

## Barriers and facilitators of early lung cancer care in Mexico

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### Abstract

**Background:** Timely diagnosis and prompt initiation of treatment are crucial for improving outcomes in lung cancer patients in Mexico. However, barriers hinder the achievement of this goal, leading to delayed diagnosis and suboptimal treatment trajectories. **Objective:** To explore barriers and facilitators contributing to late diagnosis and treatment. **Methods:** In-depth interviews were conducted in spring 2023 among a purposive sample of lung cancer patients, relatives, and health-care professionals in Mexico. Grounded theory was used to identify recurring themes and gain a comprehensive understanding of the challenges faced. Codes included: barriers and facilitators; and origin: individual, family/community, doctor, or health system. The interpretation of the data was guided by the proximal and distal determinants of care and cross-checked by a second researcher. **Results:** The study identifies multiple barriers to lung cancer diagnosis and care, including poor symptom recognition, lack of medical training, and family or caregiver burden. However, facilitators such as family perseverance, non-profit organization support, and participation in research protocols can help overcome these obstacles. **Conclusion:** Addressing barriers while leveraging the facilitators is essential for improving lung cancer outcomes.

**Keywords:** Barriers. Early cancer care. Diagnosis. Treatment. Mexico. Lung cancer.

### Barreras y facilitadores de la atención temprana del cáncer de pulmón en México

#### Resumen

**Antecedentes:** El diagnóstico oportuno y el inicio rápido del tratamiento son cruciales para mejorar los resultados en pacientes con cáncer de pulmón en México. Sin embargo, diversas barreras dificultan el logro de este objetivo, lo que conduce a diagnósticos tardíos y trayectorias de tratamiento subóptimas. **Objetivo:** Explorar las barreras y facilitadores que contribuyen al diagnóstico y tratamiento tardíos. **Métodos:** Se realizaron entrevistas en profundidad en la primavera de 2023 entre los componentes de una muestra intencionada de pacientes con cáncer de pulmón, familiares y profesionales de la salud en México. Se utilizó la teoría fundamentada para identificar temas recurrentes y obtener una comprensión completa de los desafíos enfrentados. Los códigos incluyeron barreras y facilitadores, y origen (individual, familiar/comunitario, médico o sistema de salud). **Resultados:** El estudio identifica múltiples barreras para el diagnóstico y cuidado del cáncer de pulmón, incluyendo el pobre reconocimiento de los síntomas, la falta de formación médica y la carga para la familia o los cuidadores. Sin embargo, facilitadores como la perseverancia de la familia, el apoyo de organizaciones sin fines de lucro y la participación en protocolos de investigación pueden ayudar a superar estos obstáculos. **Conclusión:** Abordar las barreras y apoyar los facilitadores es esencial para mejorar los resultados en cáncer de pulmón.

**Palabras clave:** Barreras. Facilitadores. Cáncer de pulmón. México. Diagnóstico. Tratamiento.

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## Background

Lung cancer is the leading cause of cancer-related mortality in Mexico, with the majority of cases being identified in symptomatic individuals at a late stage of the disease and less eligible for potential curative therapy<sup>1,2</sup>.

This is reflected in high mortality-to-incidence ratios<sup>2-4</sup>. At present, Mexico lacks a national public lung cancer screening program<sup>2</sup>. There are large disparities in access to well-equipped diagnostic resources<sup>1</sup>. The absence of a referral protocol further complicates matters, potentially resulting in lost patient follow-ups and difficulties navigating the health system<sup>2</sup>. Moreover, health-care centralization results in unequal distribution of services<sup>5</sup>, with specialized oncology care more prevalent in the central region near Mexico City<sup>6</sup>. First and second-level care facilities often lack infrastructure and human resources for diagnosis, whereas third-level hospitals cater only to confirmed disease cases<sup>7</sup>, potentially contributing to barriers in early diagnosis and timely treatment<sup>3</sup>. Hence, there is a critical need to intensify efforts directed at understanding the barriers lung cancer patients face in Mexico to achieve diagnosis or treatment<sup>2,8</sup>.

Krok-Schoen et al. developed a framework of patient-identified barriers<sup>9</sup>. However, because barriers have never been assessed in this population more research should be done to identify them. Thus, qualitative research becomes an indispensable tool for comprehending the experiences of individuals<sup>10-14</sup>, lung cancer patients included. Such studies delve into the multifaceted representations held by both patients and their caregivers, shedding light on critical junctures within the patient journey, such as suspicion, diagnosis, and treatment<sup>10-13,15,16</sup>. Furthermore, by triangulating the narratives of primary actors (patients) with those of secondary actors (caregivers), a relational analysis is facilitated, allowing for a comprehensive exploration of the intricacies of the lung cancer journey. Similar research integrating patients and other stakeholders in the identification of barriers has been done in other countries<sup>15,17</sup>. Other studies have also compared barriers to facilitators<sup>13</sup>. Among patients, barriers such as poor relationships with health-care providers, low levels of trust in the health-care system, lack of access, feeling unworthy of treatment, financial toxicity, disconnected interpretations of bodily changes, and lack of awareness of cancer symptoms were among the most frequently found<sup>13,18-20</sup>. Whereas illness management, coping with stress and major life changes were described as negative experiences by caregivers<sup>16</sup>.

Instead, patient self-advocacy, provider advocacy, care coordination, and good communication were facilitators of lung cancer care<sup>13</sup>.

This research endeavors to bridge a critical knowledge gap concerning the challenges and the potential facilitating roles faced by lung cancer patients, caregivers, and health-care professionals in Mexico, particularly with respect to early diagnosis and treatment. The aim is to generate evidence to allow policymakers and patient organizations to guide decision-making and identify potential areas for intervention.

