

# Advanced Stage Lung and Breast Cancer Patient's Journey: A Survey to Identify Unmet Needs in Indian Clinical Settings

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## Abstract

**Background:** Cancer patients navigate through complex and dynamic health services/systems after diagnosis to receive high-quality and effective care. An understanding of a cancer patient's journey will help in improving the quality of care. A survey was conducted on patients and medical oncologists across India with an objective to map various aspects of patient journey from diagnosis to treatment and follow-up for advanced Breast Cancer (BC) and Lung Cancer (LC).

**Methods:** A multidimensional survey was shared with adult patients diagnosed with advanced stage (stage III B and stage IV) breast or lung cancer who were undergoing therapy and medical oncologists who have more than 10-years of experience in treating breast or lung cancer.

**Results:** A total of 100 patients with a diagnosis of Stage III B/IV breast cancer (BC), 100 patients with Stage III B/IV Lung Cancer (LC), and 55 medical oncologists participated in the survey. It was noted that similar numbers of BC (49%) and LC (50%) patients were not aware about cancer symptoms and treatments while the surveyed medical oncologists believed only 11% and 20% patients were not aware of cancer symptoms and treatment, respectively. Selecting the right specialist was reported to be the primary challenge faced by patients. As per surveyed medical oncologists, only 5% of them discuss support from Patient Advocacy Groups (PAGs) with all their patients. The majority of medical oncologists (79%) reported that less than 30% of patients join PAGs. Most patients were expecting empathy and time for counselling from their medical oncologists.

**Conclusion:** Coordinated and comprehensive cancer care is essential for patients with advanced LC and BC. The survey results also highlight the importance of screening high risk populations, importance of educational material for patients, counseling on treatment plan, information about financial support programs, counseling on mental well-being, nutritional support, and information about PAGs.

**Keywords:** Breast cancer • Lung cancer • Patient journey • Survey • Oncologists • Patients • Challenges • Patient experience

## Introduction

One in five people worldwide develop cancer during their lifetime and management of cancer has become one of the most significant public health challenges of this century [1]. Cancer is the leading cause of death worldwide and accounted for nearly 10 million deaths in 2020 [2]. As per Globocan 2020, the most common cancer in terms of incidence is breast cancer (2.26 million cases) followed by lung cancer (2.21 million cases). Lung cancer (over 1.79 million deaths) and breast cancer (684,996 deaths) were the first and fifth most common cause of cancer associated death in 2020, respectively [2]. In India, as per Globocan 2020 data, breast cancer had the highest incidence with 178,361 reported new cases while lung cancer contributed to 72,510 new cases. Breast cancer contributed to 90,408 deaths while lung cancer contributed to 66,279 cancer associated deaths [3].

Cancer patients navigate through complex and dynamic health services/systems that are comprised of many inter-related, but also independent, systems (e.g., insurance, primary care, surgical oncology, medical oncology, radiation oncology, psychiatry, rehabilitation) creating an intricate multi-system

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network [4,5]. After diagnosis, cancer patients have to explore the healthcare system and interact with a wide range of individuals to receive high-quality and effective care. This allows them to make informed decisions about their treatment options, how to manage side effects, daily life activities, and living with their prognosis [5]. In a study by Smith A, et al., information support was identified as one of the principal requirements for providing supportive care to cancer patients [6]. A survey conducted by Giuliani ME, et al. demonstrated that almost 8 out of every 10 lung cancer patients (78%) have at least one unmet need. The top three unmet needs highlighted in the survey were "fears of the cancer spreading", "lack of energy/tiredness", and "uncertainty about the future" [7]. A cross-sectional study conducted on breast cancer patients by Vuksanovic D, et al. highlighted fear of cancer recurrence, stress, coordination of care, hospital parking, information provision, and availability of a case manager as the main unmet need [8]. It is thus important to identify both gaps in care as well as opportunities to improve care processes in these patients [9].

Patient experience is one of the central pillars that constitute health care quality. According to Doyle C, et al. patient experience is associated with better clinical effectiveness and patient safety [10]. Patient experience is also favorably correlated with other indicators such as improved health outcomes, healthcare resource use, and medication and treatment adherence. Doyle C, et al. assert that patient experience has two components. The rational aspect focuses on "interpersonal aspects of care", such as clinicians' potential to treat patients with dignity and compassion, to empower patients (i.e., enable them to take responsibility for their own health by providing all necessary information), and to involve patients and their families in the decision-making process. The functional aspects examine the patient's fundamental expectations for the healthcare service, considering issues like the effectiveness and efficiency of healthcare delivery as well as the cleanliness and safety of the healthcare environment [11]. A map of a cancer patient's journey will enable healthcare professionals to learn first-hand about their patients' personal experiences and needs at each stage of

the disease. In addition, it will also enhance communication and understanding in the physician-patient relationship [12]. In order to capture and shape the patient's behavior, feelings, motivations, and attitudes across the episodes of care, journey maps incorporate both the physical and emotional aspects of the patient's journey [13]. One particular benefit of this type of research is to provide nuanced clarity about peoples' experiences as they traverse health systems rather than only capturing single episodes of care [4]. These findings can help in optimizing care processes and build opportunities for patient-centered healthcare [9].

Patient satisfaction has been documented in multiple surveys, but little research has focused on the patient healthcare experience during diagnosis, from diagnosis to treatment and follow-up. The main goals of the current study were to map the patient journey from diagnosis to treatment and follow-up for advanced breast cancer and lung cancer in India and to explore the challenges faced by the patients and measures needed to enhance the standard of oncology care and outcomes for patients. The physicians' survey aimed to understand the opportunities and solutions to improve the quality of oncology care and outcomes for patients.

## Methodology

### Participants and tier-wise classification of cities

The survey for patients with advanced stage breast (all females) and lung cancer (male and females) was designed to demonstrate patients experience and engagement journey by applying a multidimensional survey. Participants were recruited by references from medical oncologists and Non-Government Organizations (NGOs)/Patient support groups or as referrals from other patients. Participants from more than eight cities in India were invited to this study to understand the regional variance and distribution of outcomes. Tier-wise cities were considered according to classification of Indian cities based on house rent allowance (HRA) in Census-2011, where cities were classified as "X (Tier 1)", "Y (Tier 2)" and "Z (Tier 3)" [14].

Adult patients (>18 years old) with a diagnosis of advanced stage (stage III B and stage IV) breast or lung cancer who were undergoing therapy and medical oncologists who have more than 10-years of experience in treating breast or lung cancer were included in this study. Exclusion criteria were patients aged less than 18 years or with breast or lung cancer diagnosis in the early stages. The anonymity and confidentiality of participants were retained during this study.

