Mixed Methods Study of Care Pathway and Delay in Obtaining Health Services by Breast Cancer Patients in India

Radhika Kuthari*, Raman Damor, Kalpita Shringarpure

Abstract

Delay in receiving treatment or untimely discontinuation can impact patient survival. This study addresses the literature gap in knowledge about care pathway of patients following initiation of treatment, quantifies the delays in obtaining healthcare services and explores the challenges faced by them in this process. Methods: A concurrent triangulation mixed method study was conducted. All breast cancer patients above 18 years, who were aware of their diagnosis and whose treatment had commenced were included with their consent. The final sample size was 150. Patient pathway was documented through in-depth interviews and delay in access, diagnosis, and various treatment modalities was quantified after reviewing patient records. Factors associated with overall delay (from onset of symptoms to initiation of treatment) were identified by bivariate analysis. Inductive thematic analysis of interviews was done to identify reasons for delay. Results: Of 150 patients, 111 (74%) consulted at least two healthcare facilities and 75 (50%) consulted only government facilities during their treatment. Majority, 124 (82.6%) patients faced delay in their care pathway; 88 (58.6%) experienced overall delay (median duration 109 days) which was significantly associated with patient's education and caregiver's occupation (p<0.05), and 48 (32%) out of 149 women were delayed in initiation of chemotherapy. Median access, diagnostic and treatment interval were 60 days, 20 days, and 6 days respectively. Median duration between surgery and chemotherapy, and surgery and radiotherapy was 10 days and 139 days respectively. The major themes that emerged in access delay were neglect, avoidance, and reliance on family. Diagnostic delay included themes of misdiagnosis and difficulty in navigating healthcare systems. Treatment delay included themes of misconceptions, avoidance, neglect, and affordability and accessibility of services. Conclusion: Majority of the patients visited at least two facilities and experienced delay in receiving healthcare services. Both patient and provider side challenges were responsible for delay.

Keywords: Access delay-diagnostic delay- treatment delay to: access delay, diagnostic delay, treatment delay

Asian Pac J Cancer Prev, 26 (6), 2097-2107

Introduction

Breast cancer is the most common cancer among Indian women, recording the highest incidence and mortality amongst all cancers. Globally, India ranks third only behind USA and China in the incidence, but records proportionately higher deaths than the two countries [1].

Early detection of breast cancer, results in a better chance of survival, reduced morbidity, and lower treatment costs. Although screening is an effective strategy for early detection, recent data shows that merely 0.6% of women have undergone breast cancer screening [2], implying that most patients self-report to facilities, which makes patient factors crucial to timely presentation to healthcare facilities.

Delay greater than three months in initiation of treatment has been linked with poor survival of patients [3]. In India, timely diagnosis and treatment are

encumbered by various challenges. Diagnosis includes complex procedures such as imaging and histopathology that have an inherent time cost, adding at least 6-18 days to the interval in the absence of external delays [4] But in reality, this period could be longer as few facilities provide diagnostics under one roof, thus, biopsies and blood samples are sent to cities and reports take time to come back [5]. Treatment also poses a challenge as 95% of the nation's cancer treatment facilities are in urban area while 70% of Indians reside in rural regions [6]. Only 10% of the 5000 radiation treatment units needed are available and nearly 40% of hospitals lack proper access to modern cancer treatment technology [7].

In the available literature, focus has been on the patient pathway uptill treatment initiation, overlooking a crucial aspect that is treatment completion. Given the multimodal nature of treatment and limited availability of hospitals that provide it, the onus lies on the patients

Department of Community Medicine, Gautam Buddha Chikitsa Mahavidyalaya, Dehradun, India. *For Correspondence: kuthariradhika@gmail.com

Radhika Kuthari et al

and their families to make crucial decisions about the patient's disease management while being unequipped with the information to do so. Literature reveals that up to a quarter of breast cancer patients discontinue their treatment leading to poor patient outcomes and mortality [8, 9]. There is little information as to the challenges faced by patients once the treatment commences. Thus, this study was conducted to document the health seeking pathway of breast cancer patients through their treatment to understand the delays and challenges they might face in receiving healthcare services.

Materials and Methods

Study Design

A concurrent triangulation mixed methods study was conducted in the oncology department of a tertiary care government hospital. This study design allowed corroboration of quantitative data (time taken in receiving healthcare services) with qualitative data (reasons for delay and challenges in obtaining services) thus providing a comprehensive overview of the patient's journey through the healthcare system. Qualitative and quantitative data were collected and analyzed simultaneously and interpretation was based on QUAN+QUAL results (Figure 1).

