

Patient and provider delays in breast cancer patients attending a tertiary care centre: a prospective study

Chintamani • Amita Tuteja • Rohan Khandelwal • Megha Tandon • Rahul Bamal • Sidharth Jain • Nikhil Narayan • S Srinivas • Yashwant Kumar

Department of Surgery and Vardhman Mahavir Medical College, Safdarjang Hospital, New Delhi, India Correspondence to: Chintamani. Email: chintamani7@rediffmail.com

DECLARATIONS

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None declared

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CM was the principal investigator who designed the study; AT, RK, MT, RB, SJ, NN, SS and YK contributed to the design of the study, and the collection and analysis of data

Summary

Objectives To find out factors that are responsible for the patient or provider delays in the diagnosis of breast cancer in India.

Design This prospective study was designed to be conducted over a period of two years including a cohort of 100 patients with locally advanced breast cancer. The delays were assessed using questionnaires prepared according to the Indian scenario.

Setting A prospective study in an Indian setting.

Participants One hundred patients with locally advanced breast cancer receiving neoadjuvant chemotherapy were included after providing informed consent and receiving ethical committee clearance.

Main outcome measures The most common factor responsible for delays in diagnosis was observed to be the health providers, although illiteracy and lack of adequate healthcare services also contributed significantly. Unregistered medical practitioners or quacks contributed significantly to the delays in reporting and diagnosis of the disease.

Results One hundred patients of locally advanced breast cancer were evaluated using standardized questionnaires to assess the delays in diagnosis. Provider delays were found to be significant (the unregistered doctors or quacks being a significant cause of delays). The average time lapse before diagnosis for rural patients was higher (67.5 days) compared to urban patients (53.7 days). The literacy levels of the patients also had a significant impact on the delays at diagnosis. The delay in illiterates was 60.6 days compared to 49.5 days for literates.

Conclusions The most common factor responsible for delays in reporting and diagnosis was observed to be at the end of the health providers, although illiteracy and lack of adequate healthcare services also contributed significantly. Unregistered medical practitioners or quacks contributed significantly to the delays in reporting and diagnosis of the disease.

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Introduction

Breast cancer is the most common cancer among Indian women and the majority of cases are locally advanced at presentation. The majority of the population in India, like in other developing countries, live in villages, and in the rural set-up the unregistered medical practitioner (quack) acts as the gatekeeper to medical services. He is often the first 'medical' person to see and examine these cases. These quacks, due to their limited understanding of cancers, cause significant delays in the diagnosis and management of breast cancer patients.

There are enough randomized trials based on mammographic screening that have provided strong evidence that early diagnosis and treatment of breast cancer can reduce the specific mortality. Moreover, in a recent systematic review of published studies, delays of 3–6 months between the onset of symptoms and the institution of treatment have been clearly found to reduce the survival rates for breast cancer patients.

Constraints to the timely diagnosis of cancer and access to treatment have been attributed mainly to the characteristics of individual patients, healthcare practitioners, or the healthcare system. The prevailing model of delays in breast cancer diagnosis and treatment recognizes only two categories of actors or agents (patients and providers) and one set of structure (the healthcare system).^{2–4}

Patient-related delays are those that occur in the period between symptom discovery, appraisal and

initial medical consultation. A delay of more than three months is associated with lower survival and most women seek care within five or six weeks of discovering a lump. Because women themselves detect most breast tumours, most studies have focused on demographic or psychosocial characteristics that may predispose certain women to avoid screening mammography or to delay seeking care. For example, the use of screening mammography by women in Canada and the United States is positively associated with income and education.^{5–7}

Practitioner-related delays occur during the interval between the first consultation when a breast abnormality is noted to a point when a definitive diagnosis is made or treatment begins. Several studies have indicated that practitionerrelated delays result from judgements about suspicious signs. Over-reliance on mammography, despite the known possibility of false-negative findings, is an example of the problem. Physicians are more likely to delay action on women's selfdiscovered breast lumps, possibly because of the known higher false-positive rates for breast selfexamination.8 Age has also been negatively associated with provider delays in many studies, suggesting less attention to assessment of younger women, who may be considered at lower risk. Provider error and misinterpretation of symptoms are difficult to assess because of the lack of objective records, but some evidence exists that continuity of care may avert delays, and having a usual source of care is a predictor of access to screening mammography.^{7–11}