## Methods

Semi-structured interviews were conducted through analog telephone calls of a purposive sample of  $n = 22$  participants. Patients from diverse age groups and backgrounds were invited to contrast healthcare-care journeys. Health professionals from different regions and working in different levels of care were invited to participate. Family members or carers of patients selected for interviews were also invited. The rationale behind the selection of patients, family members or caregivers, and healthcare workers for analysis was grounded in the pursuit of a comprehensive understanding of barriers and facilitators of care from multiple perspectives<sup>15,17</sup>. By including them, we aimed to capture the diverse experiences, perspectives, and insights pertinent to the subject matter.

The reliability and validity of telephone interviews have been extensively studied in the literature and can yield high-quality data that are comparable to face-to-face interviews, particularly when the research involves sensitive topics or when participants are geographically dispersed<sup>21</sup>.

The non-governmental organization “Respirando con Valor (RCV)” recruited patients with a lung cancer diagnosis and family or caregivers who had previously requested support from them as a patient-oriented organization. All participants were contacted by RCV and asked to participate in the study in spring 2023. Those who voluntarily decided to participate were interviewed: patients ( $n = 12$ ), family members or caregivers ( $n = 5$ ), and health-care workers ( $n = 5$ ). Ethical approval was granted by an internal committee of RCV.

The interview guide was designed following a thorough literature review on barriers to early cancer care and delays in lung cancer care<sup>9,12,13,15,20,22-25</sup>. Guided by a meticulously designed semi-structured framework<sup>26</sup>, the interviews delved into three overarching domains: (1) suspicion and diagnosis, (2) seeking care,

diagnosis, and treatment, and (3) the socio-familial milieu. Each of the domains, meticulously delineated, comprised four subcategories, thus affording a comprehensive exploration of the phenomena under investigation.

The domain of suspicion and diagnosis interrogated multifaceted aspects including cultural representations of health and illness, the onset of initial symptoms, markers of suspicion, pivotal moments of diagnosis confirmation, and the subsequent emotional reckoning inherent in confronting such diagnoses. Conversely, the domain pertaining to seeking care and treatment delved into the intricate landscape of health-care access and utilization, encompassing challenges encountered in accessing biomedical treatments, navigating hospital systems, negotiating medical pluralism, and the participants' perceptions of biomedical treatment modalities. Finally, the domain elucidates the social and familial environment probed into interpersonal challenges within familial dynamics, work-related difficulties, and the landscape of mental health and adaptive coping mechanisms amid adversity. Before each interview, the purpose and objectives were explained to participants, and a consent form was signed. Recorded data were anonymized according to the Helsinki Declaration's guidelines and securely stored with complete confidentiality.

The data analysis was rooted in the grounded theory framework<sup>27</sup>. It employed an inductive approach, leveraging empirical data derived from semi-structured interviews, facilitating the exploration of the multifaceted dimensions inherent in the journeys of lung cancer patients and the authentic realities experienced by the main actors involved in the illness trajectory. Key themes, patterns, and commonalities across interviews were identified by one researcher and cross-checked by a second researcher. Codes identified included: Barriers and facilitators; and origin: Individual, family/community, doctor, or health system.

Theoretical saturation was assessed through continuous analysis of the data during the interview process. The evaluation of theoretical saturation involved both inductive and deductive analysis. Initially, data were coded and themes were identified inductively. As new interviews were conducted, these themes were continually compared and refined. Deductively, the predefined categories based on the interview guide were also used to ensure all anticipated areas were covered. The evaluation was conducted in line with

the constant comparative method, as described by Glaser and Strauss<sup>27</sup>.

The interpretation of the data was guided by the proximal and distal determinants of care from existing literature<sup>9,15,17,28,29</sup>. The study was guided by the standards for reporting and conducting qualitative research<sup>30</sup>. Finally, from the patient narrative, data were used to calculate the time to diagnosis.

## Results

Patients varied in gender, age, duration of diagnosis, and location of residence and health-care institution. From the  $n = 12$  patients, seven were women, and five were men, with nine residing in different Mexican states and three in the Metropolitan Area of Mexico City. Most patients received treatment at third-level institutions in Mexico City: The National Cancer Institute (INCAN) and the National Institute of Respiratory Diseases (INER). Family members or carers were all women. Health-care workers were from both rural and urban areas and from different levels of expertise: Oncologist ( $n = 1$ ), pulmonologist ( $n = 1$ ), and general practitioners ( $n = 3$ ) (Table 1).

This study identified key barriers and facilitators that lung cancer patients encounter throughout their journey. We were able to attain theoretical saturation, signifying a depth of understanding characterized by robust consistency in our findings. This was facilitated by the identification of discursive regularities among the various actors involved, further enriching our insights and enhancing the overall rigor of our study. Table 2 summarizes the barriers and facilitators that arose from the data, and fits into different dimensions: individual, doctor, system, or family in the Mexican context. Finally, table 3 shows the examples of verbalizations stakeholders made with a brief description of each category.

## Discussion

### The patient

Early diagnosis and timely treatment are pivotal in improving outcomes, yet various barriers hinder the achievement of these goals. This article explores the complex web of factors contributing to delayed diagnosis and treatment of lung cancer, highlighting the perspectives of patients, their families, health-care providers, and health professionals. The voices and experiences of patients and their families should be continually

**Table 1.** Joint display of patient sociodemographic characteristics and time to diagnosis

Patient	Age	Sex	Time to diagnosis	Institution	Origin
1	50	Man	1 year	INER	Puebla
2	42	Man	1 year	INCAN	Oaxaca
3	64	Woman	6 months	INER	Tabasco
4	67	Woman	4 years	INCAN	State of Mexico
5	71	Woman	3 years	INER	Mexico City
6	47	Woman	9 years	INCAN	Guerrero
7	63	Woman	2 years	ISSEMYM	State of Mexico
8	73	Woman	4 years	INCAN	State of Mexico
9	52	Woman	1 year	INCAN	Oaxaca
10	38	Man	1 year	INCAN	Puebla
11	44	Man	3 years	INCAN	Puebla
12	63	Woman	4 years	INCAN	Nuevo León

INCAN: National Cancer Institute; INER: National Institute of Respiratory Diseases.

prioritized in future research, as their insights are invaluable in shaping patient-centered care strategies.