Sample Size and Sampling Method

Sample was collected over a period of seven months. All histopathologically confirmed breast cancer patients who were above 18 years of age and whose treatment had already commenced were included. To incorporate diverse experiences, patients in all phases of treatment i.e. chemotherapy, surgery, radiotherapy, were approached. Often, to avoid causing distress, family members do not disclose cancer diagnosis to the patients, thus patient's awareness regarding their diagnosis of cancer and treatment were established and those patients who consented to participate were included. Total 150 participants were enrolled and included in both the quantitative as well as qualitative components of the study, to enable meaningful comparison and merging of data [10]

Data Collection

Data collection consisted of in-depth interviews and reviewing records as represented in Figure 1. The in-depth interviews were conducted in local language by the Principal Investigator (PI), a female doctor, trained in qualitative methods, using a semi structured guide. Caregivers were present during the interview if the patient desired. Audio recording and simultaneous note taking was done after taking consent of both the patient and the caregiver. Private room adjacent to oncology wards were used to conduct the interview.

The interview guide was divided into three parts. The first part was access interval, which contained questions regarding symptoms, time from onset of symptoms to first contact with health care provider (HCP), reasons for contacting HCP, course of action during this interval and reasons for delay. The second part was diagnostic interval, which contained questions regarding sequence and type of facilities and HCPs visited diagnostics, time elapsed in each visit, and delays and challenges faced in the process. Similarly, third part of treatment interval focused on number, type and sequence of HCP and facilities visited for treatment, reasons for delay and challenges faced.

The sociodemographic details, clinical profile and dates of various visits, diagnostics and treatment were obtained from patient records after the completion of interview and this information was tallied with the interview findings.

Data Analysis

The interviews were transcribed and translated to English within a day and reviewed for accuracy. Inductive thematic network analysis was done manually. Interviews were read multiple times; relevant data was categorized from which codes were developed. These codes were re-read to identify recurrent patterns to develop themes which were reviewed to ensure representativeness. The



Figure 1. Diagrammatic Representation of Concurrent Triangulation Mixed Methods Design

Quantitative Data was analyzed using Microsoft® Excel® 2019 MSO (Version 2310) and Jamovi 2.2.5 [11]. The sociodemographic and clinical profile was reported in frequencies and proportions. Access, diagnostic, treatment, and inter-treatment intervals were reported in Median (IQR) after checking for normalcy using histogram. Chi square test of independence was used to find association between sociodemographic variables and Overall Delay. The following operational definitions were used to quantify time intervals and delays:

1. Access interval

Duration from onset of symptoms to first contact with Health Care Provider (HCP) both medical and informal such as untrained allopathic providers, traditional healers, and faith healers(12)

2. Diagnostic interval

Duration from first contact with HCP to confirmation of diagnosis including staging and grading [12]

3. Treatment interval

Duration from confirmation of diagnosis to initiation of treatment (12)

4. Overall Delay

Overall Delay was defined as duration from onset of symptoms to initiation of treatment exceeding 90 days [12]

Inter-treatment Intervals

The timelines suggested by Standard Treatment Guidelines Oncology, MoHFW were date of registration to surgery three weeks, surgery to first cycle of chemotherapy four weeks, surgery to first fraction of radiotherapy 200 days [13]

Ethics

Study was carried out after receiving permission from The Institutional Ethics Committee for Biomedical and Health Research (IECBHR) Medical College and SSG Hospital, Baroda (IECBHR/055-2022). Participants were enrolled after taking their written and informed consent with the option to withdraw whenever they wished. Strict confidentiality and anonymity were maintained while writing results.

Results

The mean age of patients was $52(\pm 11)$ years. Majority of the women were Hindus 127(84.7%), homemakers 98(65.3%), married 109 (72.7%), members of nuclear family 60(40%), residents of rural areas 102(80.7%) of Gujarat 121(80.7%) and had insurance 121(80.7%). About 34 (22.7%) belonged to Lower Middle Class and 43 (28.7%) were illiterate. For 64 (42.7%) of the women, their caretakers were their spouses and 25 (16.6%) of the caretakers were daily wage workers and farmers (Table 1).

Table 2 shows the clinical profile of the patients.