### Survey questionnaire

A multidimensional questionnaire was shared with the patients and medical oncologists to capture the patient's journey during and after their diagnosis and treatment. The questionnaire consisted of the socio-demographic details, recognition and handling of symptoms, patient's expectations, and satisfaction during and following diagnosis and treatment, as well as the effect of the pandemic on disease management. Statements were ranked using a five-point Likert scale to collect respondents' satisfaction and attitudes, ranging from very dissatisfied, dissatisfied, unsure, satisfied to very satisfied. Statements on improvement after treatment included: "No improvement at all, slight improvement, unsure, improved and totally improved". Statement on accessibility of diagnostic facilities and treatment included: "Not at all accessible, slightly accessible, unsure, quite accessible and totally accessible"; and statements on affordability of treatment included: "Not at all affordable, slightly affordable, unsure, quite affordable and totally affordable". The questionnaire for the medical oncologist covered queries on the process of interacting with the patients, post-treatment follow-up and oncology care post-pandemic. The participants were interviewed over the phone or emails to collect the data. The process of collecting responses was conducted over a period of 6 months between february 2021 to july 2021. Each interview involved one participant individually and lasted approximately 45 - 60 minutes. A pilot project was conducted with 5 medical oncologists and 20 patients (10 with advanced stage breast cancer and 10 with advanced stage lung cancer). The questionnaire was appropriately modified according to the responses and outcomes of these participants from the pilot study.

### Statistical analysis

Data were entered into Microsoft Excel sheets and coded appropriately. We computed and described the results on satisfaction, improvement, accessibility, and affordability with two levels. Descriptive statistics were used to analyze the

collected responses and were presented as percentage (%) and stratified by tier of cities to acknowledge data distribution.

## Results

In this survey, 100 patients with a diagnosis of Stage III B/IV Breast Cancer (BC), 100 patients with Stage III B/IV Lung Cancer (LC), and 55 medical oncologists participated. Profiles of patients and medical oncologists, patients' cancer history and awareness about cancer nearly half of medical oncologists (49%) belonged to Tier 1 cities, while 31% and 20% of them were from Tier 2 and 3, respectively. In this study, most of the patients belonged to Tier 2 cities, accounting for 44% of those with BC and 53% with LC. Details on patients' age and cancer history in family are presented in Table 1.

It was noted that similar numbers of BC and LC patients were aware about cancer symptoms and treatments at the time of diagnosis Figure 1 with around 51% of BC patients and 50% of LC being not aware of cancer symptoms. As per the survey of medical oncologists, they believed only 11% and 20% patients were not aware of cancer symptoms and treatment, respectively. The results suggest that medical oncologists' perception regarding awareness of symptoms among patients differs from patients' survey findings and may not accurately reflect correct patients awareness in Figure 1.

### Patient journey: Discovery of symptoms to initial consultation

Fatigue, difficulty in breathing and coughing were the most commonly experienced symptoms among BC as well as LC patients. Weight loss and chest pain were the common initial symptoms experienced by LC patients while noticing a lump in breast was one of the initial symptoms noticed by BC patients. Figure 1 summarizes the initial signs & symptoms noticed by patients. Around 84% BC & 85% LC patients did not suspect their symptoms to be related to cancer at diagnosis. Figure 2 depicts the trend of cancer suspicion among patients and primary care physicians (Figure 2). Majority of BC & LC patients took more than 2 weeks (64% and 58% respectively) to reach the primary care physicians for their first consultation after noticing symptoms. Around 85% of BC patients reached out to a general physician or a gynecologist for the first consultation, whereas 92% of LC patients consulted a general physician or a chest specialist (Figure 3). It was reported that selecting the right specialist was the primary challenge faced by patients, whereas travel burden and cost were the difficulties highlighted for achieving a diagnosis (Figures 4 and 5). Only 23% of BC patients and 36% of LC patients figure 2 considered to explore additional information on disease symptoms and treatment on online platforms, like YouTube and Google.

### Patient journey: From a primary care physician to an oncologist

As per the responses received from patients, nearly 50% of BC patients and nearly 25% of LC patients were referred to non-oncologists by their primary care physicians. For BC patients, the most common non-oncologist was gynecologist whereas for LC patients, the most common non- oncologist was chest physician. Only 20% of BC patients and 10% of LC patients directly consulted the medical oncologists due to persistent symptoms after initial treatment. The responses

**Table 1.** Tier-wise distribution of oncologists' and patients' profile and cancer history in family.

Variable	Mean or n (%)	
<b>Medical Oncologists, n (%)</b>	55	
Tier 1	27 (49%)	
Tier 2	17 (31%)	
Tier 3	11 (20%)	
	<b>Patients with breast cancer</b>	<b>Patients with lung cancer</b>
<b>Patients, n (%)</b>	100	100
Tier 1	35 (35%)	34 (34%)
Tier 2	44 (44%)	53 (53%)
Tier 3	21 (21%)	13 (13%)
Age, years	55.6	42.9
<b>Family history of cancer, %</b>	34%	22%

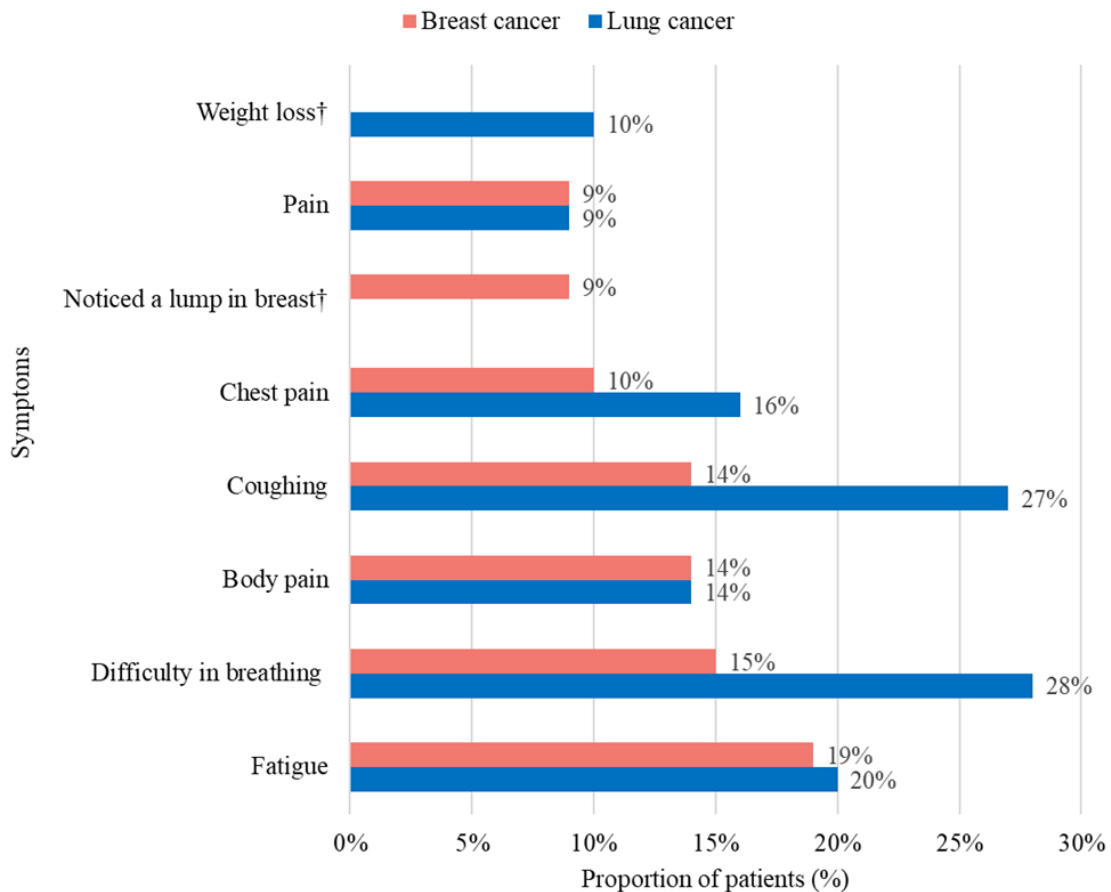


Figure 1. Initial symptoms experienced by patients – Patients’ survey. † Weight loss and lump in breast were excluded in the questionnaire for patients with breast cancer and lung cancer, respectively.

