

Care pathway of patients living with lung cancer

Rafael Turano Mota¹, Érika Ferreira Martins¹, Maria Aparecida Vieira¹, Simone de Melo Costa¹

1. Universidade Estadual de Montes Claros, Montes Claros/MG, Brazil.

Abstract

This article analyzes the feelings and difficulties of lung cancer patients and their families regarding diagnostic and therapeutic itineraries. This is qualitative research with focus group of patient/family dyads. Two categories of analysis stood out: 'Pathway start and Diagnosis' and 'In search of treatment: barriers'. The difficulty of diagnosis is discussed due to the lack of infrastructure of services, scarce financial resources of patients, inadequate public health network and unpreparedness for diagnosis. After diagnosis, we present the path in search of treatment and the financial, geographical, structural and work process barriers in public health. Patients in small municipalities or rural areas face more difficulties in accessing health services. We conclude that the care pathway in the public sector is influenced by health inequalities and vulnerabilities, reflecting less access to services and delayed diagnosis and treatment of the disease.

Keywords: Health status disparities. Lung neoplasms. Chronic disease. Health services accessibility. Public health.

Resumo

Percurso assistencial de pacientes convivendo com câncer de pulmão

Este artigo analisa dificuldades enfrentadas por pacientes com câncer de pulmão e familiares em seu itinerário diagnóstico e terapêutico. Trata-se de pesquisa qualitativa, baseada no método de grupo focal, de que participaram pacientes e familiares. Das falas dos participantes, destacam-se duas categorias de análise: "início do percurso e diagnóstico" e "em busca do tratamento: barreiras". Discute-se a dificuldade de diagnóstico causada por problemas de infraestrutura dos serviços, pela escassez de recursos financeiros dos pacientes, pela inadequação da rede de saúde pública e pelo despreparo profissional. Após o diagnóstico, apresenta-se o percurso em busca do tratamento e as barreiras financeiras, geográficas, estruturais e de processo de trabalho na saúde pública. Resultados mostram que pacientes de pequenos municípios ou da zona rural se deparam com mais dificuldades para acessar os serviços. Conclui-se que o percurso assistencial, no setor público, é prejudicado por desigualdades e vulnerabilidades em saúde que se refletem em dificuldade de acesso e demora no diagnóstico e tratamento da doença.

Palavras-chave: Disparidades nos níveis de saúde. Neoplasias pulmonares. Doença crônica. Acesso aos serviços de saúde. Saúde pública.

Resumen

Recorrido asistencial de pacientes que conviven con cáncer de pulmón

Este artículo analiza las dificultades enfrentadas por los pacientes con cáncer de pulmón y sus familiares en su recorrido diagnóstico y terapéutico. Se trata de una investigación cualitativa, con base en el método de grupo focal, en el que participaron pacientes y familiares. De los diálogos de los participantes, destacan dos categorías de análisis: "inicio del recorrido y diagnóstico" y "en busca de tratamiento: barreras". Se discute la dificultad de diagnóstico causada por problemas de infraestructura de los servicios, por la escasez de recursos financieros de los pacientes, por la inadecuación de la red de salud pública y por la falta de preparación profesional. Tras el diagnóstico, tiene lugar el recorrido en busca del tratamiento y las barreras financieras, geográficas, estructurales y de proceso de trabajo en la salud pública. Los resultados muestran que pacientes de municipios pequeños o de la zona rural se enfrentan a más dificultades para acceder a los servicios. Se concluye que el recorrido asistencial, en el sector público, está perjudicado por desigualdades y vulnerabilidades en salud que se reflejan en dificultad de acceso y retraso en el diagnóstico y tratamiento de la enfermedad.

Palabras clave: Disparidades en el estado de salud. Neoplasias pulmonares. Enfermedad crónica. Accesibilidad a los servicios de salud. Salud pública.