Nearly half the patients were diagnosed at Stage II of the disease 60 (40%) The most common initial symptom was painless lump 142 (94.7%) and reason for contacting Health Care Provider was increase in its size 72 (48%); 36 (24%) participants also listed insistence of family as a reason for a contacting healthcare provider.

Health Seeking pathway

Of the 150 women, 86 (57.3%) first approached government sector, 39 (26%) of whom presented directly to the study center. Ten women (6.7%) visited informal providers. Majority 111 (74%) of them had consulted at least two facilities during their treatment. The maximum number of hospitals visited was seven by one person. Half the patients had not contacted any private hospitals during their treatment 75 (50%). Majority of women were diagnosed 106 (70.7%) and underwent surgery 65 (52%) at the first hospital of contact while 65 (43%) and 23 (41%) of the women underwent chemotherapy, and radiotherapy respectively, at the second hospital (Figure 2).

Delays

Median access interval was 60 (30-150) days, diagnostic interval was 20 (14-39) days and treatment interval were 6 (3-10) days. Overall delay was 109 (66-217) days. Interval between surgery and chemotherapy was 30 (20-43) days between chemotherapy and radiotherapy was 25 (15-30) days and between Surgery and radiotherapy was 139 (150-167) days (Table 3) Overall delay more than 90 days was observed in 88 (58.6%) of the patients which was significantly associated with education of the patient and occupation of the caregiver. (Table 1) Number of hospitals visited for diagnosis was not associated with the delay. Surgery was delayed in 9 (7%) out 125 women, chemotherapy was delayed in 48 (32%) of 149 women and radiotherapy was delayed in 4 (7%) of 56 women. Both patient and provider side delays were observed in obtaining healthcare services, which have been discussed under three headings: access delay, diagnostic delay, treatment delay.

Access delay

A general lack of awareness about the disease and lack of urgency for healthcare was observed, as women tended to trivialize or fail to recognize symptoms, neglect their symptoms for familial duties or avoid consultation out of fear. The main themes that emerged were neglect, reliance on family and avoidance (Figure 3).

Neglect

Trivialisation of symptoms

Many women (84 respondents) developed a painless lump, which did not affect their daily routine, they assumed that it was harmless and self-limiting and did not feel the need to visit healthcare facilities. It was when the size of the lump increased or it became painful that they went for check-up.

"I thought it (breast lump) will resolve on its own, it was small and there was no pain" (65, homemaker)

"it is a lump of milk; it will melt on its own" (45, house maid)



Figure 2. Patient Healthcare Seeking Pathway. *Blue colour in the figure represents government facilities, orange colour represents private facilities



Figure 3. Themes of Access Delay

2100 Asian Pacific Journal of Cancer Prevention, Vol 26

		No delay		Delayed		Chi square	p value
		n=62	%	n=88	%		
Age of Patient (years)	<45	14	22.6	17	19.3	0.42	0.8
	45-64	32	51.6	50	56.8		
	>64	16	25.8	21	23.9		
Religion	Hindu	50	80.6	77	87.5	1.31	0.25
	Others	12	19.4	11	12.5		
Area of residence	Rural	44	71.0	58	65.9	0.42	0.5
	Urban	18	29.0	30	34.1		
Type of Family	Nuclear	27	43.5	33	37.5	2.08	0.35
	Joint	20	32.3	24	27.3		
	Third Generation	15	24.2	31	35.2		
Education of Patient	Illiterate	11	17.7	32	36.4	10.39	0.03
	Primary	11	17.7	14	15.9		
	Secondary	9	14.5	18	20.5		
	High School	18	29.0	13	14.8		
	Higher Secondary and above	13	21.0	11	12.5		
Education of caregiver	Illiterate	3	4.8	8	9.1	3.4	0.4
	Primary	3	4.8	7	8.0		
	Secondary	9	14.5	17	19.3		
	High School	22	35.5	31	35.2		
	Higher Secondary and above	25	40.3	25	28.4		
Occupation of patient	Working	20	32.3	32	36.4	0.27	0.6
	Stay at home	42	67.7	56	63.6		
Occupation of caregiver	Stay at Home	17	27.4	37	42.0	9.95	0.01
	Daily wage/Farming	8	12.9	17	19.3		
	Self Employed	20	32.3	11	12.5		
	Salaried/Pension	17	27.4	23	26.1		
Socioeconomic Class	Class I (Upper)	4	6.5	7	8.0	3.9	0.4
	Class II (Upper Middle)	10	16.1	6	6.8		
	Class III (Lower Middle)	15	24.2	19	21.6		
	Class IV (Upper Lower)	24	38.7	39	44.3		
	Class V (Lower)	9	14.5	17	19.3		
Insurance coverage	No	13	21.0	16	18.2	0.18	0.6
	Yes	49	79.0	72	81.8		
Healthcare facilities visited	1	47	75.8	59	67.0	1.34	0.25
for diagnosis	2 or more	15	24.2	29	33		

