Determinants of Patient Delay among Women with Carcinoma Breast

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Abstract

Objective: The aim of the study was to estimate the delay in seeking treatment among women with carcinoma of breast and determine the factors associated with delay. **Methods:** This was a hospital-based cross-sectional survey among 330 women attending the radiotherapy department of a tertiary care center in South India. Socio-clinical variables, duration of delay and reasons for the delay were collected by semi-structured interviews. Patient delay was assessed in categories of appraisal and illness time and system delay in diagnosis and treatment time. The probability of associated factors for the delay was estimated by logistic regression analysis. **Results:** The mean age of the patients was 54.7 yrs. 86.8% of participants had delays in seeking treatment. 33.5% had a presentation/patient-related delay with three months cut-off and 12.4% had a system delay with a one-month cut-off. In multivariate analysis, history of previous breast lump OR= 2.69 (95% CI 1.06-6.83), knowledge regarding breast cancer OR=3.96 (95% CI 1.37-11.42), referral hospital OR=4.91 (95% CI 1.66-14.57), type of medical doctor visited first OR=4.43(95% CI 2.06-9.53) and appraisal time OR=2.01(95% CI 1.06- 3.81) were statistically significant. **Conclusion:** Patient delay is significant and there are preventable factors contributing to the delay in seeking treatment for breast cancer.

Keywords: Breast cancer- Delay- Determinants

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Introduction

Breast is a symbol of motherhood, beauty as well as sexual identity in women culturally (Webb et al., 2019). The loss of or disfigurement of the organ owing to any reason is challenging to her.

Breast cancer (BC) being the most prevalent cancer globally as well as among females, exerts a significant physical, emotional and financial burden. The disability of women owing to diseases has implications for the welfare of children in the household. The prognosis of BC depends upon timely care and tumor characteristics. Since tumor characteristics cannot be altered, what attracts attention is timely care. By early diagnosis and appropriate treatment, BC has better survival rates, which is currently less among low-income countries. The five-year survival is 90% in developed countries and 66% in India against 40% in South Africa. Since delayed treatments result in more extensive surgeries, higher expenses, significant disfigurement and poor prognosis, early detection needs to be strengthened in resource-limited settings (WHO, 2022). Delays are related either to the patient or to the healthcare system. Patient delay is the delay in seeking medical attention after self-discovering a potential BC symptom. System delay is a delay within the health care system. As Patient delays are more prominent than system delays and are identified as the major hindering factor in timely care in many developing countries, (Freitas and Mathias, 2015) exploring this in detail will be beneficial.

In India, BC is standing first among the most common five cancers in the population and is one of the most common two in females. An increasing incidence rate of BC has been reported from 15 Population Based Cancer Registries (PBCR) in the country. This trend is continuing and by 2025, BC is expected to be the most common site of cancer with the projected number and incidence rate of 238,908 and 14.8%. In India, the relative proportion of female breast cancer according to the clinical extent of the disease comprised loco-regional (57%) against localized type (29%) (ICMR and NCDIR, 2020). The higher proportion of cases in the loco-regional

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category hints at bendable patient-related factors which contribute to BC delay. It is also reported from PBCRs that majority of Indian females with BC had secondary education which is considered a modest level in India. This indicated that more than basic education, there are other factors contributing to patient inertia and reporting delay. To know the point of delay precisely, we opted to divide the patient delays into appraisal, illness and presentation.

Kerala is the southern state of India. Trivandrum is the capital city and harbors one of the 15 PBCRs to represent the state. The relative proportion of BC to all sites of cancer was 28.9 in the Trivandrum district. The Crude Rate of BC in the district was 47 which is the highest among all Indian PBCRs. The Annual Percentage Change in AAR for BC in Trivandrum is 3.3 which is the 7th position among all Indian cities (ICMR and NCDIR, 2020).

Though some of the studies from Asia (Hilda et al., 2022) discussed appraisal time (AT) none seems to proceed to the analysis with AT as a separate variable. Moreover, studies that analyzed each type of delay in specific duration are very few in India. Our study stands distinct with emphasis given to appraisal, illness and presentation time, as unique influencing variables of the delay related to BC. We hope that this study may enlighten the policymakers to formulate point-specific strategies and epidemiological interventions to overcome patient delay.