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Lung cancer patients present a high mortality rate¹. Delay in diagnosis is one of the challenges faced in Brazil². In addition, the inequalities of access to diagnosis and therapy between the public and private system are notable³. Brazilian regional inequalities generate differences in access to services for timely diagnosis and adequate treatment⁴. Thus, the pathway taken in searching for treatment is marked by barriers that start even before the diagnosis⁵.

Although efforts to strengthen the cancer care network are recognized, geographic, economic and social barriers still prevail. To face these barriers, it is necessary to plan strategies that provide timely access and comprehensive care⁶. Due to this reality, this study posited the question: how do people with lung cancer and their families experience the diagnostic and therapeutic itineraries?

Understanding how these itineraries and feelings are experienced allows us to detail events and attitudes aimed at maintaining life, contributing to health care consistent with the reality of people with cancer⁷. In this context, this article encourages bioethical reflection on health inequalities and vulnerabilities, focusing on the care pathway in the public health system, on the organization of care and on oncology practices. The objective is to understand the feelings and difficulties experienced by lung cancer patients and their families in the diagnostic and therapeutic itineraries

Method

To understand feelings and difficulties arising from diagnosis and therapy itineraries, that is, the care pathway, we interviewed people with lung cancer and family caregivers, using the qualitative, dialectical, descriptive-exploratory research method⁸. Patients treated in a reference hospital located in northern Minas Gerais, Brazil, accompanied by caregivers/relatives, participated in the study. Data were collected in 2018.

Lung cancer patients, over 18 years old, of both genders and with any level of education, along with their family companions (caregivers), were included. Patients without physical conditions to participate in the research were excluded. People residing in the hospital's host city (a hub city in the northern region of the State

of Minas Gerais, with about 405,000 inhabitants) and residents of small rural municipalities in the northern region of Minas Gerais were invited to participate in the study. All patients were treated at the reference hospital by the Unified Health System (SUS).

Invitation was made by one of the researchers, the patients' physician. All people invited agreed to participate in the study. The sample was intentional (non-probabilistic), and the number of participants (n=10) followed the recommended in the literature for focus groups, between six and 15, to allow effective engagement in the discussions. The focus group technique was adopted because of its potential to investigate topics of an intimate nature, such as personal experiences regarding the lung cancer diagnosis and treatment⁹.

The meeting started with the request: "Talk about your experiences, from the suspected disease to the treatment." New questions were asked during the meeting, based on the participants' answers, keeping the focus on the care pathway, from diagnosis to therapy. Researchers did not interfere with pre-established concepts. For this purpose, the questions "How did you feel?", "Could you explain more about this?" were used.

The focus group meeting lasted about 90 minutes, in a room prepared to receive group techniques¹⁰. Each patient and family member signed an informed consent form and authorized the recording. The search for information took place until data repetition, as proposed by the discourse analysis¹¹. The context of speech production, recorded in the field diary, was also considered, as well as the historical and material conditions of the studied scenario^{8,11}.

Results and discussion

The focus group consisted of five patient-caregiver dyads, residents of the hospital's host city or of small rural municipalities. This variety of places of residence allowed to explore inequalities and vulnerabilities related to geographic territories.

Questions about the therapeutic itinerary allowed to reflect on access to services, the resoluteness of care and SUS users' common knowledge. The itinerary describes the care network pathway, the diagnosis definition and

everything related to the disease¹². From this perspective, two analytical categories were highlighted in the speeches: “pathway start and diagnosis” and “search for treatment: barriers,” with their respective subcategories (Chart 1).

Chart 1. Analytical categories and respective subcategories

Pathway start and diagnosis	<ul style="list-style-type: none"> - Sensations and suffering manifested by signs and symptoms of the disease - Search for diagnosis - Finally, the diagnosis
Search for treatment: barriers	<ul style="list-style-type: none"> - Financial and geographic barriers - SUS structural and work process barriers

Pathway start and diagnosis

This category describes the care pathway start after emergence of signs or symptoms of the disease. Respondents talked about the delay and insufficient preparation of professionals to diagnose such a complex disease, the lack of service infrastructure and the family’s financial resources, and the inadequacy of the service network regarding the seriousness of the pathology. The category also presents the sufferings that permeated the diagnostic itinerary.