As shown in other studies, social constructions of risk<sup>31,32</sup> and prevailing beliefs about illness contribute to the underestimation of symptoms and the prioritization of other life aspects<sup>5,33,34</sup>. Similarly, the lack of knowledge about lung cancer symptoms and its association solely with smoking hindered early recognition and appropriate health-care seeking. Thus, our study emphasizes the importance of raising awareness and promoting effective communication campaigns for lung cancer risk among the population. These campaigns must educate individuals about the most common symptoms and risk factors, including factors not solely related to tobacco smoke exposure.

In our sample, the notion that cancer is a punishment for smoking can lead to reduced adherence to treatment among patients. This negative discourse of guilt has been found to not only be reinforced by family and friends but also within the health-care community<sup>35</sup>. Although smoking is a major causal factor in most cases, it is not the sole cause of lung cancer in Mexico<sup>2,8</sup>. Hence, it is vital to highlight other potential causes when delivering prevention campaigns, such as family history and exposure to various toxic substances like radon, chlorine, asbestos, or wood smoke. These campaigns must prioritize destigmatizing lung cancer patients as people who smoke tobacco. This may result

in increased knowledge and reduction of poor symptom recognition, the usage of alternative remedies, and delayed self-appraisal.

Results from this study also suggest campaigns directly targeting rural communities should raise awareness about lung cancer risk factors and promote the importance of regular health check-ups. This approach helps ensure that individuals in remote areas have equal opportunities to participate in screenings and receive timely medical attention if abnormalities are detected<sup>3,36</sup>.

Moreover, campaigns targeted at health-care professionals should aim to dispel common misconceptions about lung cancer and challenge prevailing stigmas<sup>5</sup>. This will foster a more compassionate and empathetic approach toward patients, helping to mitigate any resistance or reluctance in seeking treatment due to fear or negative perceptions associated with the disease<sup>37,38</sup>.

Previously, studies have described lung cancer patients facing depression, anxiety, distress, and fatigue<sup>39-41</sup>, severely disrupting patients' lives, and affecting their self-perception, values, and overall well-being<sup>35</sup>. Although this study did not capture mental health outcomes, fear can be a potential barrier both for the patient and the carer. This is clinically relevant as the emotional and psychological well-being significantly impacts the patient's ability to cope with the disease and adhere to treatment regimens and physical activity<sup>39-41</sup>. Hence, it is also essential to integrate mental health

**Table 2.** Barriers or facilitators identified in the Mexican population in the context of lung cancer care across different dimensions

Barriers	Facilitators
<b>Individual</b>	
Poor symptom recognition and interpretation Alternative self-care practices and remedies Lack of knowledge about lung cancer Fear of diagnosis Prioritization of functional health Biographical disruption and role adjustments Stigmatization and fear of compassion/pity Limited mental health support Misconception of improvement leading to patient dropouts Treatment's secondary effects	
<b>Doctor</b>	
Lack of medical training for lung cancer identification Time constraints for thorough patient examination Underreporting and misdiagnosis challenges Doctor's lack of empathy	
<b>Family</b>	
Family or caregiver burden Family discord and divergent beliefs	Family or caregiver's perseverance and advocacy
<b>Health system</b>	
Catastrophic expenditures Reduced workforce High patient demand and insufficient diagnostic infrastructure Bureaucratization Disruptive patient journey	Non-profit organizations support Participation in research protocols Facilitators/navigators

support as part of lung cancer care. Implementing proactive mental health services from the outset of the diagnosis will help address the emotional challenges faced by patients and their families, ensuring a comprehensive approach to lung cancer management<sup>5</sup>.

### **Health-care professionals**

Our results show there is insufficient training and knowledge among general practitioners. In fact, misdiagnosis is pointed out to be a reason for longer diagnostic intervals. Thus, it is crucial to invest in comprehensive training, awareness, and sensitization campaigns for primary care physicians in both urban and rural settings<sup>3</sup>. These health-care professionals serve as the frontline in patient care and are often the first point of contact for individuals seeking medical attention. By equipping primary care physicians with the necessary knowledge and skills to identify potential cancer cases promptly, the likelihood of early diagnosis and intervention significantly improves<sup>3</sup>. Training programs should focus on enhancing physicians' clinical acumen in recognizing early warning signs and

symptoms of cancer<sup>3</sup>, especially among individuals with a history of smoking or exposure to environmental risk factors. In addition, it should emphasize the importance of thorough medical histories and appropriate diagnostic evaluations to minimize delays in diagnosis.

Oncologists play a crucial role in ensuring that patients fully comprehend the impact of their treatment on their lives, including potential side effects and how to manage them. Our results show a barrier for continuous lung cancer care is ineffective communication. It is important for oncologists to clearly communicate the possible secondary effects of treatment and provide guidance on how to address them if they occur. Patients need to understand that improvement in their condition does not necessarily signal the end of treatment, and oncologists should explain this aspect thoroughly.