Treatment for early, localized BC are breast conservation surgery, Sentinel Lymph Node Biopsy, or Modified Radical Mastectomy (Moo et al., 2018; Waks and Winer, 2019; Trayes and Cokenakes, 2021; Board, 2022). Either surgery alone or surgery with radiation therapy/chemotherapy were the treatments reported for 87.2% of patients with localized disease in India (ICMR and NCDIR, 2020). All Early BC patients were offered breast conservation surgery in a referral center in south India (Hassan Ali et al., 2019). Hence we chose to define the overall delay in terms of the primary treatment undergone by the patients. All women with a clinical diagnosis of BC who underwent any primary therapeutic intervention other than breast conservation surgery were considered delayed cases.

Materials and Methods

Study design and setting

The study design was hospital-based cross-sectional survey, and an internal comparison was also done to assess the determinants of delay in seeking treatment for BC. The study was conducted in the Radiotherapy Department of Government Medical College, Thiruvananthapuram. The department is dedicated to providing treatment to around 600 new BC cases and about 100 follow-up cases annually. The admissions in the department included referred cases as well as local patients.

Study Population, Sample size and Sampling technique

In this study, the population consisted of adult women with the clinical diagnosis of BC in stage I or II or III or primary BC with metastasis attending the Radiotherapy Department of Govt. Medical College, Thiruvananthapuram and who are willing to give consent to participate. Considering 25% delay in seeking treatment with 5% relative precision, and 10% non-response, the estimated sample size was 333. For the assessment of determinants of delay in seeking treatments, the sample size was calculated using Type 1 error of 1.96, power 80% and case-control ratio 1:1, the calculated samples size for various proposed determinants with their odds ratios and expected proportion in control, the estimated number of cases and control required was 333. All the participants fulfilling the eligibility criteria were selected consecutively from the Radiotherapy Department. Critically ill patients and patients with co-existing psychiatric illnesses were excluded from the study.

Definition of study variables Delay durations

Appraisal time: the time taken to perceive the breast changes as a sign of illness

Illness time: the time from deciding one is ill until deciding to seek professional medical care Diagnosis time: the time taken from seeking professional medical care to a clinical diagnosis Utilization time: the time making a clinical diagnosis to getting an appropriate treatment

Instruments

The tool was formulated based on expert opinion, patient interviews, patient record perusal, field knowledge of the authors and review of literature. The socio-demographic data, clinical data, delay durations and reasons for the delay were explored. To ensure the content validity of the tool, it was reviewed by an expert group of oncologists, nursing faculty and social scientists. The reliability of the tool was analyzed by using Cronbach's alpha (observed score 0.875). The tool was pilot tested among 30 women with BC attending the oncology department of the same hospital in a period well ahead of the original data collection to check the feasibility. Cognitive interviews were conducted by the authors for the tool and no major changes were required.

Study Procedure

The data were collected either in the outpatient department during the waiting time or from the wards in semi-structured interviews by the first author. Delays were described by the patients in days, weeks, months or years. Patients were helped to recollect the delays or dates by connecting the disease points to the significant events of their life such as birthdays, marriages, religious events or public days. Calendar of the respective periods was also shown to the patients to aid recollection. Hints by the relatives were helpful when the patient was clueless. Dates mentioned in patients' records were also perused and clarified during interviews and data were finalized with necessary modifications. In three events, neither the patient nor the relative could describe the period in a reliable way or the description was not intelligible and patient records also were not useful. The data from those patients were not utilized for analysis. The data collection period was from February to April 2021. The data quality was cross-checked by the authors.

Statistical Analysis

The baseline data, clinical variables and components of delay were expressed as frequency and percentage. The cases of delay in seeking treatment for BC were expressed in proportion to 95% CI. The determinants of delay were analyzed using binary logistic regression. SPSS 27 was used for statistical analysis.

Results

Socio-demographic characteristics of participants

Eligibility criteria were assessed among 433 patients, 89 patients did not fulfill the criteria and 11 patients were not willing to participate. Data were collected from 333 participants through face-to-face interviews. Data from three participants were grossly incomplete and therefore not utilized for analysis. The sociodemographic and clinical characteristics of the sample are shown in Table 1.

The study sample was dominated by women of age group 40 to 69 years (82.2%) with a mean age of 54.7 years, married (86.95%), rural residents (59.35%), having higher secondary education (69.3%), unemployed (73%) and low socio-economic status (81.1%).