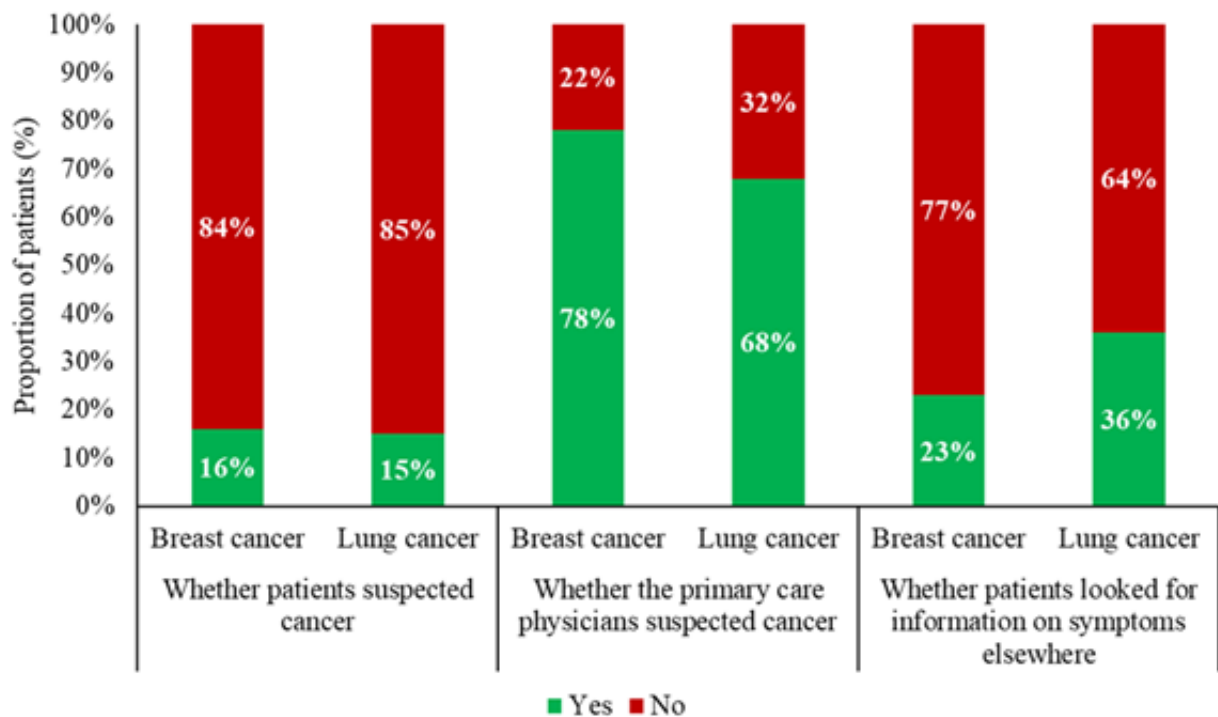


Figure 2. Cancer suspicion and information exploration – Patients’ survey.

from surveyed medical oncologists suggest that only 25% of the patients visit them on referral from primary care physicians. Besides, about 1 out of 2 patients

took more than 3 months from symptoms recognition to reaching medical oncologists.

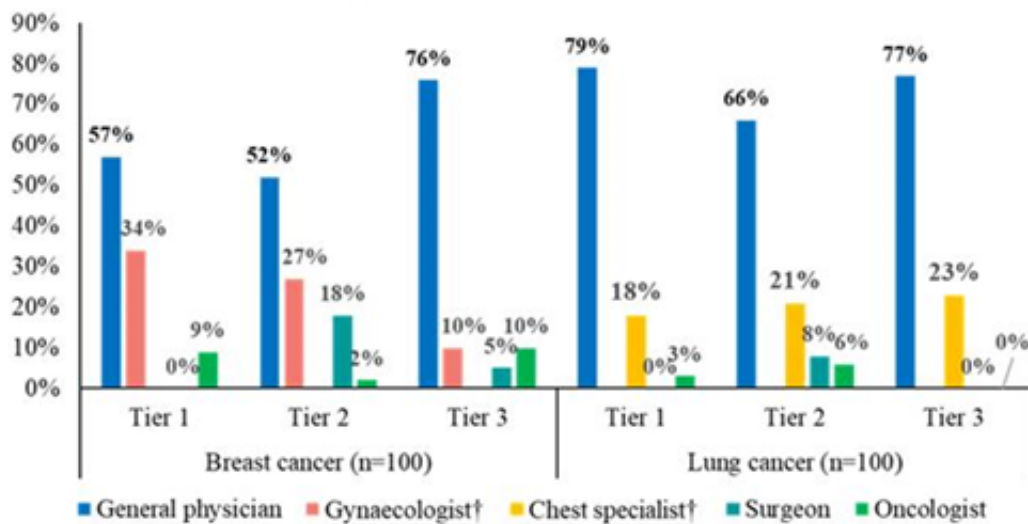


Figure 3. Type of doctor consulted first time.