Table 1. Socio Demography of Patients and Its association with Overall Delay

Incidental finding

Cancer was an incidental finding in some women (12 respondents) who attributed their symptoms to history of trauma to the chest or hand. Even in these cases the women tended to neglect their symptoms for a long time and there was no urgency in receiving treatment.

"I sprained my hand... there was tingling sensation, when I went to the hospital, I came to know there's a lump that was causing that sensation which turned out to be cancer" (50, farmer)

"for eight months, I thought the pain and lump are because I was kicked by a cow while working at the farm. I took medicine on my own, when it did not get better, I came to the hospital" (47, farmer)

Familial and social responsibilities

Some women (10 respondents) postponed checkups due to festivals, social occasions such as marriages and funerals, or family responsibilities such as household chores and caring for children and elderly in the house.

"there was a marriage at home, so I decided to show the lump after the function" (54, daily wage worker)

"It was Diwali time, there was lot of work at home so I thought I'll show later (lump)"(63, home maker)

Reliance on family

Women were dependant on family members to escort them to the healthcare facilities to assist with the process of registration, consultation, investigations, and provide



Figure 4. Themes of Diagnostic Delay



Figure 5. Themes of Treatment Delay

Table 2. Clinical Profile of the Patients

	N=150	%		
Stage of Disease				
Stage 1	6	4		
Stage 2	60	40		
Stage 3	54	36		
Stage 4	30	20		
Initial Symptoms*				
Painless Lump	142	94.7		
Painful Lump	9	6		
Change in Skin texture	14	9.3		
Incidental Finding	6	4		
Discharge	3	2		
Swelling	2	1.3		
Ulcer over breast	1	0.7		
Reason For Contacting Health Care Provider (HCP)*				
Increase in size of lump	72	48		
Insistence of Family Members	36	24		
Increase In Pain	33	22		
Discharge	15	10		
Swelling/Discomfort	8	5.3		
Fever	5	3.3		

*, Multiple Responses

monetary and emotional support. This, along with remoteness of their residence led to delay in presentation (54 respondents).

Avoidance

Fear of diagnosis, surgical procedures and COVID 19

Some women (21 respondents) either stalled health checkups or resorted to home remedies and self-medication to treat their symptoms as they were afraid that the diagnosis would be something terrible or surgery would be required.

Few women (4 respondents) also attributed delay in presentation to fear of COVID 19 infection which was on the rise at that time.

"I tried traditional medicine, tied Black Dhatura leaves on the lump... Rubbed betel leaves on it. I did these many times because I feared operation" (55, homemaker) "I prayed to God that it gets better, I took a lot of medicines but it did not heal" (47, daily wage worker)

Embarrassment

A few women (5 respondents) were embarrassed about sharing their problems with family members and of examination by doctors, which delayed their presentation to the hospital

Wage loss

A few women (10 respondents) were concerned about the loss of their or their family members' wages if they visited the hospital as the consultations always took a long time and they could not afford to miss work.

Diagnostic delays

Two themes that surfaced in diagnostic delay were misdiagnosis and difficulty navigating the healthcare system. Misdiagnosis subthemes included seeking informal providers and diagnostic uncertainty, whereas overburdened facilities and multiple visits were subthemes of the latter (Figure 4).

Misdiagnosis

Seeking Informal Providers

A few women (10 respondents) initially approached their local pharmacies and informal practitioners, who only provided symptomatic treatment and did not refer them to healthcare facilities.

"I went to the compounder; I thought it will get better with medicine" (45, home maker)

Diagnostic uncertainties

Despite timely presentation to the hospital, there were occasions when health care providers attributed the breast lump to benign conditions and sent them back. False negative and inconclusive reports also added to the delay. These women (34 respondents) returned years later for re-evaluation when their symptoms worsened.