### **Family and carers as barriers and facilitators**

Results point to family members being both a barrier and a facilitator. On one hand, the family environment can significantly impact a patient's health-care decision

**Table 3.** Barriers and facilitators identified in the Mexican population in the context of lung cancer care, description of each category, and quotes that exemplify the theme

Barriers	Description	Verbalizations/quotes example
Poor symptom Recognition and interpretation	Patients may normalize or attribute symptoms to other causes, such as injuries or falls, further delaying medical help and early diagnosis. Patients may have explanatory models for their symptoms that do not align with biomedical explanations like smoking or exposure to toxins. They may attribute symptoms to other factors, such as injuries, distress, or other non-related causes. These explanatory models can contribute to delayed diagnosis and may lead to feelings of frustration and guilt after receiving the diagnosis.	<p>“I did smoke three cigarettes a day, but honestly, I think, as I mentioned before, that it was the fall from the scaffolding that caused it.” (Patient, February 2023).</p> <p>“Throughout my lifetime, I have inhaled many things, I maintained elevators, fumigated, used a lot of chemicals, and toxic substances. In these jobs, they provided helmets, but never face masks or gloves, so I think it could be that way I developed cancer”. (Patient, March 2023).</p> <p>“Sometimes I regret how I faced the problem initially. We must not underestimate cancer, I thought it was gastritis at first, I only had slight intercostal pain but my advice to other people is prevention, pay attention to your own body, do not be afraid or underestimate it.” (Patient, March 2023).</p>
Alternative self-care practices and remedies	Patients may adopt self-care practices as the first strategy, relying on knowledge shared within their social circle. Self-care includes self-medication and a combination of allopathic and traditional or alternative practices. This approach may delay seeking biomedical care, especially if the symptoms are not perceived as severe.	<p>“Now I’m following a protocol, and they tell you not to take certain things, but before going to the INCAN, I took syrups and chlorine dioxide for lung problems, my dad would tell me to drink herbal remedies with lemon and honey, I even consumed capsules made from rattlesnake and skunk.” (Patient, February 2023).</p>
Lack of knowledge about lung cancer	Patients and their family members often have limited knowledge about lung cancer and its symptoms before diagnosis. Awareness campaigns primarily focus on other types of cancer, leading non-smoking patients to dismiss the possibility of lung cancer. Lack of awareness and understanding among the general population and healthcare professionals at the primary care level contributes to delayed diagnosis of lung cancer.	<p>“I hadn’t heard anything about lung cancer until it happened to me. I only knew that, due to smoking, that was our belief, that smokers get cancer. But now we know that there are other factors like asbestos or wood smoke.” (Patient, February 2023).</p> <p>“I actually thought that it could only happen to smokers, then they explained to me that it can happen to anyone due to several other reasons. In fact, at first, I thought that perhaps it was tuberculosis.” (Patient, March 2023).</p>
Fear of diagnosis	Fear of having a more serious illness, including cancer, can also discourage patients from seeking care.	<p>“Honestly, I suspected that something was wrong, but as an adult, I was afraid of having something serious, especially for the sake of my child. One tends to deny it and time goes by.” (Patient, February 2023).</p>
Prioritisation of functional health	Patients may prioritize functional health, including work productivity and caregiving for vulnerable individuals, over their own health concerns. The social construction of risk leads to the underestimation of symptoms, particularly if they do not significantly impact daily activities. This delay in recognizing symptoms and seeking care can lead to advanced disease stages at the time of diagnosis.	<p>“In rural areas, preventive care doesn’t reach them, and there are insufficient services available. Since these people have a certain mindset, they don’t go to the doctor until they feel sick and are unable to work. I’ve had patients who tell me, ‘My animals, my crops are a priority,’ and they are more dedicated to that than to their own health.” (Health-care professional, March 2023).</p> <p>“We visit the doctor only when we are very sick. We take things for granted, and we never say to ourselves, I am partly to blame, I did this, and I did that. We also normalize a cough because we must deal with everyday life and it’s tough. It is hard for us to admit that we do not take care of ourselves because we prioritize other things such as our job or our family”. (Patient, March 2023).</p> <p>“When I started having symptoms, my mother got sick, and even though I knew something was happening to me, I didn’t seek help because I thought it would be less serious and my main priority was to look after her.” (Patient, March 2023).</p>

(Continues)

**Table 3.** Barriers and facilitators identified in the Mexican population in the context of lung cancer care, description of each category, and quotes that exemplify the theme (*continued*)