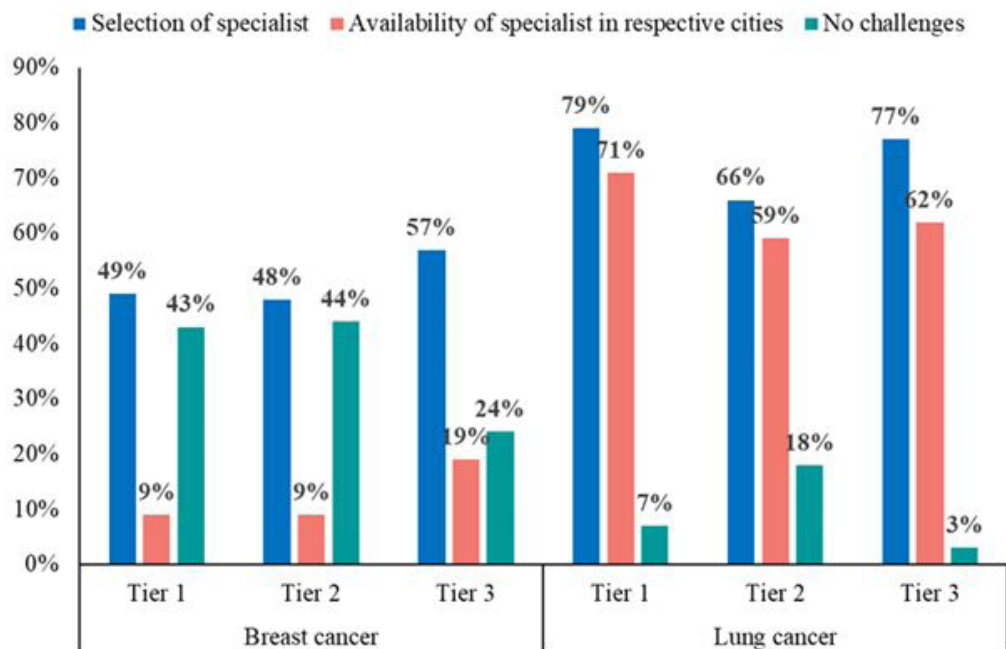


Figure 4. Challenges faced to reach physicians.

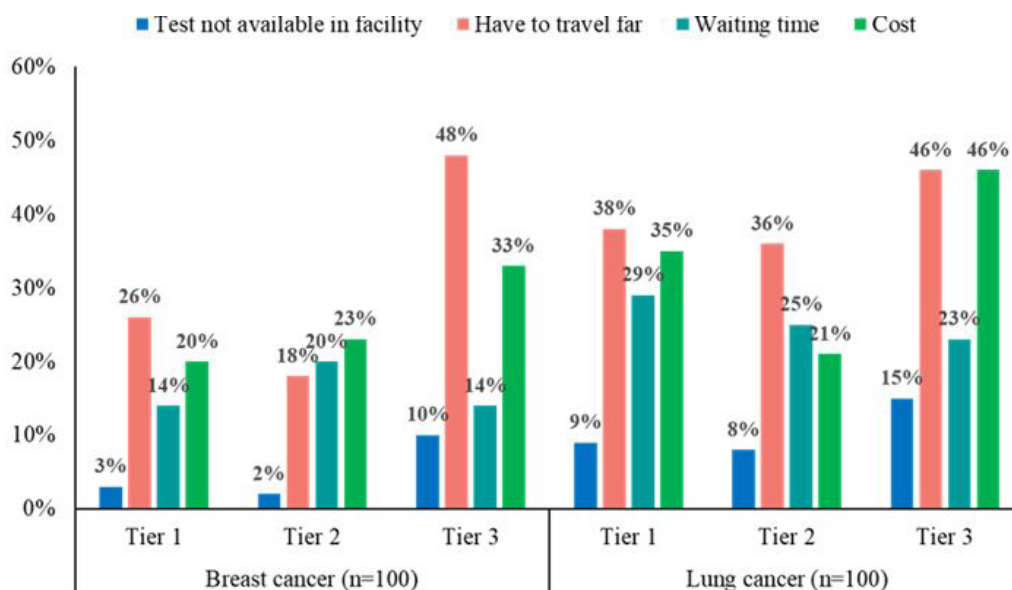


Figure 5. Changes faced for diagnosis.

The most commonly faced challenge for both BC and LC patients was distance to the clinic/hospital when reaching out to medical oncologists, especially those residing in Tier 2 and 3 cities. Around 37% of medical oncologists reported that the major challenge faced by patients was lack of awareness on how to diagnose the cancer and misdiagnosis among primary care physicians (Figure 6).

Medical oncologist's survey revealed that 3 out of 4 BC patients' families were screened for cancer after confirmed diagnosis. The results of patient survey revealed that around 20% of BC patients and 28% of LC patients considered seeking a second opinion from other medical oncologists to confirm their primary diagnosis. The most common reason for seeking a second opinion was to confirm the diagnosis in both BC (70%) and LC patients (66%).

### Patient-Physician interaction: Patient expectations and patient satisfaction

Only 27% of BC patients and 30% of LC patients were informed by the oncologists about available financial support programs which include govt, hospital, insurance etc. Among which, government programs were most commonly mentioned, and patients had maximum information about them (Figures 7 and 8). Doctor's recommendation was the most common factor contributing to patients' decisions on the choice of treatment, followed by safety issues and consideration of the quality of life (Figure 9). In most cases, patients did not receive additional support from counsellors, psychologists, and dieticians. However, more patients with lung cancer in Tier 1 were assigned support from counsellors and psychologists. Around 7 out of 10 BC and LC