"I have been visiting the hospital for hypertension treatment for the last ten year. When I first felt the lump, I told my doctor and he sent me to surgery department, there they checked the lump and told me not to worry, its normal lump which occurs sometimes as report (cytology) was normal. Then one year later it started discharging pus and I showed in the same hospital again, they investigated the lump and it turned out to be cancer" (60, widow)

Table 3. Time Interval between Access, Diagnosis, Table 3.	Freatment Initiation and Treatment Modalities
--	---

	Minimum duration	Maximum duration	Median duration	Interquartile range
Time Intervals (days)				
Access	3	5096	60	30-150
Confirmation of Diagnosis	4	730	20	14-39.25
Treatment Initiation	1	372	6	3-10
Overall	15	5117	109	66.5-217.5
Between Treatment				
Surgery to Chemotherapy	10	730	30	20-43
Chemotherapy to Radiotherapy	13	329	24.5	15-30
Surgery to Radiotherapy	139	464	160	150-167

Asian Pacific Journal of Cancer Prevention, Vol 26 2103

Radhika Kuthari et al

"I am a staff nurse, when I first noticed a small ulcer, I showed it in surgery, they gave me antibiotics and did dressing. No investigation was done. The ulcer healed, but after one and half years, the ulcer reappeared, which was investigated. First report was inconclusive, on reinvestigation, it was cancer" (54, nurse)

Difficult navigation of healthcare system Multiple visits and lack of guidance

The multiplicity of diagnostic procedures was overwhelming for the patients. As many of the private clinics and diagnostic centres were not equipped to provide all investigations, the patients (37 respondents) had to visit multiple facilities for confirmation of diagnosis, staging and grading of the cancer which added to the diagnostic interval. Some women (3 respondents) who presented to the study centre, a one stop facility for cancer also found it difficult to navigate the system. Many a times they lost their way in the process of multiple referrals to various specialists and diagnostic departments. There was a general lack of guidance by the consultants regarding the process of diagnosis which added to the diagnostic delay.

"first, to show my lump I went to gynecology department, who sent me to surgery. I did not understand where to go so I went back home. Then one week later I returned and asked people for directions to reach surgery, from there they sent me for investigations. It took me two hours to find that place. After investigations they sent me to cancer department, to find that building I had to make so many rounds of hospital" (39, homemaker)

Overburdened facilities

Many women (67 respondents) also complained that there was always a long waiting line for sonography or MRI and they received appointments of later dates at government facilities. Additionally, there were instances of machine breakdowns leading to delays.

Usually, it takes one day to get Sonography done, but here they give appointment for a week later, that is why it took time. CT report also took time, we went three times; all three times the machine was not working, two weeks were wasted in that (45, homemaker)

Treatment delays

For majority of the patients, treatment was initiated within a week of confirmation of diagnosis. However, there were instances of delays due to patients and providers. Themes of access delay such as neglect and avoidance were observed, in addition to which, two themes that emerged were treatment related misconceptions, and affordability and accessibility of services. (Figure 5)

Treatment related misconceptions More harm than good

Families played a crucial role in the decision-making process regarding treatment, and occasionally sought advice from their neighbours and close friends. In one instance, the caregivers deferred surgery of their old mother on advice of their peers that treatment would do more harm than good. "She has had three heart attacks and we were told that the operation is risky, so neighbours and family advised to keep her at home. Now we have come back because she is complaining of pain in the lump" (caregivers of 85-year female)

Lack of perceived need

Few women (7 respondents) felt better following surgery and despite doctor advice, defaulted chemotherapy as they did not perceive the need for it, returning years later when their symptoms reappeared.

"Fifteen years ago, my breast lump was operated, there were no further complaints or discomfort so I did not show again, then one year ago the lump re appeared and I had to undergo operation again" (42, home maker with recurrence)

In a peculiar case, a female postponed surgery as she did not want to be bed ridden in the 'Hot weather' which highlights the lack of urgency for treatment. *Avoidance*

Fear of treatment and its side effects

Some (5 respondents) women were afraid of undergoing surgery while few others (11 respondents) were afraid of the side effects of chemotherapy and radiotherapy and postponed therapy till symptoms worsened.

"my hair will fall off with chemotherapy, I don't want to take it" (40, homemaker)

"I feared radiotherapy (sek), but after a year the operation site started bleeding and I could feel the lump again so I came back to the hospital" (41, homemaker)

Avoidance of negative experiences

An old woman with recurrence of symptoms after remission was afraid of being re-diagnosed with cancer and restarting treatment. In another instance a woman missed a few chemotherapy cycles as she felt discomfort following the sessions.