Barriers	Description	Verbalizations/quotes example
Family discord and divergent beliefs	Complex dynamics and differing perspectives within the patient's family regarding the management of the patient's health condition can arise. It reflects the divergence of opinions and support levels among family members, which can significantly impact the patient's healthcare decisions and emotional well-being. Support from family and friends initially fosters encouragement, but negative comments over time may lead to abandonment or resistance to treatment. The concept of family as a source of support is challenged when some family members show disinterest or indifference, becoming an additional barrier to continuing treatment.	"My family has not been able to fully understand my situation. They even say it is better not to take her to the hospital, they are only going to torture her without major benefits. We are 8 siblings and most of them believe the effort is worthless, and to be honest I only receive support from my niece. I often say to myself, 'if we don't try, we'll never know'. At first, some relatives gave me some support, but as time went by, they flew away, they wanted a normal life and we feel alone because the road is very long." (Patient, March 2023).
Time constraints and thorough patient examination	Limited time for conducting thorough medical histories at the primary care level hinders early diagnosis of lung cancer. General practitioners may overlook or misdiagnose lung cancer symptoms due to time constraints, resulting in delays in seeking appropriate specialized care.	"To be absolutely honest, we don't have enough time to examine our patients thoroughly. Most of the time, we only have roughly 15 min to perform the check-up because we have another patient waiting outside; pregnant woman, injuries, etc. Therefore, we do sometimes fail to explore more and send patients to a second level, we must be more suspicious from the very beginning". (Health-care professional, February 2023).
Lack of medical training	Insufficient training and knowledge among general practitioners lead to delayed or missed diagnoses. General practitioners may not consider lung cancer as a possibility and may treat symptoms as unrelated conditions (flu or musculoskeletal injuries).	"Look, there is not so much dissemination about lung cancer because it is not one of the main types of cancer. But I also think that many general practitioners delay diagnosis because we don't have the proper knowledge or training. I try to be up-to-date, and if I have any doubts, I consult a pulmonologist, not underestimate the case, and try to refer the patient to the specialist." (Health-care professional, March 2023).
		"I went to the health center for my cough, this was in January 2020. They told me it was just the flu and gave me cough syrup. Then in March, they even tested me for COVID-19, but it came back negative. Months went by, but I kept losing a lot of weight, and I couldn't work anymore. I reached a weight of 50 kg and was very weak when the pneumologist saw me." (Patient, March 2023).
		"At both, the primary and secondary levels of care, biopsies are not performed, and there are not enough trained doctors who can differentiate lung cancer because they lack the knowledge. There are only a few bronchoscopies being conducted due to the insufficient number of specialists." (Health-care professional, March 2023).
Disruptive patient journey	Patients may resort to seeking both public and private healthcare, to expedite diagnosis and treatment due to the chronicity of symptoms and worsening condition. Seeking private specialists for diagnosis or explanations not received from general practitioners in public health centers or private clinics is a common approach.	"Doctors told me it was a throat infection, so I took antibiotics. At first, I felt better, but then the symptoms returned, and they would prescribe something else, but it wouldn't go away. I also started experiencing back pain and extreme fatigue until 1 day I felt like I was suffocating, and they rushed me to the emergency room." (Patient, February 2023).
		"I went to three private doctors, first I went to my general practitioner whom I trusted because he had seen my children, but he told me that the cough might be asthma, but never mentioned anything about cancer. Then I went to the SIMI clinics, where they told me it was allergies until I was finally taken to a pneumologist." (Patient, February 2023).

(Continues)

**Table 3.** Barriers and facilitators identified in the Mexican population in the context of lung cancer care, description of each category, and quotes that exemplify the theme (*continued*)

Barriers	Description	Verbalizations/quotes example
		“INER has been amazing, I am very grateful to God and the doctors and nurses, but one has to take action because sometimes, if you wait for public healthcare, 3 or 4 months pass and your cancer grows. I don’t feel that the attention is bad, but at INER, for example, the PET scan was not available, so I had to get it done privately. In my life, every minute counts, and I have always tried to find an alternative.” (Patient).
Reduced workforce	A critical shortage of adequately trained medical professionals leads to delayed lung cancer diagnoses and limited access to essential procedures like biopsies and bronchoscopies.	“At both, the primary and secondary levels of care, biopsies are not performed, and there are not enough trained doctors who can differentiate lung cancer because they lack the knowledge. There are only a few bronchoscopies being conducted due to the insufficient number of specialists.” (Health-care professional, March 2023).
High patient demand and insufficient diagnostic infrastructure	The high number of patients seeking services at tertiary-level institutions leads to increased waiting times for appointments and diagnostic studies. This influx of patients can overwhelm the healthcare system, affecting the quality and timeliness of care provided to cancer patients. Health settings often lack the necessary infrastructure for comprehensive diagnostic tests and examinations, such as X-rays and ultrasounds. The absence of essential diagnostic tools delays the identification of lung cancer. Patients may need to seek external services or invest their own resources to access specific tests, leading to additional financial burdens.	<p>“INER has been amazing, I am very grateful to God and the doctors and nurses, but one has to take action because sometimes, if you wait for public health care, 3 or 4 months pass and your cancer grows. I do not feel that the attention is bad, but at INER, for example, the PET scan was not available, so I had to get it done privately. In my life, every minute counts, and I have always tried to find an alternative.” (Patient).</p> <p>“When he arrived at INER his health had worsened already, he was not eating, he was not walking, and they told us that he was in a terminal phase. They only prescribed him tramadol with paracetamol due to the severe pain. They told him that cancer had already metastasized to the colon and kidneys. I think that what delayed us the most was the biopsy because we had to wait for it to be performed. Nowadays I think that maybe we could have sold something, anything really to speed up the process and maybe my husband would be better off.” (Family-caregiver, March 2023).</p> <p>“They delayed some studies like the PET scan, they told me it would take up to 3 months at INCAN, and it’s because there are few machines for a lot of people who need support. I’ll be honest, most of my studies I did privately, outside the institution, and that helped me a lot. But I think many people get lost due to the waiting times because they don’t have the resources to do certain studies privately.” (Patient).</p>
Catastrophic expenditures	Patients from rural areas face significant economic burdens in accessing treatment at centralized urban hospital institutions. The costs of external tests, medications, transportation, accommodation, and meals in Mexico City contribute to barriers in treatment continuity. Some patients can only afford one meal a day due to financial constraints. Transportation under specific conditions and precautions, such as taking flights instead of buses, further increases costs. The economic impact creates imbalances within the family, and some patients and their families may resist continuing treatment due to financial strain.	<p>“Sometimes we spend 3 h going and another 2 h returning. I cannot use the underground, so we take a taxi to INCAN, and it charges us \$600 round trip, and that is because he is a neighbor. But sometimes I do not just go for the consultation; I also go to the laboratory, the pneumology, and the dermatology consultation. They say the treatment is comprehensive, so in 1 month, I have several trips to the hospital, 4 or 5 times, not all on the same day.” (Patient, February 2023).</p> <p>“We do not have enough information about what to do, where to go. Treatments are very expensive, and in my town, people do not really know what to do or where to go. Those of us who have the possibility to go to the city have some hope, but those who do not, they die. Money gives you the opportunity to be cured. If you do not die from cancer, you die from not having the correct treatment or access to the right drugs”. (Patient, February 2023).</p>