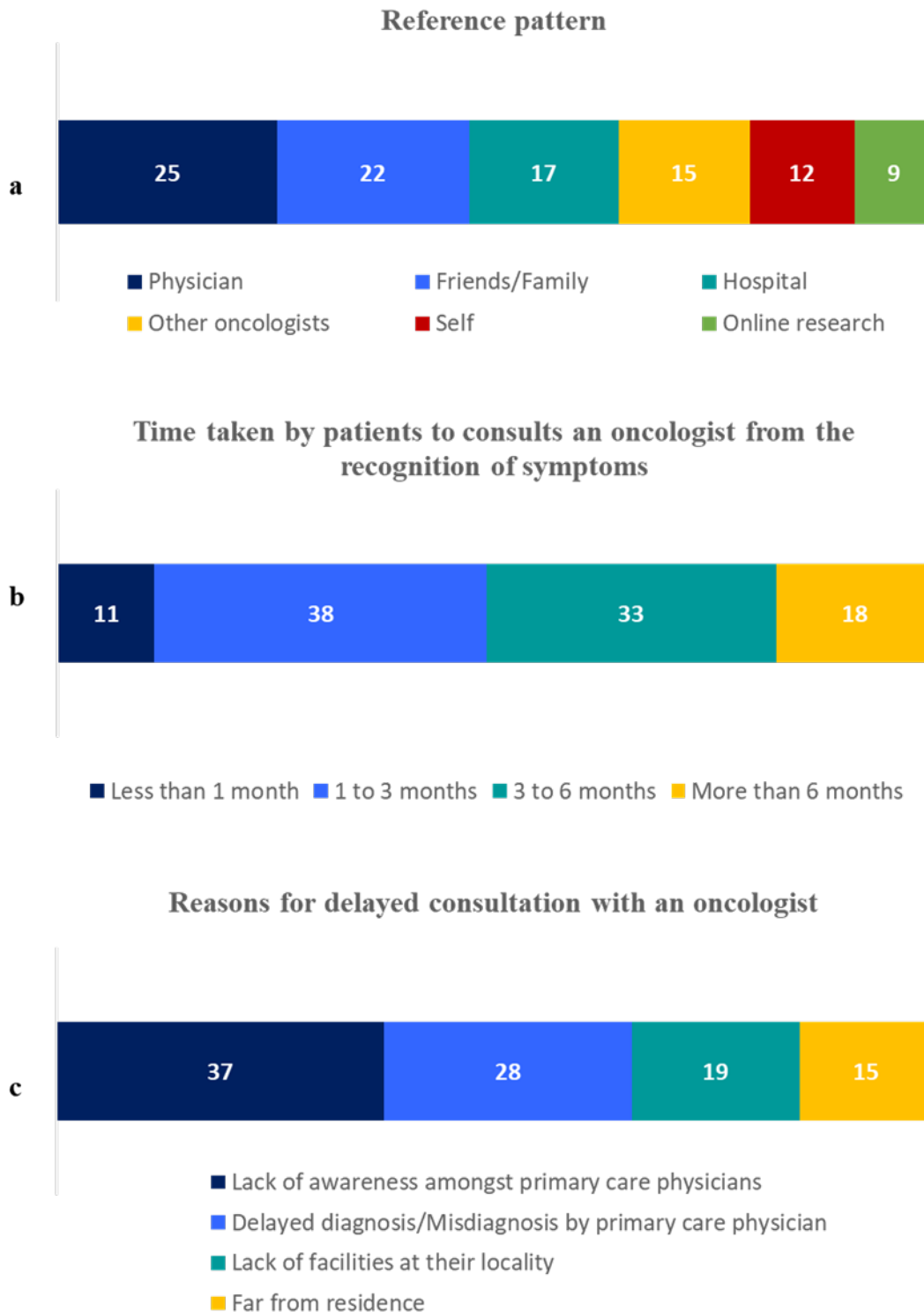


Figure 6. Oncologist-reported results regarding patients' journey from symptoms to diagnosis (n=55), %.

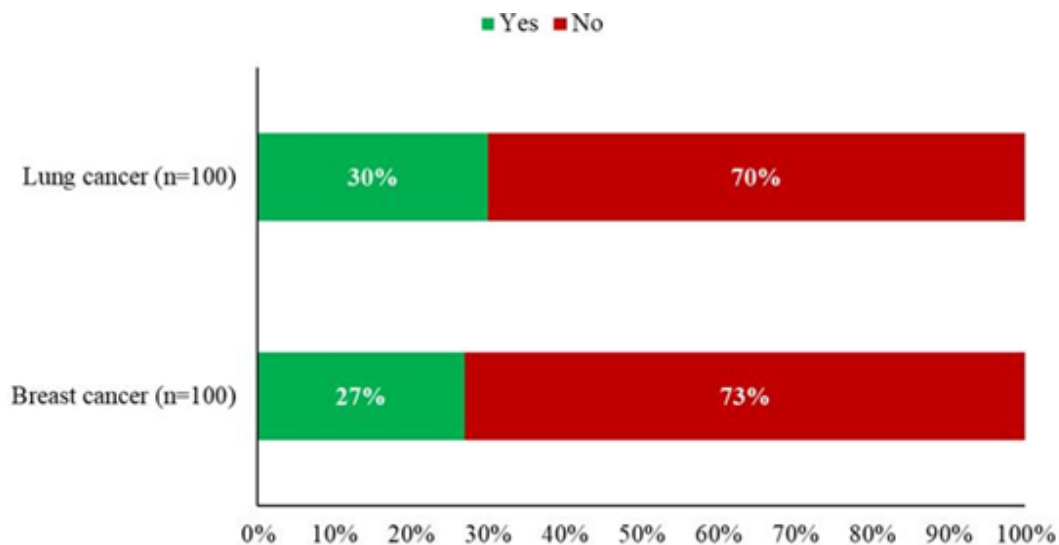


Figure 7. Whether be informed about financial support program.

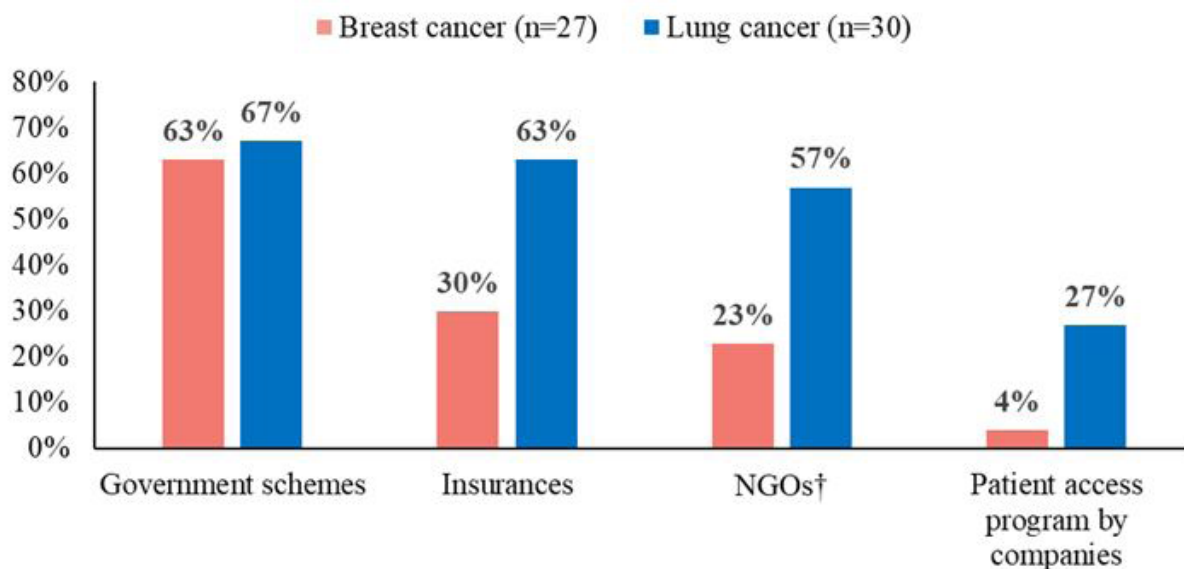


Figure 8. Type of informed financial schemes.

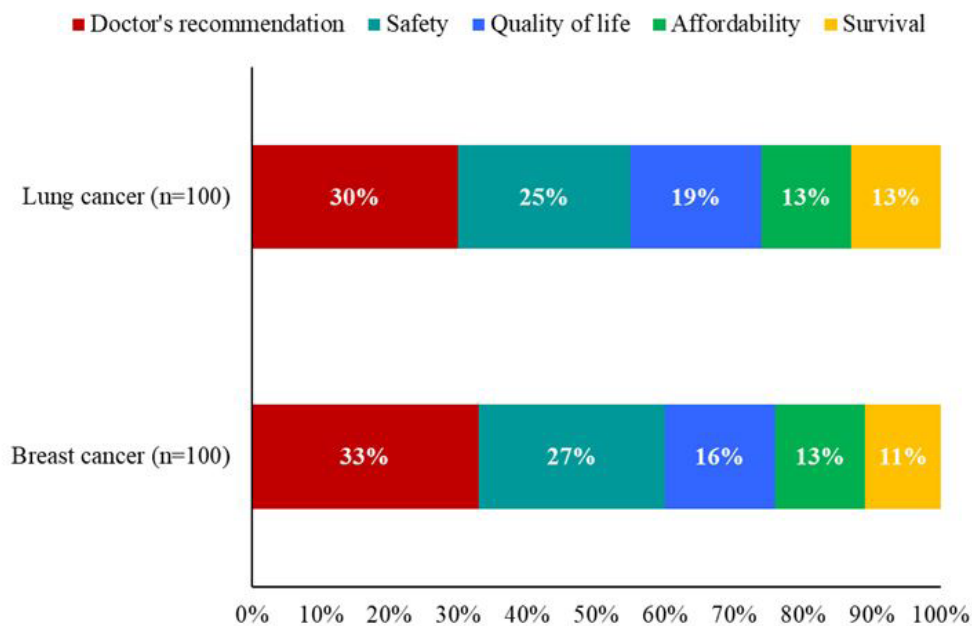


Figure 9. Factors contributing in patients decision.

patients felt improvement in overall symptoms and quality of life after treatment. Most patients were satisfied with their first counselling from medical oncologists and treatment procedures (Table 2). About 68% of BC patients and 44% of LC patients were actively engaged in the consultation and were also involved in deciding the course of treatment with their medical oncologists (Figure 10).