"lump has returned, I am afraid they will again say its cancer and start treatment...what is the use" (60, homemaker with recurrence)

Affordability and accessibility of services

Expenditure on travel, accommodation, and treatment

Private health care facilities were the closest options for several women residing in villages. Few women (2 respondents) postponed surgery until they had saved enough money. Some (6 respondents) who could not afford private medical care were compelled to visit government hospitals, which were further away and resulted in expenditure on travel, accommodation, and loss of income of accompanying family members. Planning these trips led to delay and inconvenience to the patients.

Some ladies (4 respondents) from other states and distant villages postponed radiation therapy for months as daily travel was not feasible and they could not afford lodgings in the city.

"... after surgery the doctor asked me to go to government facility for chemotherapy. There are no good hospitals near our village, so we came here for treatment"

(36, homemaker)

"I come from Uttar Pradesh, so it takes ten to fifteen days just to get tickets to reach this place" (28, homemaker)

Lack of knowledge about existing insurance schemes

Majority of the patients in this study underwent surgery within a week of diagnosis. Those who underwent surgery in private, came to the study centre when they could not afford further treatment, which was when they were registered for insurance. In some cases (10 respondents), due to incomplete documents, the registration process took months leading to delay in initiation of chemotherapy.

Women who lacked insurance were likely to visit multiple facilities in search of affordable options. Interestingly, some patients (6 respondents) who were insured, visited multiple private facilities in search of hospitals empanelled under the scheme, leading to delay in surgery.

"She has PMJAY card, we consulted so many private hospitals but they said this card is not accepted here. So we finally came here for treatment" (Son of 68 year female)

Neglect

Women (6 respondents) tended to postpone their treatment especially surgery and chemotherapy due to social and family responsibilities

Facilitators

There were some facilitators to timely presentation to the hospitals. Family members who were educated or in medical field, insisted on timely check-ups. Awareness about breast cancer, through camps or social circles also facilitated timely checkups.

"My husband is a school teacher, he insisted to get the lump checked" (40, homemaker)

"Relative was staff nurse, told her within 2-3 days of signs and she insisted I showed a doctor" (66, female)

"Some ladies in the society had similar problems, so I thought what if I also have the same problem. I told my daughter in law, who told my son and he immediately took me to the hospital" (60, widow)

"I had attended awareness camps on breast cancer, so I told a staff nurse in my society who asked me to go to the hospital" (60, homemaker)

Discussion

This study maps out the patient pathway from symptom recognition through therapy and provides crucial insights into the challenges faced by them that result in delay in their care. In this study, many of the participants were illiterate, stay at home, married women that belonged to lower socio-economic strata and resided in rural areas. These women represent the more vulnerable section of Indian society.

Majority of the women were diagnosed with locally advanced disease, like the findings of Indian cancer registry [14]. This may be attributed to median overall delay greater than three months. The overall delay albeit long, was lesser than that recorded in North East

DOI:10.31557/APJCP.2025.26.6.2097 Delays in Care Pathway of Breast Cancer Patients in India

India and the country capital, Delhi [15, 16]. The most common presentation was a painless lump and the women tended to neglect and trivialise their symptoms. In some cases, the symptoms were attributed to other conditions, reflecting their unawareness about the disease. Another theme that emerged in access delay was avoidance of health check-ups due to fear of diagnosis and surgical procedures or embarrassment in sharing their problems, because of which they resorted to self-medication, and offering prayers to God. Women also tended to neglect their symptoms to care for their family and attend social functions. Their dependency on family members to escort them to the hospital added to delay in accessing health care services. These findings provide context to why patient's education and occupation of the caregiver were significantly associated with overall delay. Education of patients was also a significant delay factor in studies conducted in Delhi and North East [16, 17]. Hospital-based studies in other states also reported a longer mean access delay of 8 to 10 months [18]

In this study, more than half the patients initially presented to government facilities, majority of whom presented directly to the study center. Nearly half the patients availed only government services, a contrast to the studies of North East India and Western Rural India [16, 18], which reported that majority of the patients preferred private practitioners as fewer facilities were available, though this difference was not associated with delay. In current study, three fourth patients consulted at least two hospitals during their treatment, most of whom changed hospitals for chemotherapy and radiotherapy. Analysis also revealed that chemotherapy was delayed more often than surgery and radiotherapy, due the need to change hospitals.

