76 had waited 6 months or more before seeing their doctor ('delayers').

Results: Women with breast symptoms who presented promptly to GPs recognized the seriousness of the symptom they had discovered more quickly than delayers. Perception of seriousness was influenced by the nature of the initial symptom and how far it matched the individual's expectations of breast cancer as a painless breast lump. Other factors affecting help-seeking included attitudes to GP attendance, beliefs about the consequences of cancer treatment, and perceptions of other priorities taking precedence over personal health.

Conclusions: This analysis suggests that women need further information about the different types of breast cancer symptoms to assist symptom recognition, as well as encouragement to seek medical advice for a symptom is ambiguous. In addition, women may benefit from greater awareness of the benefits of early detection and reassurance about the improvements in quality of breast cancer care.

Introduction

DELAYED presentation of symptomatic breast cancer of six months or more is associated with lower survival rates from this disease.¹ While some of this delay is health provider-related, an estimated 36.8% of women wait at least six months before seeking medical help with breast symptoms.¹ A recent fall in deaths from breast cancer has been reported, owing to improved survival from a combination of earlier diagnosis, breast screening, and better treatment.² The relative contribution of these factors remains to be evaluated. In the meantime, breast cancer mortality continues to represent a major public health problem and further gains in survival might be achieved by encouraging women who delay presenting to seek help more quickly. It is therefore important to understand the factors that influence patient delay and to develop strategies for reducing it.

In a quantitative analysis of delayed presentation of breast cancer³ a number of risk factors for patient delay were suggested, including discovery of a symptom that does not include a lump, not disclosing the symptom discovery to someone else, being prompted by others to seek help, and presenting to the general practitioner (GP) with a non-breast problem. No information about disease, Just neglecting, Financial constraints, Husband or family not allowing, Taken treatment anywhere else. A complementary qualitative analysis was undertaken to examine important beliefs and attitudes associated with medical help-seeking that were not easily accessible using a quantitative approach. Qualitative methodology has been used effectively with other illnesses to identify key influences on patients' decisions to consult their physician.^{4,5}

Method

The participants in the study were 210 who were diagnosed as breast cancer and registered in Aurangabad cancer registry. They included 134 patients who had presented within 6 months of symptom discovery and 76 who had delayed more than six months before presenting. This division was informed by recent evidence which suggests that the majority of women seek help within 6 months of symptom discovery and that delays greater than 6 months between onset and diagnosis may be detrimental to survival.¹ The division of participants into two groups enabled exploration of any variations in attitudes and beliefs to help-seeking between those who sought help promptly and those who did not.

Data were collected using a semi-structured, open-ended interview conducted by a female researcher who was not involved in the clinical management of the patients. Topics to be discussed in the interview were derived from the existing literature on delayed presentation in breast cancer. The interview schedule was piloted and refined prior to the study. The interviews were non-judgmental and did not enquire directly about any delay in help-seeking; instead, it sought to gather a history from women of their experiences from symptom discovery to diagnosis and treatment. Women's thoughts and feelings about symptom discovery were explored, as was their behavior in relation to the symptom and who they confided in or sought advice from, including close friends, family, and health professionals. The resulting interview elicited a narrative of each woman's illness from symptom discovery to treatment. Participants were assured anonymity in the writing up of research findings. Interviews were conducted in the medical oncology outpatient's clinic at Government cancer hospital and lasted between 30 to 60 minutes. These

tudy was approved by the Government medical college and Hospital Research Ethics Committee. Answers given in mother tongue of participants was translated into English and analyzed.

Data analysis

Data were analyzed using the 'framework' method of qualitative data analysis.⁷ Transcripts were studied repeatedly to identify and list important and recurrent themes in women's accounts of their experiences. This framework of themes and patterns generated an index of major themes and sub-themes, each of which was assigned a number so that the index could be applied systematically to all the transcripts. Segments of text were numbered according to the numerical codes from the index. Charts were then constructed for both groups for each major theme showing brief summaries of the interviewees' thoughts and experiences, as well as relevant segments of verbatim text.