Sensations and suffering manifested by signs and symptoms of the disease

This subcategory presents experiences related to symptoms or signs of body illness prior to diagnosis. There was a consensus on emergence of persistent cough: “I coughed day and night and (...) it got worse” (E1). The cough was extremely strong: “I got very sick and felt like throwing up” (E2); “coughing, I had shortness of breath” (E3). Medication was prescribed: “they prescribed a cough medicine” (E4), but the perception was that “the body was getting used to the medication” (E2). Besides the cough, the patients reported of body pain, tiredness and a feeling of despair: “body aches at the end of the day” (E1); “(...) I started getting tired, I walked a little and got tired” (E2); “(...) I was desperate, it was a terrible tension” (E5).

Changes in routine, triggered by illness, can generate depressive crises, insecurity, fear of death, job abandonment or change, which can lead to financial losses, as well as other concerns and emotional dysfunctions¹³. Symptoms such as fatigue, apathy and psychomotor slowness were also related to lung cancer¹⁴. From this perspective, professionals must develop a qualified listening and consider the patient’s complaint to reach the diagnosis as soon as possible, minimizing the suffering of this itinerary.

Search for diagnosis

This subcategory describes experiences in searching for diagnosis. The body increasingly expresses itself, and the patient seeks specialized consultations. There was delayed recognition of signs and symptoms of the disease for the diagnosis of lung cancer for all participants, who pointed out weaknesses in health services at different levels of care: “I went to some [health] units and to a hospital. (...) they gave me a lot of corticoid and my situation got worse (...) And I was always looking for doctors (...) But none of them requested exams. And it made my situation worse” (E1). Patients felt insecure: “Because I’m in the dark. (...) You need a diagnosis to receive treatment” (E1).

Another study informs that, in the initial phase of a medical consultation, it is common for patients not to be given an opportunity to express themselves openly¹⁵. Professionals often limit the amount of information requested and adopt closed questions that control the patient’s speech. Thus, the doctor cannot identify all the patient’s concerns. It is not enough to register complaints, it is also necessary to understand the perspectives on the disease and the feelings it triggers¹⁵.

With the health condition worsening, exams begin to be requested, but the care pathway difficulties remain: “I walked a lot, going from place to place all the time, you know? Sometimes, I scheduled an exam, it’s not here, it’s there” (E4); “you are put on the back burner” (E1). It can be inferred, therefore, that there are communication failures in the service network, since patients do not have basic information, such as the correct address to undergo the required exams.

The fragmentation of SUS network must also be considered, which generates difficulties in access, low quality of services, inadequate use of



resources, overpriced costs, and user dissatisfaction. This fragmentation results from the lack of coordination between the different levels and places of care in the network. For those who use the health system, fragmentation is perceived in the lack of access, the discontinuity of care and the mismatch between services and the patients' needs¹⁶.

Thus, patients wander through the services in search for a diagnosis. Patients reported searching for consultations and exams in the private service as a way to speed up the process in view of the lack of specialists and bureaucratic slowness in the public network: “[the doctor] *immediately referred me to the pulmonologist, but he said that there was none there (...). We spent a lot (...). On taxi service and also paying for the exam*” (E4); “*everyone is resorting to the private [service]*” (E1).

According to the National Humanization Policy, welcoming citizens, respecting their rights and health needs should be guaranteed in an equal manner. According to this policy, welcoming is essential to ensure access to services, which in turn must be resolute¹⁷. However, users face difficulties in accessing healthcare in small towns. This is the reason why the World Health Organization recommends implementing policies for professionals to settle in rural areas¹⁸. In Brazil, the Federal Council of Medicine, in the Medical Demography survey, showed the inequality between Brazilian macro-regions, with unfavorable results for small municipalities¹⁹. Programs aimed at internalization have been proposed, such as the *Mais Médicos* program, and it is important to assess their contributions to reducing regional disparities²⁰.