### Patient expectations, adherence to treatment, and awareness of different support

Most patients were expecting empathy and time for counselling from their medical oncologists. The expectations from the hospital staff included patient assistance and supportive care (Table 3). Both patients' belief in doctors and overall improvement after treatment were necessary for treatment adherence (table 3) only 5% of BC patients and 13% of LC patients were aware of compassionate access programs, while 33% of BC patients and 43% of LC patients were informed about ongoing clinical trials. Awareness of patient advocacy groups was low with only 5% of BC patients and 17% of LC patients

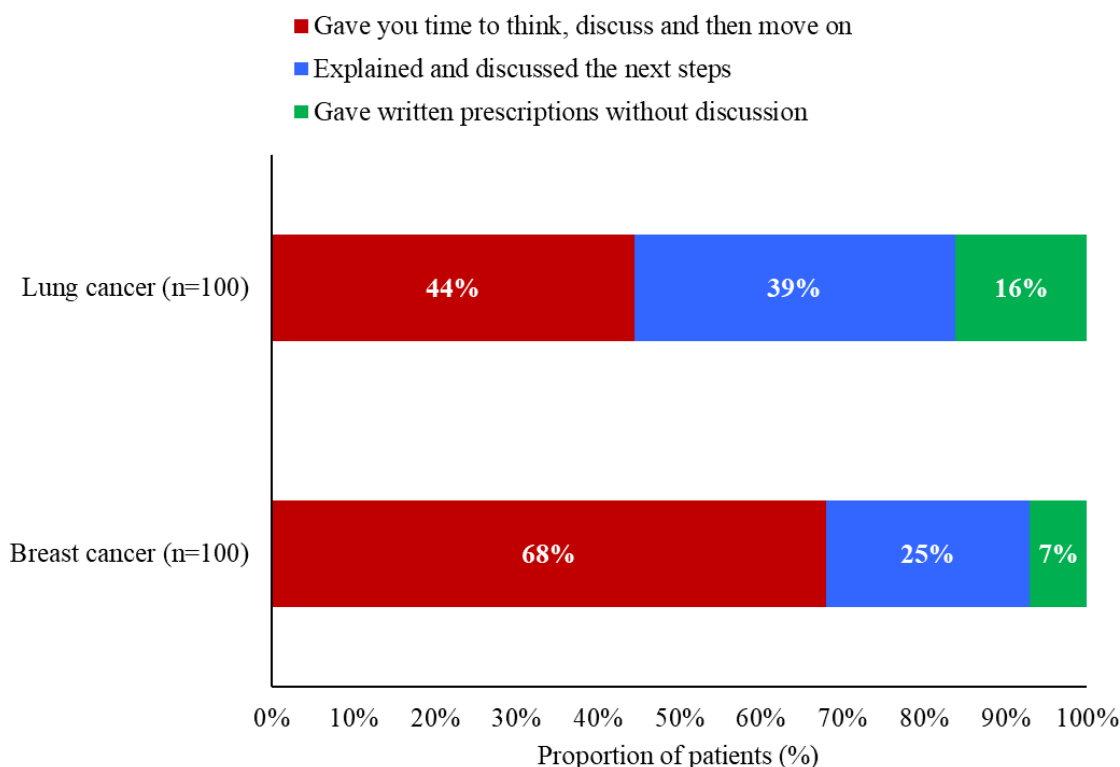
having such knowledge, among which only 23% of BC patients and 20% of LC patients reported joining the patient advocacy groups. As per surveyed medical oncologists, only 5% of them discuss support from patient advocacy groups or NGOs with all their patients and 20% have no discussion about PAG's with their patients Figure 7. The majority of medical oncologists (79%) additionally reported that less than 30% of patients join PAGs (Figure 11 and Table 3).

### Effect of the COVID-19 pandemic

The pandemic adversely impacted the follow-up with medical oncologists and hospitalization for BC and LC patients. During the pandemic, about 23% and 29% of BC and LC patients, respectively, resorted to online consultations; of them, 41% of LC and 65% of BC patients reported being satisfied with it. Based on the survey of medical oncologists, it was found that online consultation was started by 69% of them post pandemic. Among them, 58% were comfortable with the consultation and 53% faced challenges while communicating with patients virtually. The common challenges of virtual consultation included