Three transcripts were discussed by two of the authors to ensure agreement about which themes and sub-themes to adopt and to assess whether selected data were representative of the themes.

Results

Qualitative analysis suggested that the help-seeking process is influenced by a mixture of knowledge, perceptions, beliefs, and attitudes, including: (a) the process of symptom interpretation; (b) attitudes towards attending a GP; (c) beliefs and fears about the consequences of medical help-seeking; and (d) perceptions of competing priorities. In addition, it was possible to ascertain factors associated with eventual help-seeking in those who delayed. Each of these themes will be discussed separately, although there is clearly some overlap between them.

(a) Interpretation of symptoms

A central theme to emerge from the accounts of women who had delayed presenting to the GP related to problems with identifying and labelling the initial symptom they discovered as one which might prove to be breast cancer: '*I didn't realize it was serious*', was a frequent comment which was often linked to the nature of the symptom. Symptom interpretation was influenced by the presence or absence of a breast lump, the characteristics of a breast lump, the presence or absence of pain associated with the symptom, and the experience of any previous breast symptoms.

40 of the 78 women who delayed presentation did not have a breast lump as an initial symptom and often stated that, if they had felt a breast lump, then they would have been aware of the implications:

'I never realised there was anything wrong. Because I couldn't feel a lump and the only thing I knew about breast cancer was you should feel a lump ... there was an inversion of the nipple ... but I never knew that was a symptom.' (7047, Delayer.)

'Every time I ... tested myself there were no lumps, it was just that there was this dent down my breast.' (7034, Delayer.)

This belief is borne out by their help-seeking behaviour once a breast lump did appear, which often provoked eventual presentation to a GP. In contrast, non-delaying patients were more likely to have discovered a symptom which matched their expectations of breast cancer presen-

tation — namely a 'pea-shaped breast lump':

'It was almost like a frozen pea, a little lump ...' (7116, Non-delayer.)

Non-delayers experienced far less ambiguity about the implications of their symptom discovery and expressed more concern that the change they found might represent a serious health threat:

'It was a lump that just appeared overnight ... straight away, I just knew it was cancer.' (7101, Non-delayer.) (Translated in English from mother tongue of participants)

For those women who delayed despite having found a breast lump, the precise nature of this lump was sometimes reported as ambiguous and failed to meet expectations of what a breast cancer lump would feel like:

'It wasn't a lump as you are supposed to feel it, like a pea... it was just a hard mass.' (6171, Delayer.) (Translated in English from mother tongue of participants)

Another prevalent belief expressed by some of those who delayed GP attendance was that, when breast cancer presents, it is painless, which gave a false sense of reassurance to some of those who experienced pain: '*They say you don't get pain with cancer ... I didn't connect it with anything*'; although, paradoxically, for a few women it was the lack of pain which inhibited their help-seeking: '*...because it didn't hurt, I didn't take any action*'.

(b) Attitudes to general practitioner attendance

Another major theme to emerge from the data related to feelings about when it was justified or appropriate to request an appointment with a GP. The accounts of those who delayed consulting a GP reflected many more inhibitions about 'bothering' the doctor with something that might prove to be trivial, than the non-delaying group:

'I mean some people are health conscious, they keep examining themselves and go to the doctor about their toenail, you know, stupid things, ear-ache or sore throat, things you could treat yourself, they waste people's time ...' (6101, Delayer.)

'I feel that a lot of people have lumpy breasts anyway and they get quite neurotic about it.' (7012, Delayer.)

Those who presented promptly appeared to be more confident about sharing their health concerns both with those around them and with health professionals:

'...and having listened to all the blurb that says do something immediately, I rang my GP and made an appointment for the next day.' (7072, Non-delayer.)

There was some evidence from their accounts that they were more likely to be regular attenders at their general practice for routine health checks and to hold more 'consumerist' attitudes to medical care:

'My body is telling me that something is not right. And I noticed the lump and thought I'd best get it sorted out. I'm not one to make a fuss or anything. If there is something wrong with me I just go straight to the doctor, I don't have any inhibitions about going.' (7080, Non-delayer.)

