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Research Article

A Study to Assess the Factors Associated with Delay in Diagnosis of Carcinoma Breast and Carcinoma Oral Cavity among the OPD and IPD Patients at Dr. Bhim Rao Ambedkar, Institute Rotary Cancer Hospital, AIIMS, New Delhi

Vijayshree Singh[1], Kamlesh Kumari Sharma[1], S. V. S. Deo[2]

[1]Department of Medical Surgical Nursing, All India Institute of Medical Sciences, New Delhi, India, [2]Department of Surgical Oncology, Dr. B. R. Ambedkar Institute Rotary Cancer Hospital, All India Institute of Medical Sciences, New Delhi, India

ABSTRACT

Aim: This study aims to generate evidence on the extent and type of delay in diagnosis of carcinoma breast and oral cavity so as to provide ground for addressing the underlying issues. **Materials and Methods:** This quantitative descriptive study was conducted; data were collected by consecutive sampling from 60 carcinoma breast and 60 carcinoma oral cavity patients during July 2017–December 2017; using self-developed semi-structured questionnaire by interview method. All adult newly registered patients who correctly remembered their clinical history were enrolled in the study. Analysis was done using SPSS. Ethical clearance was obtained from the Institutional Ethics Committee. Primary delay is the duration between onset of symptoms till first medical contact while secondary delay is the duration between first medical contacts till final diagnosis with the help of biopsy. **Results:** Primary delay was 30 days (0 days–3650 days) found in 41% of subjects while secondary delay was 60 days (14 days–1095 days) present in 62.5% of subjects. The most common self-reported factor for primary delay and secondary delay was lack of awareness (45.8%) and false assurance (40%), respectively. Worsening of symptoms as reason behind seeking medical help (adjusted odds ratio [OR] 12.71; confidence interval [CI]: 3.5–45.57) and spouses of the head of family (adjusted OR 3.08; CI: 0.99–9.59) are independent predictor for primary delay. Lack of health insurance (OR 3.9; CI 1.24–12.31), negative family history of cancer (OR 2.94; CI 1.14–6.1), and false assurance given by the first medical personnel (OR 13.01; CI 4.4 38.39) are independent predictors of secondary delay. **Conclusions:** Significant delay was present in diagnosis. Both patient and health care workers contribute to these delays.

Keywords: Breast cancer, Oral cancer, Primary delay, Secondary delay

Address for Correspondence: Ms. Vijayshree Singh, Department of Medical Surgical Nursing, All India Institute of Medical Sciences, Ansari Nagar, New Delhi, India. E-mail: Vijayshreesingh281@gmail.com

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Introduction

Worldwide, cancer has become a major health issue and it is one of the leading causes of mortality and morbidity in both developing and developed countries.[1] Breast cancer is the most common cancer among women population in India and it accounts for 27% of all cancers in women.[2] Oral cancer is the most common cancer in India amongst men and it accounts for 11.28% of all cancers in India.[3] Delay in diagnosis is a very significant factor as overall response to the treatment, type of surgery employed, and prognosis

and survival depends on stage of cancer. Cost of treatment increases in the advanced stage cancer.[4]

Delay can be at any point of time, right from the identification of the symptoms till definitive treatment initiation. Delay can be categorized as patients delay/primary delay and professional delay/secondary delay.[5] Primary delay is duration between self-identification of symptoms and contact with medical personal while secondary delay is duration between first medical contact and definitive diagnosis with the help of biopsy.

Need of the hour is to prevent undue delay in their diagnosis so as to prevent burden both on the health-care delivery system and the caregiver.[6] This study is planned to explore the extent of both type of delay and factors associated with delay in diagnosis.