Table 1 The type and qualifications of the provider and the correlation with delays in diagnosis										
		Type of doctor first consulted	Mean time between onset of symptoms and first consultation (days)	Average number of consultations before diagnosis is reached	Mean time between onset of symptoms and diagnosis (days)					
Rural	65 (65%)	53 quacks 9 registered medical graduates 3 postgraduates	67.5	3.9	80.4					
Urban	35 (35%)	10 quacks 10 registered medical graduates 15 postgraduate medical doctors	53.7	2.4	65.6					

Table 2 The time lapsed between the onset of symptoms and diagnosis										
Age (years)	Number	Mean time between onset of symptoms and first consultation (days)	Average number of consultations before diagnosis is reached							
25-40	28	53.3	2.3	66.5						
40-55 >55	39 33	58.6 60.2	3.2	71.8 74.6						

System-related delays are of particular concern. Access to resources for diagnosis and treatment may be limited geographically or used ineffectively. The coordination of care may also be problematic in some regions; one study showed that patients in seven Canadian provinces visited multiple providers and facilities for diagnosis following abnormal screening mammograms. This is costly in terms of time and money. The same study indicated that ineffective communication between sites subjected some women to fragmented care, whereas others had less difficulty when designated providers coordinated their progress through the system. 12,13

With this background, the study was contemplated with the aims and objectives to quantify

the patient and provider delays in breast cancer patients and to study the possible causative factors for the delay. There was an intention to find an Indian solution to an Indian problem.

Materials and methods

One hundred patients with histologically proven breast carcinoma were interviewed using a structured questionnaire regarding the onset of symptoms, time delay between the onset of symptoms and consultation with a doctor, type of doctor consulted, time delay between onset of symptoms and diagnosis, et cetera. Patient-related delay was defined as the period between the onset of symptoms and consultation with a qualified doctor. Provider-related delays were defined as the period between first consultation and diagnosis.

Observations

The majority of patients (65%) were from a rural background and 63% of these first contacted an unregistered medical practitioner after the onset of symptoms; 81.5% of patients from the rural background first contacted a quack, compared with only 28.5% patients from an urban background (P <0.05). Patients with a rural background

Table 3									
The literacy levels of patients and delays in diagnosis									
Literacy levels	Number	Type of doctor first consulted	between onset of	Average number of consultations before diagnosis is reached	between onset				
Illiterate	61	48 quacks 6 MBBS 7 postgraduates	69.6	3.9	83.2				
Up to class 10 or O level/ GCSE equivalent	26	12 quacks 7 medical graduates 7 medical postgraduates	56.7	2.5	67.1				
Above class 10 or O level/GCSE equivalent	13	3 quacks 6 MBBS 4 postgraduates	49.5	2.1	57.5				

took almost 2 weeks longer to consult a doctor than a patient from an urban background (Table 1).

There was no significant difference observed among patients of different age groups. This could be due to the small sample size of the current study (Table 2).

In the present study, it was observed that the majority of the cases were illiterate (61%) and 78.6% of them first contacted a quack after the onset of symptoms compared with only 38.4% of literate patients. Of the literate patients, 61.5% first contacted a registered doctor compared with only 21.3% of literate patients. The majority (76.9%) of patients that were educated above class 10 (O level/GCSE equivalent) contacted a registered medical practitioner after the onset of their symptoms, compared with only 21.3% of illiterate patients (Table 3).

Conclusions

The majority of patients in this study were from a rural background and were illiterate. Literacy rates and rural background were found to be significant factors leading to a delay in reporting to a qualified doctor. There were a significant number of these patients that had first reported to the unregistered medical practitioner or a quack leading to a delay in their diagnosis. Better awareness, education and trained healthcare workers in rural areas can reduce delays in the diagnosis of breast cancer in India and may thus improve the outcome.

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