'I was going to see the doctor fortnightly and I'd just got-

that sorted out when I ... saw a dimple and I told her about it.' (6110, Non-delayer.)

This contrasted with the reported behaviour of those who delayed seeing their GP:

'I don't have a smear test or anything. I don't go for tests' (7111, Delayer.)

'As I say, I haven't seen a doctor for years and years' (7112, Delayer.)

Beliefs about consequences of cancer treatment: Some of those who delayed seeing their doctor reported past experiences of cancer in which a loved one had died a protracted or painful death. Although this event may have occurred many years ago and the woman may acknowledge that 'things have changed since', the memory remains nonetheless:

'I did feel frightened because it was only a few months ago we lost my father with cancer, and not very much was done for him, he was just sort of sent home and left to get on with it, and I could just imagine myself — same sort of thing happening to me.' (7001, Delayer.)

Some women were unaware that choices now exist; for example, with regard to treatment by breast conservation or mastectomy, or that treatments exist to counter the toxic effects of chemotherapy. In contrast, the non-delaying group made fewer references to negative experiences or attitudes towards medicine or health professionals. Where they had experienced cancer in others close to them, this experience tended to be perceived in a more positive way. Non-delayers were more likely to perceive medical consultation as a problem-solving measure to obtain reassurance or treatment, rather than a behavior which is likely to have negative consequences.

Perception of competing priorities

A theme running through many of the accounts of women who had delayed help seeking related to the effect of competing events and difficulties, which were prioritised over and above their personal health. These comprised problems relating to other members of the family, work, and holidays. Some of those who cited domestic problems were aware that their symptom might be serious but nevertheless felt too busy to arrange a medical appointment. For some, it seemed to reflect a tendency to place the needs of others above their own:

'It sounds awful to neglect your body, but life was busy and I'm a bit of a martyr, I don't necessarily put myself first. I let my job take me over.' (171, Delayer.)

'My mother died, it went on for a few months and ... I didn't go to the clinic ... if it was my daughters and my husband I'd see it was done, but yourself you tend to leave.' (7010, Delayer.)

This contrasted with that of those who presented promptly, who often related to using the people around them as a 'sounding board' to endorse their decision to seek immediate help, regardless of other domestic or work-related problems they or others might be experiencing:

'Work was getting on top of me, I just felt tired all the time, I just felt depressed, everything was happening all at the same time.' (7080, Non-delayer.)

(e) Triggers to action

It was possible to ascertain influences which provoked eventual help seeking in the accounts of women who delayed. At any point in the process, a change in symptom or disclosing symptom discovery to another person could facilitate recognition of the potential seriousness of the situation and the decision to seek medical advice. The data suggest that women monitored the situation, keeping their symptoms under review:

'... kept feeling it in the bath until sure ... there was a lump ... I would leave it a few days and have another go ...' (7012, Delayer.)

There was evidence that when the symptom changed, or an additional breast symptom appeared, they took action and sought medical help at that stage:

'I mentally kept an eye on it and I thought, that has got bigger. So I made an appointment to go to the doctor's.' (7038, Delayer.)

For a large proportion of delayers this point was reached when a breast lump appeared, while for others it was the development of pain or discomfort:

'Yes, I lived with it. Occasionally it would ache. Then in the summer it dimpled, which I knew was a danger sign, I knew it shouldn't be dimpling. And my husband said, "Go and get it sorted out".' (171, Delayer.)

For some, the influence of close others, a change in life circumstances or information received via the media either prompted or supported the decision to seek help:

'I happened to speak to a friend who had breast symptoms in the past ... and she said "You must go straight away".' (108, Delayer.)