Materials and Methods

A descriptive, exploratory, cross-sectional study design was selected. The study was conducted at B.R.A.I.R.C.H, cancer hospital of AIIMS, a tertiary care hospital, New Delhi. Ethical clearance was obtained from the Institutional Ethics Committee (IECPG-81/22.03.2017). Inpatients and outpatients with carcinoma breast and carcinoma oral cavity meeting the inclusion criteria during the study period (July 2017–December 2017) were enrolled using consecutive sampling technique. Patients who were newly registered for treatment, above 18 years of age, who could understand and respond to questions in Hindi or English, were included in the study. Pilot study was conducted with 30 subjects. The sample size was calculated based on the pilot study at α 5% and power 80%. A total of 143 (73 carcinoma breast +70 carcinoma oral cavity) patients were screened for study and 123 met the inclusion criteria. Three carcinoma breast patients refused to participate in the study. Remaining 120 were enrolled in the study. Data were collected using two tools: Tool 1 is a self-developed structured tool to assess the demographic and clinical variables. It contains total 21 items which includes 15 items on sociodemographical details and 6 items on clinical details. Under sociodemographic details, socioeconomic status was determined using modified Kuppuswamy scale 2014 version. The second tool is self-developed semi-structured tool containing 20 items to assess the delay. Validity of the tool was established by five nursing, three medical experts, and one social worker. Reliability was established by test-retest method with Cronbach's alpha score of 0.82.

Tool was converted into Hindi by language experts, IRCH, AIIMS. Tool was tried out on 20 subjects (10 carcinoma breast and 10 carcinoma oral cavity).

Statistical analysis

The data were analyzed using SPSS software version 16. Descriptive statistics, frequency, mean, and standard deviation were used for describing the demographic variables. Inferential statistics included Chi-square test and Fisher's exact test. Logistic regression was used to assess independent predictors of delay in diagnosis of carcinoma breast and carcinoma oral cavity. The level of significance was taken as <0.05.

Results

In Table 1a, the mean age of participants was 45 ± 11 years. Majority of them belonged to the age group of 38–48 years. About 63% of them were female. Majority of the patients were Hindu (82.5%). About 60% of them resided in urban area. Most of them belonged to nuclear family (53.3%). About 40% of patients were spouse of head of the family while 30% themselves were the head of the family. About 23% of patient was educated up to high school. Majority of them belonged to middle class (71%). About 75% of them were not having health insurance. About 58% of patients were having health-care facility available within 4 km of their residential area. Majority of the patients (60.8%) had to travel only 30 min to reach to the health-care facility.

Table 1b shows the clinical characteristics of the study subjects. Half of the patients were carcinoma breast and half were recruited from carcinoma oral cavity (as per the study design). About 26% of them were having history of cancer in the family. Majority of the patients (76%) had presented in the advance stages, that is, Stages III and IV. The most common first clinical symptom was lump or proliferative growth in 54% of patients.

Extent of primary delay, secondary delay: Median primary delay was 30 days (IQR: 9, 90 days) (min – 0 days and max – 3650 days). Secondary delay was 60 days (IQR: 20,120 days) (min – 14 days and max – 1095 days). Total delay (i.e., primary delay T1+secondary delay T2) was 122 days (IQR: 46,242) (min – 16 days and max – 4380 days).

Table 2a shows self-reported factors for primary delay in diagnosis of carcinoma breast and carcinoma oral cavity. As shown in Table 3a, the most commonly reported factor for primary delay was lack of awareness (45.8%) of participants. The other reasons were social and family reasons (10%), thought that the symptoms would subside at its own (7.5%), reliance on alternative medicines (5.8%), painless symptoms (5.8%), more distance to the health-care facility (5%), lack of guidance (4.2%), and symptomatic treatment for pain (3.3%).

Table 2b shows self-reported factors for secondary delay in diagnosis of carcinoma breast and carcinoma oral cavity. False assurance by first medical personnel was the main cause behind the secondary delay as reported by 40% of the participants. Poverty/cost of treatment (18.3%), multiple referrals (15%), trying alternative medicines (14%), taking symptomatic treatment for pain (13%), social/family reasons (8.3%), apprehension/fear (8%), lack of responsibility

Table 1a: Sociodemographic profile of participants (*n*=120)