**Table 2.** Type of additional support received and patients' satisfaction on counselling and treatment (n=200).

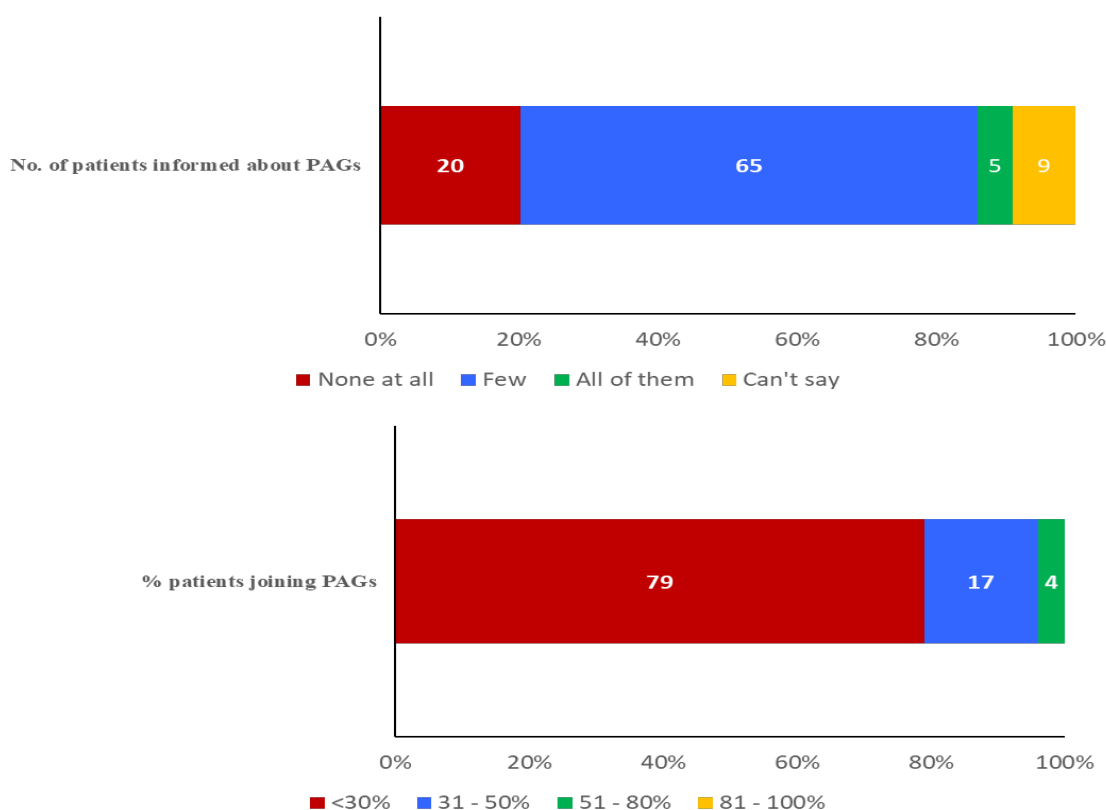
Variables	Patients with Breast Cancer (n=100)			Patients with Lung Cancer (n=100)		
	Tier 1	Tier 2	Tier 3	Tier 1	Tier 2	Tier 3
Type of Received Additional Support, %						
Counsellor	17%	14%	29%	47%	30%	0%
Psychologist	23%	7%	5%	38%	25%	0%
Dietician	29%	27%	43%	29%	15%	15%
None	49%	64%	43%	32%	53%	85%
Patients' satisfaction on oncologist counselling, %	Satisfied	Not sure	Dissatisfied	Satisfied	Not sure	Dissatisfied
Different treatment options	91%	6%	3%	92%	6%	2%
Side effects	88%	9%	3%	92%	6%	2%
Life expectancy	86%	11%	3%	86%	14%	0%
Quality of life	89%	6%	5%	84%	15%	1%
Financial aspects	78%	15%	7%	83%	14%	3%
Patients' satisfaction on treatment, %	Yes	No		Yes	No	
Information on how treatment will affect cancer	89%	11%		90%	10%	
Information on how treatment will affect cancer	95%	5%		87%	13%	
Cost of treatment	89%	11%		97%	3%	
Quality of life after treatment	97%	3%		93%	7%	



**Figure 10.** Experience of patients during consultation with an oncologist.

**Table 3.** Expectations of patients from oncologists and hospital staff and factors related to treatment adherence (n=200).

Variables	Patients with Breast Cancer (n=100)	Patients with Lung Cancer (n=100)
<b>Expectations from oncologists, %</b>		
Empathy	38%	41%
Time for counselling	36%	41%
Awareness about disease, treatment and adverse effects	23%	34%
Good treatment	1%	5%
None/Nothing	14%	5%
<b>Expectations from hospital staff, %</b>		
Patient assistance	64%	66%
Empathy/Behavior	31%	29%
Better care during hospitalization	30%	43%
Requirement of a counsellor	3%	10%
<b>Factors impacted treatment adherence, %</b>		
Patient's belief in doctor	52%	51%
Overall improvement	48%	49%



**Figure 11.** Oncologists' experience on patient's engagement with patient advocacy groups. PAG: Patient Advocacy Group.

lack of technical know-how among patients, network issues, and diminished receptiveness among less educated patients.

## Discussion

Targeted therapies have significantly improved the prognosis and overall survival of patients with advanced lung and breast cancer. However, the impact of a terminal diagnosis, lengthy hospital stays, and treatment affects every aspect of patients' lives such as physical, psychological, social, cognitive, financial, and spiritual [12-15]. The patients are mostly satisfied with their physicians, but their range of supportive care needs remain unmet, which leads to poor quality of life [16]. Typically, an advanced lung and breast cancer patient's journey entails identification of symptoms that prompt a general physician visit, referral to a specialist, diagnosis, treatment, and follow-up [17]. Patients' experiences through each of these stages (patient journey) provide deeper insight into their individual needs that could enhance their quality of life and improve

psychosocial outcomes such as depression, distress, and anxiety. Evaluation of patient journey uses a multidimensional approach that offers an opportunity to identify gaps and areas of improvement [12]. Numerous quantitative studies have highlighted specific aspects of patients' experiences such as emotional well-being, physical symptoms, social functioning, communication, progressive cancer, and survivors' reintegration into day-to-day life but advanced cancer patients' journey through all stages has not been studied [12-18]. The current study depicted the journey and experience of patients with advanced lung and breast cancer, from the appearance of symptoms to post-treatment follow-up.

The public's unawareness of cancer symptoms is the major barrier to seeking early medical help that contributes to advanced-stage diagnosis at presentation [19]. In the present study in India, about 50% of the patients were not aware of cancer symptoms and treatment. The findings were consistent with other studies which found that about 51% of BC and more than 50% of LC patients were unaware of the symptoms before the diagnosis [20,21].

Primary care physicians (General Practitioners (GP), gynecologists or



consulting physicians) play a key role in the early diagnosis or suspicion of cancer as a majority of patients first consult primary care physicians following the onset of symptoms. In this study, 92% of the LC patients initially consulted a general or a chest physician whereas more than 85% of BC patients visited a GP or a gynecologist. Primary care physicians will examine the signs and symptoms, and cancer is suspected if the patient has symptoms related to cancer. Unexplained weight loss, unusual fatigue, and pain are considered to be three general warning signs of cancer [22,23]. In India, most lung cancer patients are initially suspected to have tuberculosis, as both have similar symptoms and radiographic features, resulting in increased time to diagnosis of lung cancer [24]. In a study conducted by Maghous A, et al. about 24.4% of BC patients were misdiagnosed after physical breast examination by primary care physicians as they considered a lump to be benign without performing a biopsy [25].

This study showed that around 32% and 22% of primary physicians didn't suspect patient symptoms were related to lung and breast cancer, respectively. Lack of awareness on how to diagnose the cancer (37%) and misdiagnosis (28%) amongst the primary physicians are the major challenges faced by the patients to reach an oncologist. In addition, the referral to non-oncologist was an additional barrier on delay to reach an oncologist. Hence, decisions taken by primary care physicians may significantly impact the cancer trajectory. Second opinion to confirm the primary diagnosis was sought by less than 30% of patients in both breast and lung cancer groups. The findings were consistent with the study by Shmueli L, et al. conducted at Israel which observed that 38% of patients sought a second opinion because they had doubts about the diagnosis [26]. The advanced healthcare system in India is largely centralized and inaccessible to people living in rural areas [27]. Advancing healthcare infrastructure in rural areas requires a multipronged approach from government and private sectors which is time-consuming [28]. Hence, education of primary care physicians, public awareness about screening methods for high-risk populations and awareness about cancer symptoms amongst the general population and primary health care workers play an important role in early diagnosis of cancer and right time to referral [19,22].