Discussion

This study suggests that the most important stage in the help-seeking process for women with breast cancer is the initial one, where the patient identifies and labels the symptom. The analysis indicates that symptoms which fail to match the expectations of breast cancer presenting as a discrete breast lump may contribute to the delay in seeking treatment. This supports findings from quantitative studies that non-lump symptoms are associated with patient delay^{3,8,9} and suggests that the public perception of the presenting symptoms of breast cancer may need to be broadened. Any intervention aimed at achieving this would need to be informed by further, larger scale studies to confirm these qualitative findings. Further research is also required to determine the predictive value of individual breast symptoms in predicting or excluding breast cancer. Educational messages would need to be designed with some care so as not to cause undue alarm among women and an overload of referrals and demands for consultations in both primary and secondary care.

The way in which patients interpret and label their symptoms has been shown to influence help-seeking behavior with a range of other illnesses.^{5,10} Symptom interpretation appears to be a critical factor influencing the timing of seeking medical help for patients having a heart attack. Those who call for medical help promptly appear to be more likely to recognize their symptoms as cardiac in origin and are able to recognize a wider range of symptoms of a heart attack.¹¹ In a recent study, patients took longer

to seek medical help if their experience of a myocardial infarction did not match their preconceptions of a heart attack.¹² It is possible that some or all of the themes emerging from this analysis might be applicable to help-seeking for other cancers. For example, studies of delayed help-seeking with other medical conditions, including dyspepsia, rectal bleeding, and symptoms of testicular cancer, also suggest that perception of the seriousness of the symptom and other health beliefs are influential in the decision to seek medical help.^{4,13-15}

The finding that some women are hesitant to 'bother' their physician, particularly when they feel their symptoms are ambiguous, suggests scope for physician to be more proactive, particularly with women who are at higher risk of breast cancer. This might include routine enquiry about breast symptoms when women consult about other health matters.

Despite believing the symptom could be cancer, some women delayed seeing a doctor because they feared the consequences of medical intervention. These fears had often been influenced by past experiences of cancer in relatives or friends. Current health education about cancer tells us how to identify cancer symptoms but provides little information about the consequences of a cancer diagnosis. There may be some benefit in reassuring women of the benefits of early treatment on prognosis, that surgery is minimal if the cancer is diagnosed early enough, and that there have been advances in the management of the side-effects of chemotherapy. Such education would need to be informed by more data on current beliefs and attitudes about breast cancer and its treatments in the general population. Similar findings emerge from the breast cancer screening literature which suggests that attenders for screening have more faith in the health care system than non-attenders, perceiving positive, rather than negative, consequences as the likely outcome of screening.¹⁶ Fear of hospitals, operations, and medical tests has been identified as a major barrier to help-seeking with angina.¹⁷

There is evidence from this study that some women who delay their presentation actively keep their symptoms under surveillance, monitor changes, and act quickly as soon as they recognize the potential seriousness of the

symptom. This challenges the traditional view that many women who delay presentation must be 'in denial' about their situation.¹⁸⁻²⁰ 'Denial' in the context of breast symptom discovery usually appears to refer, not to a denial of the reality of the symptom, but a response which enables an individual to 'reduce a threatening portion of reality to allow the person to function under less psychic stress.'²¹ It has been argued, however, that what appears to be denial of serious medical problems or non-compliance with treatment could be interpreted as the individual's wish to explore other options or simply displaying an optimistic or hopeful attitude.²² Given the retrospective nature of this kind of research, it is difficult to get a clinical impression of the individual's emotional response at the time of symptom discovery; by definition it is a response of which the patient is unaware and cannot report, and so has to be inferred. Some women who delayed did not prioritise their health over competing demands, despite evidence that those who present promptly have lives that are at least as busy and stress-filled.²³ The breast cancer screening literature also finds that practical difficulties related to family or work are a frequent reason that women give for not attending breast screening, despite evidence that attenders for screening have more actual home or work commitments.²⁴

A recent systematic review of the literature concerning risk factors for delayed presentation of breast cancer highlighted the paucity of good quality studies and concluded that further primary research is required in this area to inform interventions to reduce delay.²⁵ The results of this qualitative work provide some clear hypotheses to be tested in large-scale quantitative studies: namely that help seeking is influenced by symptom interpretation, and attitudes towards GP attendance and beliefs about the consequences of cancer treatments. If confirmed, these findings suggest implications for the education of the general population and perhaps also of primary health care teams and family planning clinics.