Variable	Frequency
Age (years) mean(±SD)	45(±11)
18–≤28 years	1
>28–≤38 years	34
>38–≤48 years	40
>48–≤58 years	32
>58–≤68 years	13
Sex	
Male	45
Female	75
Religion	
Hindu	99
Muslim	16
Sikh	1
Christian	2
Others	2
Residential area	
Urban	72
Rural	48
Family structure	
Nuclear	64
Joint	55
Extended	1
Patient relationship with head of the family	
Self	40
Husband/wife	48
Son/daughter	25
Grandson/daughter	1
Others	6
Marital status	
Single	4
Married	105
Widow/widower	9
Living separately/divorcee	2
Education	
Illiterate	27
Primary school	4
Middle school certificate	17
Up to high school certificate	28
Intermediate or post high school diploma	15
Graduate or postgraduate	26
Professional or honors	3
Socioeconomic status[k]	
Upper-middle	21
Lower-middle	50
Upper-lower	48
Lower	1
Health insurance	
Yes	30
No	90
Distance of residence from nearest health-care facility (appx.)	
≤4 km	70
>4–≤9 km	24
>9–≤14 km	9
14 km	17

(Contd...)

Table 1a: *(Continued)*

Variable	Frequency
Travel time from residence to the same health-care facility (appx.)	
≤30 min	73
>30 min–≤59 min	27
>59 min–≤ 3 h	20

[k]Socioeconomic status was calculated with the help of modified Kuppuswamy scale (2014)

Table 1b: Clinical profile of study participants(*n*=120)

Variable	Frequency (*n* %)
Diagnosis of patients	
Ca breast	60
Ca oral cavity	60
Family history of cancer	
Yes	31
No	89
Pathologic stage	
Stage 1	13
Stage 2	31
Stage 3	39
Stage 4	37
First clinical symptoms	
Redness	3
Ulcer	31
Lump	65
Boil/furuncle	8
Others	12
No symptoms	1

Table 2a: Self-reported factors for primary delay in diagnosis of carcinoma breast and carcinoma oral cavity (*n*=120)

Factors	Yes	No	Did not consider as delay
Lack of awareness	55	28	37
Social and family reason	12	71	37
Thought that the symptoms will subside at its own	9	74	37

*More than 1 response possible

Table 2b: Self-reported factors for secondary delay in diagnosis of carcinoma breast and carcinoma oral cavity (*n*=120)

Factors	Yes	No	Did not consider as delay
False assurance by first medical personnel	48	33	39
Poverty/cost of treatment	22	59	39
Trying alternative methods	17	64	39

*More than 1 response possible

toward self/motivation (6.7%), distance from residence (3.3%), treatment for other diseases (2.5%), and negative biopsy (2.5%) were found to be the main reasons behind secondary delay as per patients.

Table 3a shows association between primary delay in diagnosis of carcinoma breast and carcinoma oral cavity

and selected variables. For ease of analysis, subgroups are merged to form broader groups. Table shows that there is a significant association of primary delay in diagnosis of carcinoma breast and carcinoma oral cavity with rural area of residence ($P = 0.041$), low level of education ($P = 0.021$), lower socioeconomic status ($P = 0.003$), less travel time from residence to health care facility ($P = 0.027$), stage at the time of presentation ($P = 0.003$), initial symptom of lump or growth ($P = 0.016$), and worsening as the reason behind the seeking medical ($P = 0.001$). Other variables, that is, age, sex, religion, family structure, relationship with head of family, marital status, health insurance, distance of nearest health-care facility, and family history of cancer were not significantly associated with primary delay.

Table 3b shows association between secondary delay and various select variables. The table reveals a statistically significant association of secondary delay with male gender ($P = 0.022$), rural residency ($P = 0.007$), lack of health insurance ($P = 0.039$) and negative family history of cancer ($P = 0.021$), and false assurance given by the first medical personnel ($P = 0.001$) while age, religion, family structure, relationship with head of family, marital status, education level, socioeconomic status, stage at the time of presentation, person/system of medicine being approached for initial symptoms, and type of health facility (govt. and pvt.) were not significantly associated with secondary delay.