The median diagnostic interval in this study was 20 days and extended up to two years, a contrasting finding to doctors in South India, diagnosing breast cancer within 13 days [19] The biggest challenge patients faced in diagnosis was navigating medical centres. Visit to multiple facilities or departments, for a variety of investigations and a general lack of knowledge and guidance delayed the process. Misdiagnosis by healthcare providers or patient tendency to approach informal providers for relief, led to the longest delays. Inconclusive reports complicated and delayed diagnosis.

This study is unique as it also documents the delays and challenges in obtaining various treatment modalities. Treatment interval was minimal. However, there were instances of delay which were multifactorial. Family played a crucial role in the decision-making process and their opinions also affected the course of treatment. Family's lack of perceived need of treatment and patient's avoidance due to fear of surgery, side effects of chemotherapy or radiotherapy led to treatment default and such women returned when their symptoms worsened. Studies across India report that financial burden contributed to discontinuation and delay in treatment [8, 16, 20] This study also notes that affordability and accessibility of services was a barrier to timely treatment and provides insight into how finance influenced patient health seeking behaviour. Majority of the patients

Asian Pacific Journal of Cancer Prevention, Vol 26 2105

Radhika Kuthari et al

were poor and resided in rural areas. They had to save money to afford the cost of surgery as well as travel and accommodation for chemotherapy and radiotherapy which are day care procedures. Many women were unaware of Ayushman Bharat PMJAY; a cashless insurance scheme initiated by the government that provides free healthcare at government as well as private empanelled facilities [21]. They were insured on arrival to the study centre following surgery in private facilities, which led to delay in initiation of chemotherapy as registration was a time-consuming process. Contrastingly, women who were insured, were held up because of exploring multiple hospitals for surgery as they did not have information about empanelled facilities. This could explain why insurance coverage was not associated with overall delay, as most women were insured after initiation of treatment and not during diagnosis and because insurance did not account for outof-pocket expenditures.

It is imperative to mention that there were some facilitators to timely utilisation of healthcare services such as insistence of family, awareness camps and consultation with relatives of medical background, from which we can infer that raising awareness and motivating patients may help in early presentation to health care facilities. Proper communication with the patient and their family, keeping in mind their education and financial status is required. The consultants can facilitate easy navigation of limited resources by guiding the patients through the process, simplifying information, and counselling them about the need to complete treatment and addressing their fears. Although government insurance schemes are available, the underutilisation may be addressed by raising awareness and providing complete knowledge about the same to relieve financial stress. Despite the differences in the patient pathways and duration of delays, unawareness, neglect, fear of diagnosis and treatment, misdiagnosis, and affordability and accessibility of services were documented across India indicating that patient experiences remain vastly similar. Thus, the qualitative findings of the present study, may be transferrable to other states and provide valuable insight to the policy makers to improve existing services and patient outcome.

Author Contribution Statement

All authors contributed equally in this study.

Acknowledgements

None.

References

- Ferlay J, Ervik M, Lam F, Laversanne M, Colombet M, Mery L, et al. Global cancer observatory: cancer today (version 1.1). Lyon, France: International Agency for Research on Cancer. 2024 Sep 23. Available from: https://gco.iarc.who. int/today.
- IIPS. International Institute of Population Sciences (IIPS) and ICF. National Family Health Survey (NFHS-5), 2019-21:India: Volume 1 [Internet]. Mumbai; 2021 [cited