Acknowledgements

We are grateful to the In charge government cancer hospital for allowing us to this study in oncology clinic.

REFERENCE

- Richards M, Westcombe A, Love S, et al. Influence of delay on survival in patients with breast cancer: a systematic review. *Lancet* 1999; 353:1119-1126. | 2. Richards M, Stockton D, Babb P, Coleman M. How many deaths have been avoided through improvements in cancer survival? *BMJ* 2000; 320: 895-898. | 3. Burgess C, Ramirez A, Richards M, Love S. Who and what influences delayed presentation in breast cancer? *Br J Cancer* 1998; 77(8): 1343-1348. | 4. Delaney B. Why do dyspeptic patients over the age of 50 consult their general practitioner? A qualitative investigation of health | beliefs relating to dyspepsia. *Br J Gen Pract* 1998; 48:1481-1485. | 5. Cornford CS. Why patients consult when they cough: a comparison of consulting and non-consulting patients. *Br J Gen Pract* | 1998; 48:1751-1754. Glaser B, Strauss A. The discovery of grounded theory. New York: Alding; 1967. | 6. Ritchie J, Spencer L. Qualitative data analysis for applied policy research. London: Routledge, 1994. | 7. Gould-Martin K, Paganini-Hill A, Mack T, Ross R. Behavioral and biological determinants of surgical stage of breast cancer. *Prevent Med* 1982; 11: 429-440. | 8. MacArthur C, Smith A. Delay in breast cancer and the nature of presenting symptoms. *Lancet* 1981; 14 March (8220 Part 1): 601-603. | 9. Cameron L, Leventhal E, Leventhal H. Symptom representations and affect as determinants of care seeking in a community dwelling, adult sample population. *Health Psychol* 1993; 12(3): 171-179. | 10. Rushton AC, J Calnan, M. Patients' action during their cardiac event: qualitative study exploring differences and modifiable factors. *BMJ* 1998; 316:1060-1064. | 11. Home R, James D, Petrie K, et al. Patients' interpretation of symptoms as a cause of delay in reaching hospital during acute myocardial infarction. *Heart* 2000; 83(4): 388-393. | 12. Lydeard S, Jones R. Factors affecting the decision to consult with dyspepsia: comparison of consulters and non-consulters. *J R Coll Gen Pract* 1989; 39: 495-498. | 13. Crosland A, Jones R. Rectal bleeding: prevalence and consultation behaviour. *BMJ* 1995; 311: 486-488. | 14. Post G, Bellis S. The significance of delay in treating patients with potentially curable testicular cancer. *South Med J* 1980; 73(1): 33-35. | 15. Sutton S, Bickler G, Sancho-Aldridge J, Saidi G. Prospective study of predictors of attendance for breast screening in an inner-city area. *J Epidemiol Community Health* 1994; 48(1): 65-73. | 16. Gardner KC, A. Barriers to referral in patients with angina: qualitative study. *BMJ* 1999; 319: 41 8-421. | 17. Greer S. Psychological aspects: delay in the treatment of breast cancer. *Proc R Soc Med* 1974; 67: 470-473. | 18. Magarey CJT, Todd PB, Blizzard PJ. Psychosocial factors influencing delay and breast self-examination in women with symptoms of breast cancer. *Soc Sci Med* 1977; 11: 229-232. | 19. Wool M. Extreme denial in breast cancer patients and capacity for bereavement relations. *Psychother Psychosom* 1986; 46:196-204. | 20. Burgess C, Ramirez A, Smith P, Richards M. Do adverse life events and mood disorders influence delayed presentation of breast cancer? *J Psychosom Res* 2000; 48:171-175. | 21. French K, Porter AMD, Robinson SE, et al. Attendance at a breast screening clinic: a problem of administration or attitudes? *BMJ* 1982; 285: 617-620. | 22. Ramirez A, Westcome A, Burgess C, et al. Factors predicting delayed presentation of symptomatic breast cancer. *Lancet* 1999; 353:1127-1131. |