In urban areas, the majority of the public or private diagnostic centres have adequate modern and advanced facilities to diagnose and treat disease conditions but in rural parts only primary medical and health services are available. Therefore, patients residing in rural areas would have to travel long distances to receive specialized medical services which is a time-consuming and expensive process [29]. Similar findings were observed in the current study as most of the lung and breast cancer patients, especially those residing in Tier 2 and 3 cities, were living far away from the clinic/hospital, and had difficulty in reaching out to these facilities and the oncologist. However, medical oncologists survey results found that the diagnostic centers were far away only for 4% of patients as they usually practice at hospitals with good diagnostic setups.

The patient-centric approach involves providing tailored and quality information to patients which is essential to successful communication. Studies have shown that patients who possess relevant information are more involved in shared decision-making and are satisfied with treatment choices. They also have better self-management and coping skills [30]. In the present study, only one in three LC patients and one in four BC patients sought additional information on online platforms like YouTube, Google search engines, blogs, and medical journals. The findings were significantly less than that reported by Loiselle CG which found that about 60% of patients sought information about their cancer. Most of the patients looked for information online besides interacting with family and peers [31]. Currently, the volume of information available on the internet is overwhelming. The increasing incidence of misinformation and lack of knowledge about reliability of the source negatively impact the confidence of the patients and/or their families. The traditional information distribution follows a reactive trend instead of proactive which can be considered as a missed opportunity to ensure that the patient or patient's family receives required and relevant information in a timely manner. The information also needs to be well-aligned with the stage in the patient's cancer journey [32].

In the present study, about 90% of the patients were satisfied with primary counseling by the oncologist and treatment procedures. About 44% of LC patients and 68% of BC patients were actively involved in the consultation and deciding the course of the treatment with an oncologist. Shared decision-making is a key element in enhancing patient satisfaction with the overall treatment experience, which in turn improves adherence to treatment. Empathy during consultation and trust in their physicians improve the clinician-patient relationship which is important for shared decision-making. Due to limited time during the consultation, it is challenging for physicians to provide and explain all

the information to patients that is needed to make decisions [33]. Close relatives of BC patients are at increased risk of developing these cancers due to lifestyle, shared environment, and hereditary genetic factors [34,35]. A trained patient counselor in addition to an oncologist can help in providing essential information to the patients and their family members who might be at risk of developing BC. The doctor's recommendation was the most important deciding factor in LC and BC patients' treatment. In advance care planning, a medical oncologist's role is not only limited to providing the best quality treatment to the patients but also to address their supportive care needs to improve their quality of life during the cancer journey. Therefore, medical oncologists may help in better patient care by learning a variety of abilities, such as effective and empathetic communication style, fostering shared decision-making, better monitoring of treatment and disease consequences, symptom management, and coping with the psychological needs of the patient [36].

Due to low life expectancy, a diagnosis of advanced cancer impacts a patient's emotional well-being. Psychological interventions are necessary to manage problems such as depression, fatigue, anxiety, disruption, and pain which would improve quality of life. Survival and patient-reported outcomes are the two main outcomes of most cancers, and it has been observed that improved quality of life leads to better patient-reported outcomes [37]. In this study, less than 10% of the LC patients and about 40% of BC patients sought psychologist consultation which suggests that medical oncologists are more focused on disease outcomes and psychological interventions are lacking. Similarly, patients would also benefit from dietician support as nutritional deficiency results in low-performance status, frequent hospitalization, reduced survival, and ultimately impaired quality of life [38].

The patients are mostly satisfied with their physicians but they expected to be more empowered with information about their condition benefits, and adverse reactions of anti-cancer treatment, to be more involved in treatment planning and decision making, proper management of side effects, to gain support for financial issues by informing them about programs offered by the government or private organizations, reassurance from medical staff and sensitivity towards their emotional needs [15,39,40]. Taking time, the ability to listen, honesty, experience, compassion and attentiveness were the qualities patients expected from physicians [15,39,40]. Time for counseling and empathy were the two most important expectations of the patient from an oncologist in this study while patient assistance such as navigation support to access the treatment and support towards affordability solutions were the major expectations of a patient from the hospital staff.

In this study, the awareness about patient advocacy groups was only 17% and 5% in LC and BC patients respectively, among which only 23% of BC patients and 20% of LC patients enrolled in a group. It was also noted that only 5% of medical oncologists discuss support from patient advocacy groups or Non-Governmental Organizations (NGOs) with all their patients, and less than 30% of patients join these groups. A survey conducted among 275 Japanese cancer survivors found that 135 (49%) patients were aware of patient support groups of which only 17% of patients joined a group [41]. Additionally, only 13% of LC and 5% of BC patients were made aware of the compassionate access programs offered by pharmaceutical companies, while 43% of LC and 33% of BC patients, were aware of clinical trials. Studies have observed that peer support group activities such as health education, stress management, and problem-solving ease psychological distress and provide emotional relief to patients. Cancer support also enables them to cope with a cancer diagnosis, make treatment decisions and manage expectation which leads to improved quality of life and patient-reported outcomes [42,43]. In India 'Lung Connect' support group was created during the COVID-19 pandemic to support patients with lung cancer and their caregivers throughout their treatment journey. It helps in addressing their emotional, social, physical, functional, and financial needs by allowing them to interact together, talk to the physicians, and get accurate information. Hitaishini, Maina, Breast Cancer India and Aastha are some of the support groups for breast cancer present in India. ALK positive India is the first patient support group dedicated to ALK-positive lung cancer patients. Indian Cancer Society survivorship and rehabilitation center, Indian Cancer Society, Chatur Arogya Mandal, Udhavum Ullangal Public Charitable Trust, Yuvraj Singh Foundation, Sanjeevani Life Beyond Cancer, Women's Cancer Initiative – Tata Memorial Hospital, and Cancer Patients Aid Association are some of the cancer care NGOs playing a significant role in helping patients and spreading awareness.

During the COVID-19 pandemic, cancer care teams adopted virtual consultations through "telehealth" modes. In the present study, 41% of LC

and 65% of BC patients coped well with the online consultations as family members could easily join the consultation sessions. The impression that virtual consultation was safer during the pandemic was advantageous to the patients [44].

## Conclusion

Coordinated and comprehensive cancer care is essential for patients with advanced lung and breast cancer. The survey recommends the need for educating primary care physicians to establish early diagnosis and right time to referral. The survey results also highlight the importance of screening high risk populations and the importance of educational material for patients to understand their disease and treatment. Patients should be provided the required support to gain access to the treatment. Patients should be informed about availability and eligibility of various financial support program. In addition, counseling on mental health, nutritional support, and information about patient support groups is also crucial. These efforts will ultimately improve outcomes for patients with cancer.

## Declarations

**Ethics approval statement:** Not applicable

**Consent to publication:** Not applicable

**Data availability statement:** The datasets used and/or analysed during the current study available from the corresponding author on reasonable request.

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## Conflict of Interest

All the authors are full-time employees of Pfizer India. Additionally, Ankita Jain declares stock ownership in Pfizer Ltd.

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