Table 4a shows association of primary delay in diagnosis of carcinoma breast and carcinoma oral cavity with select variables on multivariate logistic regression. On multiple regressions, only three variables were found to be the predictors of primary delay. The odds for primary delay were higher among subjects where worsening of the symptoms (adjusted odds ratio [OR] 12.71; confidence interval [CI]: 3.5–45.57) was the reason behind seeking medical help as compared to subjects where appearance of symptoms was the reason. Subjects who had primary delay were 2.63 times more likely to present in advanced stages (adjusted OR 2.63; CI: 1.0–6.9). Spouses of the head of family are independent predictor for primary delay with marginal significance (adjusted OR 3.08; CI 0.99–9.59).

Table 4b shows association of secondary delay in diagnosis of carcinoma breast and carcinoma oral cavity with selected variables on multivariate logistic regression. On multiple regressions, only three variables were found to be the predictors of secondary delay. The odds for secondary delay were higher among subjects who were not having health insurance (adjusted OR 3.91; CI 1.24–12.31), who had negative family history (adjusted OR 2.94; CI 1.0–8.66), and

Table 3a: Association between primary delay in diagnosis breast and select variables ($n = 120$)

Variables	Primary delay		*P*-value
	No delay (≤30 days)	Delay (>30 days)	
Sociodemographic variable			
Area of residence[α]			
Urban	48	24	0.041
Rural	23	25	
Education level[α]			
Illiterate	9	18	
Primary/middle school	14	7	
10th/12th/post high school Diploma	28	15	
Grad/postgraduate/professional/ honors	20	9	0.021
Socioeconomic status[α]			
Lower	21	28	0.003
Middle	50	21	
Travel time from residence to the nearest health-care facility (appx.)[α]			
≤30 min	49	24	0.027
>30 min	22	25	
Clinical variables			
Stage at the time of presentation[α]			
Early (Stages I and II)	33	11	0.007
Late (Stages III and IV)	38	38	
Nature of the initial symptoms[α]			
Non-lump	39	16	0.016
Lump/growth	32	33	
Reason behind seeking medical help[α]			
Appearance of symptoms	40	9	
Persistence of symptoms	21	19	0.001
Worsening of symptoms	10	21	

(*) Statistically significant at $P<0.05$; α Chi-square test for association, ≠ Fisher's exact test of association

Table 3b: Association of secondary delay in diagnosis of carcinoma breast and carcinoma oral cavity with select variables ($n = 120$)

Variables	Secondary delay		*P*-value
	No delay (≤30 days)	Delay (>30 days)	
Sociodemographic variable			
Sex[α]			
Male	11	34	0.022
Female	34	41	
Area of residence[α]			
Urban	34	38	0.007
Rural	11	37	
Health insurance[α]			
Yes	16	14	0.039
No	29	61	
Family history of cancer[α]			
Yes	17	14	0.021
No	28	61	
Clinical variables			
Advice given by the first medical personnel[α]			
Referred	38	26	0.001
False reassurance	7	49	

(*) Statistically significant at $P<0.05$; α Chi-square test for association is used,≠ Fisher's exact test of association was used

Table 4a: Association of primary delay in diagnosis of carcinoma breast and carcinoma oral cavity with select variables on multivariate logistic regression (*n*=120)

Variable	Primary delay		Unadjusted odds	Adjusted odds (95% CI)
	No delay (≤30 days)	Delay (>30 days)		
Stage at the time of presentation				
Early	33	11	1	1
Advanced	38	38	2.29	2.63(1.0–6.9)
Reason behind seeking medical help				
Appearance	40	9	1	1
Persistence	21	19	4.02	3.99(1.33–11.89)
Worsening of symptoms	10	21	9.33	12.71(3.5–45.57)
Relationship with the head of family				
Self	27	13	1	1
Spouse	26	22	1.75	3.08(0.99–9.59)

Odds ratio was calculated after adjusting for variables, that is, area of residence, level of education, SES, travel time from residence to health-care facility, and nature of first clinical symptoms. CI: Confidence interval