(Continues)

**Table 3.** Barriers and facilitators identified in the Mexican population in the context of lung cancer care, description of each category, and quotes that exemplify the theme *(continued)*

Barriers	Description	Verbalizations/quotes example
		“I was lucky enough, because a doctor from Oaxaca who is very humanist, helped me, he moved quickly and thanks to him that’s how I entered the protocol. In my community people sell their lands, cattle, or other belongings to pay for the treatment, and if they run out of money, they are already presumed dead, because it is difficult to pay for the treatment. I think that doctors are available, but it is a reality, if you don’t have money, you cannot ask for help”. (Patient, March 2023).
		“My backbone really hurts, so I cannot travel by bus, I must fly to Mexico City and this implies elevated costs as you may imagine. One of my brothers helped me, but the last time he was there for 10 days, and we barely ate, when I came back, I was all swollen and very tired”. (Patient, March 2023).
Bureaucratization	The bureaucratic processes in the healthcare system can be time-consuming and frustrating for patients seeking treatment. Administrative hurdles may delay access to essential tests and therapies, causing unnecessary anxiety and stress for patients and their families.	“There are people who arrive with luggage and sleep at INER, we all understand the high demand for services, and that is something that impacts me a lot and saddens me even more than my own treatment because the waiting hours are terrible at INCAN. Sometimes you spend the whole morning for a consultation and don’t leave until 3 in the afternoon.” (Patient).
Underreporting and misdiagnosis challenges	Lack of regionalized care and awareness campaigns contributes to the underreporting and delayed diagnosis of lung cancer.	“According to our knowledge, the incidence of lung cancer appears to be less frequent in the country, but there is underreporting because, for example, a general physician who doesn’t know what lung cancer is, might think that the patient died from a chronic obstructive pulmonary disease, pneumonia, or another respiratory disease. This situation leads to inadequate registration.” (Healthcare professional, March 2023).
Biographical disruption and role adjustments	The illness and its treatment disrupt the lives of both patients and their family environment. Changes in roles and dynamics within the family occur, and introspection leads to adjustments in life goals and attitudes toward others. Family caregivers take on new roles and responsibilities to support the patient’s treatment journey. Some patients find a renewed focus on family and attempt to make up for lost time with loved ones.	“Many things have changed. Now my wife is the one who goes to work, and I stay at home taking care of the children. I play board games with them, watch movies, and review their homework. I am more present for them; I want to make up for lost time.” (Patient, February 2023).
		“Sometimes I ask my patients: How come you stopped coming here for your treatment, then they tell me, ‘I don’t have anyone to leave the children with’ or ‘my husband is working’, it is tricky because a disease changes your routine and you have to adjust in many different ways”. (Healthcare professional March 2023).
Limited mental health support	Patients and family caregivers may face barriers in accessing professional mental health support due to time, money, and energy constraints. Many choose to address mental health through religious beliefs and support from religious institutions, considering them helpful in navigating difficulties during cancer treatment.	“Actually, I wouldn’t seek support for mental health, to be honest. What I need is treatment, that’s all. I feel supported by my family and the church I attend.” (Patient, February 2023).
		“Some of us may say that we don’t need help, but that’s not entirely true. I would love to talk about some of my problems, but to be honest, once I leave the hospital, I just want to get home and rest. I would say I’m not against receiving therapy but sometimes I don’t have time or stamina to focus on other stuff.” (Patient, March 2023).

*(Continues)*

**Table 3.** Barriers and facilitators identified in the Mexican population in the context of lung cancer care, description of each category, and quotes that exemplify the theme (*continued*)

Barriers	Description	Verbalizations/quotes example
Family or caregiver's burden	Family caregivers, often female relatives, assume a significant role in accompanying and supporting patients throughout their treatment journey. They act as a "guardian" and are responsible for organizing appointments, providing emotional support, and acting as communicators between the patient and healthcare professionals. The role of family caregivers can be emotionally and physically taxing, leading to stress and anxiety.	"One day I started feeling unwell, I began to feel dizzy, and my blood pressure skyrocketed. The doctors told me that it was probably due to stress and advised me to see a psychologist. But I asked them: 'When? And with what money?'. I used to tell people that nobody knows what I'm going through. If they asked me, I had already touched a part of hell because I couldn't sleep, due to the travels, taking him to his appointments. I couldn't detach myself from him because I saw him writhing in pain. We decided that our child would go to live with my parents because we didn't want him to see us like that. Then I thought, it's not just my mental health anymore, it's my blood pressure. I thought, 'what if we both die, who will take care of my child?'" (Family caregiver, February 2023).
Doctor-patient relationship	Some patients reported encountering doctors who lacked effective communication skills and appeared cold and distant when delivering diagnoses. This lack of empathy can make patients feel abandoned and affect their emotional well-being. A positive doctor-patient relationship is crucial for providing the necessary support and guidance throughout the cancer journey.	"Sometimes the doctors give you the basics, they give you the diagnosis, but they don't provide any further information. It feels cold and insensitive. The journey of treatment begins, and you don't know what to expect, you feel alone." (Patient, March 2023). "Usually, doctors don't listen to us, or for example, they talk to our relatives in private, so we feel anxious and dumb. I think maybe they could be a little bit more straight-forward with their explanations and tell us things in an honest and easier way so we can understand what's going on". (Patient, February, 2023).
Treatment's secondary effects	Weariness associated with the treatment itself, such as radiotherapy or chemotherapy, may also lead to resistance in continuing with the treatment.	"Chemotherapy sessions do knock you down. Sometimes you already want to throw in the towel and quit, but you must not let yourself down, depression is an important obstacle, and you must stay active as much as possible. I do my own things, I get up and try to do my own daily routines, I don't limit myself, I try to live my life normally". (Patient, February 2023).
Misguided improvement and patient drop-outs	Some patients may feel overly confident in the initial success of the treatment, leading to a false sense of improvement and abandonment of treatment.	"We have seen patients who arrive in a very critical condition, start feeling better with the treatment, and then abandon it, thinking they are much better. That is dangerous and something we need to emphasize." (Health-care professional, March 2023).
Stigmatization and fear of compassion/pity	Patients may use synonyms or avoid naming their condition as cancer when discussing it with others to avoid stigmatization and pity. The fear of being perceived as weak or helpless may lead to selective disclosure of the diagnosis only to trusted individuals.	"Now I dare to share my problem with more people, but to this day, I haven't told some family members and friends about my problem. I don't like them seeing me like this and then feeling sorry for me." (Patient, February 2023).
Facilitators	Description	Verbalizations/quotes example
Facilitators/ Navigators	The presence of a "navigator or facilitator" assists patients in accessing specific tests and confirms the suspicion of lung cancer, guiding them through the process. Facilitators or navigators act as referral agents and help patients access specific hospital institutions more quickly. They also suggest patient participation in research protocols and enable institutional connections for those with limited resources from rural contexts. The support from facilitators is particularly beneficial for patients facing socioeconomic problems and non-smoking lung cancer patients.	"A doctor told me about the organization called 'RCV,' they responded quickly, I told them my story, and they said they could get Erlotinib at a lower price, 10,000 pesos when it's much more expensive outside, like 30,000 or even 40,000 pesos." (Patient, March 2023).  "Firstly, the attention should be more regionalized as we lack more centers of excellence in the east, northeast, center, and south of the country, that is why so many patients are currently channeled to Mexico City. I wish there were more possibilities to refer patients. Some doctors only treat in private medicine, but for example, those of us who work in both (the public and private sectors), sometimes we try to support patients who don't have a strong financial capacity. It would be much better if these patients wouldn't depend upon a facilitator, but