2025 Apr 2]. Available from: https://www.dhsprogram.com/pubs/pdf/FR375/FR375.pdf.

- 3. Richards MA, Westcombe AM, Love SB, Littlejohns P, Ramirez AJ. Influence of delay on survival in patients with breast cancer: a systematic review. Lancet. 1999;353(9159):1119– 26. https://doi.org/10.1016/S0140-6736(99)02143-1.
- 4. Bleicher RJ. Timing and Delays in Breast Cancer Evaluation and Treatment. Ann Surg Oncol. 2018;25(10):2829–38. https://doi.org/10.1245/s10434-018-6615-2.
- Banavali SD. Delivery of cancer care in rural India: Experiences of establishing a rural comprehensive cancer care facility. Indian J Med Paediatr Oncol. 2015;36(2):128. https://doi.org/10.4103/0971-5851.158848.
- Munshi A, Ganesh T, Mohanti B. Radiotherapy in India: History, current scenario and proposed solutions. Indian J Cancer. 2019;56(4):359. https://doi.org/10.4103/ijc. IJC 82 19.
- Grover S, Gudi S, Gandhi AK, Puri PM, Olson AC, Rodin D, et al. Radiation oncology in india: Challenges and opportunities. Semin Radiat Oncol. 2017;27(2):158-63. https://doi.org/10.1016/j.semradonc.2016.11.007.
- Smita K, Biswajit D, Sunu LC. High Dropout & Early Deaths on Chemotherapy in Real World Sounds Alarm Bells: Audit from Department of Medical Oncology of a Tertiary Care Cancer Centre in South India. Asian Pac J Cancer Care. 2018;3(4):87. https://doi.org/10.31557/apjcc.2018.3.4.87.
- Vidhya R, Kalaichelvi K, Suresh Kumar S, Raja G, Karthik R. Characteristics and Outcomes of Breast Cancer-Retrospective Analysis from a Tertiary Center in India. Asian J Med Res. 2019;8(2):MC04-MC08. https://doi. org/10.21276/ajmr.2019.8.2.MC2
- Creswell JW, Clark VLP. Designing and Conducting MIXED METHODS RESEARCH. Third. California: Sage Publications; 2018. 184–190 p.
- Jonathon L, Damian D, Ravi S. The jamovi project (2021). jamovi (Version 1.6) [Computer Software]. Sydney, Australia. 2021 [cited 2022 Dec 29]. Jamovi desktop jamovi. Available from: https://www.jamovi.org/download. html.
- WHO, World Health Organization. Guide to cancer early diagnosis [Internet]. World Health Organization. Geneva; 2017. Available from: https://apps.who.int/iris/bitstream/ handle/10665/254500/9789241511940-eng.pdf;jsessionid =2646A3E30075DB0FCA4A703A481A5494?sequence=1
- 13. D 'cruz AK. Standard treatment guidelines oncology, Ministry of Health & Family Welfare, Government of India [Internet]. [cited 2025 Apr 3]. Available from: https:// clinicalestablishments.mohfw.gov.in/sites/default/files/ standard-treatment-guidelines/2611.pdf.
- 14. Mathur P, Sathishkumar K, Chaturvedi M, Das P, Sudarshan KL, Santhappan S, et al. Cancer Statistics, 2020: Report From National Cancer Registry Programme, India. JCO Glob Oncol. 2020;(6):1063–75. https://doi.org/10.1200/GO.20.00122.
- Dwivedi AK, Dwivedi SN, Deo S, Shukla R, Pandey A, Dwivedi DK. An epidemiological study on delay in treatment initiation of cancer patients. Health N Hav. 2012;04(02):66– 79. https://doi.org/10.4236/health.2012.42012
- 16. Kumar A, Bhagabaty SM, Tripathy JP, Selvaraj K, Purkayastha J, Singh R. Delays in diagnosis and treatment of breast cancer and the pathways of care: A mixed methods study from a tertiary cancer centre in north east India. Asian Pac J Cancer Prev. 2019;20(12):3711–21. https://doi. org/10.31557/APJCP.2019.20.12.3711
- 17. Chintamani, Tuteja A, Khandelwal R, Megha T, Bamal R, Jain S, et al. Patient and provider delays in breast cancer patients attending a tertiary care centre: a prospective study.

JRSM Short Rep. 2011;2(10):1-4. https://doi.org/10.1258/ shorts.2011.011006

- Gangane N, Anshu, Manvatkar S, Ng N, Hurtig AK, Sebastián MS. Prevalence and Risk Factors for Patient Delay among Women with Breast Cancer in Rural India. Asia Pac J Public Health. 2016;28(1):72–82. https://doi. org/10.1177/1010539515620630
- Lakshmanan M, Chayampurath R, Trivikraman R, Paramasivam S, M. P. S. Delay in diagnosis of breast cancer in a developing country: a single centre observational study in a tertiary care hospital in North Kerala, India. Int J Res Med Sci. 2017;5(10):4604. https://doi.org/10.18203/2320-6012.ijrms20174605
- 20. Mohanty SK, Wadasadawala T, Sen S, Khan PK. Socioeconomic variations of breast cancer treatment and discontinuation: a study from a public tertiary cancer hospital in Mumbai, India. BMC Womens Health. 2023;23(1):1. https://doi.org/10.1186/s12905-023-02275-6
- Health and Family Welfare Department Government of Gujarat. Guideline for Empanelment of Hospital [Internet]. [cited 2025 Apr 3]. Available from: https://ma.gujarat.gov. in/RFPofHospital.html.



This work is licensed under a Creative Commons Attribution-Non Commercial 4.0 International License.