Table 4b: Association of secondary delay in diagnosis of carcinoma breast and carcinoma oral cavity with select variables on multivariate logistic regression (*n* = 120)

Variable	Secondary delay		Odds ratio (95% CI)	Adjusted odds (95% CI)
	(≤30 days)	(>30 days)		
Health insurance				
Yes	16	14	1	1
No	29	61	2.40 (1.035–5.58)	3.91 (1.24–12.31)
Family history of cancer				
Yes	17	14	1	1
No	28	61	2.6 (1.14–6.1)	2.94 (1.0–8.66)
Advice given by first medical personnel				
Referred	38	26	1	1
False assurance	7	49	10.23 (4.0–26.08)	13.01 (4.4–38.39)

Odds ratio was calculated after adjusting for area of residence. CI: Confidence interval

who were given false assurance by first medical personnel (adjusted OR 13.01;CI 4.4–38.39).

Discussion

Primary delay (T1) was defined as the duration of more than 30 days between onset of symptoms till first medical contact and it was reported by 41% of the subjects. Secondary delay (T2) was defined as the duration of more than 30 days between the first medical contact till final diagnosis with the help of biopsy report and it was reported in 63% of the subjects. Primary delay in the present study is comparable with Dwivedi *et al*.[7] who reported median primary delay of 30 days among patients of all cancers in all organs in New Delhi. However, median secondary delay reported by them was 33 days (IQR: 8124 days) which was almost half of our findings. This can be explained on the basis that they had taken into consideration all the cancers so variation in median is expected; also they have enrolled large sample size, approximately 4 times the sample size of the present study.

Nair *et al*.[8] in their study in Mumbai reported primary delay of 90 days which is incomparable to our findings. However, consistent with our findings, they too reported secondary delay of 60 days. This discrepancy can be explained on the basis of the difference in demographic profile and access to health-care facility. Self-reported factors for primary delay in diagnosis in this present study were also reported by one study in Mumbai and Central India but their percentage varies.[8,9]

As per our study findings, there was a significant association of primary delay with rural area of residence, low level of education, lower socioeconomic status, and less travel time from residence to health-care facility. A statistically significant association of primary delay is also noted with advanced stage at the time of presentation, initial symptom of lump or growth, and worsening as the reason behind the seeking medical help.

There was a significant association of secondary delay in diagnosis of carcinoma breast and carcinoma oral cavity with male gender, rural residency, lack of health insurance and negative family history of cancer, and false assurance given by the first medical personnel. Ramasamy and Sivapatham[10] reported that 85% of the patients present in Stage III/IV; similar findings in our study were 76% which were in clinically advance stages. Chintala *et al*.[11] also reported that low SES, low education level, and ignorance on the part of patients were significantly associated with delay ($P < 0.05$) which is consistent with our study except ignorance on the part of patients which was not evaluated in the present study. Khan *et al*.[12] reported too that the low education level (adjusted OR 2.26; CI 1.25–4.10) and SES (adjusted OR 2.29; CI 1.06–4.94) were two independent predictors of primary delay among carcinoma breast patients in Islamabad. Our study findings proved a strong positive association of these two variables with primary delay.

A significant delay in diagnosis of carcinoma breast and carcinoma oral cavity is present on the part of the

patients as well as on the physicians. Primary delay can be purely attributed to the patient's characteristic such as sociodemographic, economic, and selected clinical variables while for secondary delay factors were related to both patient and first consulting physician.

Conclusions

There is a need for generating awareness about these cancers and need for reporting early among the population. Skill training is also required for primary health-care physicians for prompt identification and early referral of patients.

Conflicts of Interest Statement

The authors whose names are listed above certify that they have no affiliations with or involvement in any organization or entity with any financial interest (such as honoraria; educational grants; participation in speakers' bureaus; membership, employment, consultancies, stock ownership, or other equity interest; and expert testimony or patent licensing arrangements), or non-financial interest (such as personal or professional relationships, affiliations, knowledge, or beliefs) in the subject matter or materials discussed in this manuscript.

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