(Continues)

**Table 3.** Barriers and facilitators identified in the Mexican population in the context of lung cancer care, description of each category, and quotes that exemplify the theme (*continued*)

Facilitators	Description	Verbalizations/quotes example
		instead, receive proper help from a fair and efficient system. It is indeed great to be able to support patients when we can, but I genuinely believe that if a general practitioner could have the tools to know how to attend to suspect and channel cancer patients, it would be far easier." (Health personnel, March 2023).
Participation in research protocols	Participation in research protocols provides an alternative for patients to receive treatment, especially due to the high costs of medications like oral chemotherapy pills. The funding from pharmaceutical companies covers treatment costs, but patients need to cover other expenses like transportation and accommodation. Despite the challenges, patients view research protocols as an essential option for accessing treatment and extending their life expectancy.	<p>"I am in a protocol that finances the entire treatment thanks to the pharmaceutical company Janssen because the pills cost 130,000 pesos, or so I've been told. Imagine if one had to pay for them out of pocket, I wouldn't be here anymore." (Patient, March 2023).</p> <p>"When I entered INCAN, I couldn't even lift up a pen. I was very skinny back then, nowadays, I greet the police at the entrance and tell them, 'don't you recognize me? I'm still here, and if I'm still alive, it's because of the protocol'. They literally gave me a life expectancy of 5 more years, so I stick to the protocol and everything they tell me to do, because I trust them." (Patient, March 2023).</p>
Non-profit organizations support	Facilitators or navigators recommend seeking support through non-profit organizations like "RCV." These organizations provide assistance through donation or sale of oncology medications at a reduced cost, support with transportation expenses to Mexico City, and in some cases, food supplies. These organizations play a crucial role in helping patients access affordable care and resources during their cancer journey.	<p>"A doctor told me about RCV, they responded quickly, I told them my story, and they said they could get Erlotinib at a lower price, 10,000 pesos when it's much more expensive outside, like 30,000." (Patient, March 2023).</p> <p>"There are moments of need for the patient that are crucial to continue with the treatment, and there is where foundations and associations have a meaningful role, managing resources to absorb some of these costs." (Health professional, March 2023).</p>
Family or caregiver's perseverance and advocacy	This entails unwavering commitment, advocacy for medical attention, emotional support, and resourcefulness. Caregivers persistently motivate loved ones, navigate the healthcare system, and overcome resistance, playing a pivotal role in the well-being and healthcare journeys of their family members facing health challenges. The catalyst, a friend or family member, maybe the one who motivates and supports the patient in seeking medical attention when needed.	<p>"Then he told me, 'I don't want to live anymore, whatever has to happen will happen, so better save money for the burial'. Then, I replied, 'I know it's tiring, but you have to face a disease like this, we won't ever let you down'. I said to him, 'you're going to have to put up with it'. As a family member, it's extremely important to constantly motivate them. At that time, he had 10 radiotherapy sessions and couldn't eat." (Family caregiver, March 2023).</p> <p>"He was always healthy and in good shape, he did not get sick easily, and that is why he never really paid attention to us when we told him that we saw him deteriorating. We constantly reminded him to visit a doctor, but it was only until a nephew decided to take him involuntarily that he attended. He was in fact deceived because they told him that the consultation was for his mother and not for him." (Family-caregiver, March 2023).</p> <p>"My granddaughter was the one who told me, 'I see you more tired, grandma. Have you been to the doctor? That's strange.' And they took me to a specialist who already suspected my condition." (Patient, February 2023).</p> <p>"He was always healthy, and rarely got sick, and that's why he dismissed our concerns when we told him he didn't look well and should see a doctor. It was actually a nephew who took him, deceiving him by saying they were going to his mother's appointment." (Family caregiver, March 2023).</p>

RCV: Respirando con Valor; INCAN: National Cancer Institute; INER: National Institute of Respiratory Diseases.

and emotional well-being positively. However, complex dynamics and differing perspectives within the patient's family can arise, leading to varying levels of support and even abandonment or resistance to treatment. Thus, creating awareness of the disease and supporting the patient by mediating with the family might prove useful to reduce negative outcomes.