Clinical characteristics of participants

The clinical characteristics of the participants are shown in Table 2. The Initial self-interpretation of symptoms by the samples were as follows, nothing serious (46.84%), something serious (21.02%), infection (6.36%), may be cancer (4.50%), cancer (4.20%), will subside by itself (7.20%) and usual which occur every month (9.0%). Majority of the women did not attribute the symptoms to cancer. The first change noticed in the breast by the samples were lump (51.7%), swelling (42.7%), nipple discharge (1.2%), skin changes (0.6%) and other features like pricking, heaviness, pain or dimpling (3.30%). The primary intervention undergone by the participants for BC were breast conservation surgery (13.4%), modified radical mastectomy (51.5%), chemotherapy (33.9%) and radiation therapy (1.2%). The sample was dominated by those in stage III of BC (47.7%) followed by 46.5% in stage I+II and 5.70% in stage IV.

Various delays

Among the samples, 286 (86.7%) women had a delay in seeking treatment and 44 (13.3%) had no delay. Figure 1 shows the time period from the self-initial interpretation of the symptom to the actual receipt of appropriate treatment. The current study identifies an appraisal delay among 10.5% of the participants and an illness delay among 23%. To redefine, 33.5% had presentation/patient-related delay. With a three months cutoff, in the current study, diagnosis delay was 3.3% and treatment delay was 1.53% and the total was 4.83%. With one month cut-off, the system delays were 7.3% (diagnosis) and 5.1% (treatment), together it was 12.4%.

Variables associated with delay

Table 3 denotes the variables associated with delay in seeking treatment

Among those reported delays in the study, the reasons

Table 1. Sociodemographic Characteristics of Participants (N = 330)

Variable	Frequency	Percentage	
Age in years		·	
30-39	26	7.9	
40-49	98	29.7	
50-59	98	29.7	
60-69	77	23.3	
70-79	27	8.2	
80-89	4	1.2	
Marital status			
Unmarried	8	2.4	
Married	287	87	
Widow	35	10.6	
Domicile			
Rural	196	59.4	
Urban	134	40.6	
Religion			
Hindu	230	69.7	
Christian	52	15.8	
Muslim	48	14.5	
Education			
Above higher secondary	47	14.2	
Below higher secondary	229	69.4	
No formal education	54	16.4	
Education of spouse/guardian			
Above higher secondary	38	11.5	
Below higher secondary	231	70	
No formal education	61	18.5	
Occupation			
Govt./Private/self employed	27	8.2	
Agriculture/Manual	62	18.8	
Unemployed	241	73	
Occupation of spouse/ guardian			
Govt./Private/Business	64	19.4	
Agriculture/Manual	240	72.7	
Unemployed	26	7.9	
Socio-economic status			
Below Poverty Line	270	81.8	
Above Poverty Line	60	18.2	

for the same were explored. Lack of knowledge about the disease and symptoms (58.7%), family-related factors (10.8%), lockdown and COVID-19 (1.3%) and fear of diagnosis (1.3%) were reported. The variables associated with delay in seeking treatment were history of previous lump $\chi^2 = 5.03$, p < 0.025, fear of diagnosis of cancer $\chi^2 = 15.04$, p < 0.001, knowledge regarding BC $\chi^2 = 6.95$, p < 0.008, type of institution referred $\chi^2 = 9.67$, p < 0.002, type of doctor first visited $\chi^2 = 16.19$, p < 0.001, and appraisal time $\chi^2 = 4.48$, p < 0.034.

Table 2. Clinical Characteristics of Participants (N = 330)

Variable	Frequency	Percentage	
Stage of cancer			
Stage I	43	13	
Stage-II	110	33.3	
Stage-III	158	47.9	
Stage-IV	19	5.8	
Co-morbidities			
Yes	150	45.5	
No	180	54.5	
History of Hospitalization			
Yes	39	11.8	
No	291	88.2	
History of previous lump			
Yes	25	7.6	
No	305	92.4	
First changes in breast			
Breast lump	172	52.2	
Swelling	141	42.7	
Nipple discharge	4	1.2	
Skin changes	2	0.6	
Others	11	3.3	
Self-initial interpretation of symptom			
Nothing serious	156	47.2	
Something serious	70	21.2	
Infection	21	6.4	
May be cancer	15	4.5	
Cancer	14	4.2	
Wait for cure so did not seek help	24	7.3	
Usual which occur every month	30	9.2	
Primary intervention for carcinoma breast			
Breast conservation surgery	44	13.4	
Modified radical mastectomy	170	51.5	
Chemotherapy	112	33.9	
Radiation therapy	4	1.2	

Probable factors (determinants) for delay

Table 4 denotes the probable factors (determinants) for delay in seeking treatment.

The variables which were significantly associated with delay were selected and the successive univariate and multivariate analysis delineated the probable factors for the delay as shown in Table 4. In multivariate analysis, history of previous breast lump OR= 2.69 (95% CI 1.06-6.83), knowledge regarding BC OR=3.96 (95% CI 1.37-11.42), referral hospital OR=4.91 (95% CI 1.66-14.57), type of medical doctor visited first OR=4.43 (95% CI 2.06-9.53) and appraisal time OR=2.01 (95% CI 1.06- 3.81) were statistically significant.

Discussion

The current study explored the delay and its determinants in seeking treatment among women with BC attending the radiotherapy department in a tertiary care center in southern India. There is no consensus in the available literature on the time interval between various events in BC to be considered as a delay. The authors adhered to the international guidelines for reporting the delay and associated variables (Weller et al., 2012).

Many of the published studies selected the cut-off period as three months for various categories of delay (Abu-Helalah et al., 2016; Tesfaw et al., 2020; Hanafi et al., 2022). There had been international studies that reported similar percentages of patient delay as in our study namely 32.2% from Jordan (Abu-Helalah et al., 2016) and 43.3% in Indonesia (Hilda et al., 2022). A higher patient delay of 75.7% was found in Ethiopia (Tesfaw et al., 2020) and 70.1% in Morocco. (Maghous et al., 2016) while a slightly lower rate of 25% was found in Syria (Hanafi et al., 2022). The neighboring country of Pakistan reported a similar presentation delay of 39% (Khan et al., 2015). There were more intricacies described in the patient-side delay in the popular Anderson model such as behavioral delay (Walter et al., 2012), which needs to be explored in future studies.

Regarding system delay, Hanafi et al., (2022) identified that 13.9 % of patients received a confirmed diagnosis more than three months after presentation, and 2.3 % started treatment at least three months after the diagnosis. The total system delay was 16.2%. The total delay of 4.83% at three-months cut-off in the our study is obviously lesser probably attributed to the stronger secondary prevention approaches prevailing in the state. The total system delay was 81.5% in Jordan (Abu-Helalah et al., 2016) which was also higher than our study results.

Some of the published studies chose a cut-off period of one month for system delay. When we used this time base, the system delays were 7.3% (diagnosis) and 5.1% (treatment), together it was 12.4%. Our diagnosis delay was in contrast with the study report of Hilda et al., (2022) who reported a delay of 64.7%. In a similar study, Maghous et al., (2016) reported a system delay of 13.9% and it is matching with our findings. The same author reported a combined delay of 16.1%, which was not explored in our study.

Authors had explored the reasons for delay among the samples. When reports on reasons for delay were searched for, a middle Indian study found that unawareness (88%), financial issues (86%), shyness (64%), going for alternative treatment (25%), having painless lump (52%), fear of losing breast (30%) and poor support from family (18%) were the reasons for delay (Shah et al., 2020). Similarly, the main reported reasons for the delay in the presentation to a healthcare facility were ignorance of the nature of the problem (65.6%), limited/lack of knowledge that symptoms were suggestive of cancer (16.7%), misdiagnosis (16.7%) in Jordan (Abu-Helalah et al., 2016) and lack of awareness of the cause of symptoms (41.5%), low perceived severity (27.7%) and fear of surgery intervention (26.2%) in Indonesia (Hilda et al., 2022).

A recent qualitative study describes that cancer delays were mostly patient related and the causes were



Figure 1. Distribution of Women Based on Appraisal Time, Illness Time, Diagnostic Time and Utilization Time n = 330

fear of diagnosis and denial (Xolisile et al., 2021). Lack of knowledge was the major reason for the delay in seeking treatment for breast problems in different parts of the world. Awareness programs adapted to the cultural context may be helpful (Rivera-Franco and Leon-Rodriguez, 2018).

Education, seriousness accorded to the symptom by the patient and awareness about BC (p<0.001) were highly significant variables associated with delay in middle India (Shah et al., 2020). In China, age, rural background, education, and treatment outside the study institution were associated with delay (p>0.05) (Li et al., 2019). Though knowledge of cancer was an associated variable, education was not significantly associated with delay in our study.

The patient-related factors of delay in our study were in line with the report of an integrative review conducted with studies from developing and developed countries which identified that non-attribution of symptoms to cancer, fear of the disease and treatment and low educational level as the most frequent causes of patient delay. Less comprehensive health insurance coverage, older/younger age and false negative diagnostic tests were the three most common causal factors of system delay globally (Freitas and Mathias, 2015), but these were excluded from our study.