Although family members can also act as facilitators, this can be emotionally and physically taxing. Family caregivers, often female relatives, assume significant roles in supporting patients throughout their treatment journey. Support for family members is advised in addition to supporting the patient's mental health.

### **Health system barriers and facilitators**

Results show the health-care system itself is a barrier to lung cancer care. For instance, limited time for conducting thorough medical histories at the primary care level can result in overlooked or misdiagnosed symptoms. In addition, high patient demand and insufficient diagnostic infrastructure were called out, as well as a reduced workforce to provide care to lung cancer patients. Thus, the health system necessitates a robust enhancement of diagnostic infrastructure at the primary and secondary levels of health care<sup>3</sup>. In addition, public policies must be formulated to decentralize health-care services<sup>3,5</sup>, ensuring equitable access to quality care for all patients. Initiatives such as telemedicine<sup>42</sup> can be leveraged to bridge the gap and provide specialist consultations and support to primary care physicians in underserved regions. This approach is likely to result in better patient survival rates and alleviate the financial burden that families often face in accessing health-care services<sup>1</sup>.

Establishing seamless communication channels between primary care centers and specialized oncology institutions can expedite the referral process, thereby reducing the time between symptom presentation and definitive diagnosis<sup>43</sup>. Such coordination is particularly crucial in rural areas where access to tertiary health-care facilities may require additional logistical arrangements<sup>3</sup>.

Results from our study show it is essential to urgently address the ethical, economic, and emotional conflicts arising from the need for institutional exclusivity for patients with social insurance who want to receive lung cancer treatment at specialized third-level institutions from the Ministry of Health. By encouraging patients to relinquish their social security benefits to access free treatment at these institutions, additional barriers to oncological treatment adherence are created, causing

emotional and financial stress. Thus, policies aiming to reduce catastrophic expenditures should be put in place for all population groups.

Patients often view research protocols as essential alternatives for accessing treatment. However, pharmaceutical companies and research institutions must adopt a comprehensive approach to patients by covering expenses such as transportation, lodging, and meals for both patients and their family caregivers during research protocols. This will help overcome socioeconomic barriers, leading to improved greater coverage and equity.

Patients navigated logistical and administrative issues in the health system that hindered their care. Similar to the literature, bureaucratic processes within the health-care system became time-consuming and frustrating for patients, causing unnecessary stress<sup>5</sup>.

A critical finding of this study is the role of medical navigators or facilitators in guiding patients through the health-care system and facilitating access to timely diagnosis and treatment. Their involvement becomes crucial, especially for patients from rural or semi-urban areas. These individuals act as referral agents, helping patient's access specific hospital institutions more quickly and suggesting participation in research protocols.

Patient navigation programs can also help in reducing delays in lung cancer care<sup>44</sup>. These can help make the patient journey less disruptive in the context of a fragmented health system. They can also have a history of helping patients to have access to mental health services or peer groups that might mitigate the fear of diagnosis, treatment, and death. Hence, the navigator or facilitator role can significantly improve patient outcomes<sup>45-50</sup>.

It is imperative to recognize the need for ongoing research in this field. Continuous investigation into the barriers and facilitators faced by lung cancer patients in Mexico will not only deepen our understanding but also inform the development of targeted interventions and policies. Engaging with health-care professionals at various levels of the health-care system will also be essential to inform policy changes and improve the overall quality of care for lung cancer patients.

### **Limitations**

While this study has made significant strides in understanding the barriers and facilitators faced by lung cancer patients in Mexico, it is important to acknowledge that it may not capture all possible factors

influencing this complex phenomenon. Factors such as geographical variations, socioeconomic disparities, and differences in health-care accessibility might contribute to variations in the barriers and facilitators experienced by different individuals and communities.

Although interviews conducted through telephone may have limitations, the quality of the data that emerged depends on the expertise of the interviewer<sup>51-53</sup>. This was chosen as the preferred data collection method and as a pragmatic choice necessitated by logistical challenges surrounding patient transportation and the limited access to Internet connectivity among participants. This approach has been previously used in complex settings<sup>21,52-54</sup>.

## Conclusion

Lung cancer patients interviewed in Mexico face barriers to care such as: feeling unworthy of treatment, financial toxicity, lack of awareness of cancer symptoms, and poor symptom recognition and interpretation. Barriers such as poor relationships with health-care providers, and low levels of trust in the health-care system were not found.

Caregivers feel burdened, while also continuing to advocate and persevere in reaching access to diagnosis or treatment. However, doctors do not appear to have an advocating role. Similarly, non-for-profit and patient navigation programs seem to facilitate the patient's journey, and participation in research protocols seems to be an alternative that increases access to treatment.

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## Conflicts of interest

Elysse Bautista-González declares no conflicts of interest. However, it is noted that she was granted the

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## Author contributions

Elysse Bautista-González: conceptualization, methodology design, formal analysis, translation, writing-original draft, review, and editing. Gunther Adolfo Hasselkus-Sánchez: methodology design, data collection, formal analysis, writing-original draft, review, and editing.

## Ethical considerations

**Protection of humans and animals.** The authors declare that no experiments involving humans or animals were conducted for this research.

**Confidentiality, informed consent, and ethical approval.** The study does not involve patient personal data nor requires ethical approval. The SAGER guidelines do not apply.

**Declaration on the use of artificial intelligence.** The authors declare that no generative artificial intelligence was used in the writing of this manuscript.

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