Internationally, visits to providers ≤ 3 times (OR 0.15, 95% CI 0.06–0.37, p <0.001) and having a family history of cancer were significantly associated with diagnosis delay (OR 2.28, 95% CI 1.03–5.04, p = 0.042) in Indonesia (Hilda et al., 2022). Also, delay in diagnosis was associated with age, family income, health insurance, place of residence, marital status, menopausal status, history of breast disease, awareness of breast self-examination, type of first symptoms, tumor histology type, BMI and comorbidity in Iran (p < 0.05 for all) (Foroozani et al., 2020).

Rural residence (AOR=3.72; 95% CI=1.82– 7.61), illiterate (AOR=3.8; 95% CI=1.71– 8.64), having a painless wound (AOR=3.32; 95% CI=1.93, 5.72), travel

Table 3. Variables Associated with Delay in Seeking Treatment (N = 330)

Variable	No Delay	Delay	p Value
	n = 44	n = 286	
History of previous breast lump			
Yes	7	18	0.025
No	37	268	
Fear of diagnosis of cancer			
Yes	2	4	0.001
No	284	40	
Knowledge regarding cancer			
Good	40	207	0.008
Poor	4	79	
Type of institution referred			
Cancer Care Centre	6	9	0.002
Others	38	277	
Type of Doctor visited first			
Cancer Specialist	13	25	< 0.001
Others	31	261	
Appraisal time			
<1week	22	96	0.034
>1week	22	190	

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Variable	Odds Ratio	(95% CI)
History of previous breast lump Yes No (Ref.)	2.69	(1.06-6.83)
Knowledge towards cancer Good (Ref.) Poor	3.96	(1.37-11.42)
Referral Hospital Cancer Care Centre (Ref.) Others	4.91	(1.66 -14.57)
Type of doctor they visited first Cancer Specialist (Ref.) Others	4.43	(2.06-9.53)
Appraisal time <1week (Ref) >1week	2.01	(1.06-3.81)

Table 4. Multivariate Analysis on Factors Affecting Delay in Seeking Treatment among Women with Breast Cancer (N = 330)

distance $\geq 5 \text{ km}$ (AOR=1.66; 95% CI=1.09– 3.00), having no lump/swelling in the armpit (AOR=6.16; 95% CI=2.80– 13.54), and no history of any breast problem before (AOR=2.46; 95% CI=(1.43–4.22) were predictors for long patient delays in Ethiopia (Tesfaw et al., 2020). Diagnosis delay was associated to a personal reason in 70.1 % of patients and with a medical reason in 13.9 % of patients in a cross-sectional study in Africa. A longer delay was reported among rural women and those who lived far from referral centers (Maghous et al., 2016). In contrast to these, the rural residence was not a significant factor of delay in our study. Since government insurance was available for people with lower incomes in the country, financial issues was not projected in our study.

Strengths and Limitations

The experience of the second author as an oncology nurse enhanced quantitative reflexivity and rigor in the study. Moreover, being an active member of a non-governmental voluntary organization that focuses exclusively on the early detection of cancer among women, she could regard communications realistically. Patients were inherently willing and yielding owing to the supportive treatment facilities provided in the setting and the non-urgent nature of the data collection point.

The data were collected from a single Governmentowned institution that primarily catered to patients of lower socioeconomic strata. Due to the retrospective nature of this study, opportunities to confirm the reasons and durations for the delays were limited. We couldn't maintain the significance of some of the variables in multivariate analysis and they did not present in the final regression model, possibly because most of the variables collected are subjective and the proportion of delay was higher.

Author Contribution Statement

Athirarani MR conceived the concept, designed the tools, checked the data, designed and performed the analysis and participated in writing. Sreekutty SJ performed review of literature, collected data and completed preliminary writing. Rosenara Beegum contributed to the study design and tools, checked the data and participated in writing. Sujitha Elavally participated in study design and tool development, verified the data and wrote the paper.

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Ethical considerations

The study got approval from the Institutional Human Ethics Committee of Govt. Nursing College, Thiruvananthapuram, Kerala (IEC No. CNT/ IEC/44/6/2020). Written informed consent was obtained from the study participants.

Availability of data

Data are available with the second author for reference.

Conflict of interest

Authors declare that there is no conflict of interest.

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