Broken equipment also justifies the search for the private sector to do exams requested in the public network. Also with regard to exams, patients reported that the original documents have not been returned by the Municipal Health Department: “*Why did [the Municipal Health Department] return the exam photocopy? And it didn't schedule [an appointment]. We did private [exam] (...) to show it to the doctor*” (E2). This is a flaw in the structure of the services, because, according to ethical principles and legally established rights in Brazil, the medical records belong to the patient.

On the pilgrimage in search for a diagnosis, patients also sought to consult with specialists from the private sector, such as gastroenterologists: “*I didn't even know it was in the lung*” (E1). Private

consultations, however, are often limited to prescriptions and referrals: “*For every situation I mentioned that I was in pain or that I was weak, he would give me a medication. (...) I got very sad when leaving the place because no exam was requested. (...) I went immediately to the pharmacy (...) he referred me to the cardiologist*” (E1).

The excerpt refers to excessive and unnecessary medicalization, which seeks to be fought by quaternary prevention. Quaternary prevention requires transparency and analysis of what should or should not be indicated, as well as the ability to resist pressure in the field of emotions and economic interests that lead to the risk of over-medicalization²¹. One participant commented on failure in patient welcoming, suggesting the need to invest in human training to develop the professionals' skills and competences in the relational and communicational area: “*I got there telling everything (...). And he says I'm anxious? (...) There are moments in life that we get anxious, precisely because of poor health (...) [and] lack of attention from doctors*” (E1).

Communicating is a basic human activity that legitimizes social relations. It is a process that creates and recreates information, whether transmitted verbally or not. Through communication, one can understand the other's feelings and emotions, fears and anxieties²². However, one of the participants highlighted failures in providing essential information, such as guidelines on how to access medication: “*And he prescribed some very expensive medicines. (...) I said: 'Hey, doctor, I've heard these medicines are provided by SUS.' [And the professional answers:] 'No, they are too strict. We write the prescription, it goes back and forth, back and forth, even if they pay me I don't do it'* [sic] (E2). The statement is from one of the patients living in the rural area, who are usually those who most lack basic information on access to health¹⁹.

Finally, the diagnosis

This subcategory portrays the long-awaited – albeit sad – diagnosis. The search ends, but the trajectory is long, painful, and generates anxiety: “*I was a bundle of nerves! I said: 'Hey, doctor, you don't need to deceive me'*” (E5); “*I wanted the diagnosis faster, and the doctor couldn't give it*” (E4). At this stage, patients recognized that the time had come to start treatment: “*I sat there,*

crying to blow off steam. But, in the face of that situation, I cheered up. (...) Well, first thing, where to start, which doctor I'm going to see, which specialist doctor" (E1).

The diagnosis is surprising, but the long journey seems to prepare and strengthen the patient to receive the news: *"When [the doctor] talked about the disease (...) I felt lost. We had already been almost sure, [because] the doctors said (...) "We are going to do more exams, we are going to do more complex exams" (E4).* In addition to the time spent living with the symptoms, excessive medication, consultations with specialists and the difficult pilgrimage through the services stood out on the pathway to diagnosis: *"I had been taking medication, you know, and seeing several doctors. (...) I imagined [it was cancer], because it didn't even scare me" (E2).*

Late diagnoses, low frequency of patients receiving therapy with curative intent and inadequate treatments reflect the significant delay and inefficiency of the diagnostic process in the public health system². When it is given, the diagnosis causes emotional damage: *"there was psychological and emotional exhaustion" (E1).* Between the lines, we observed a resistance in pronouncing the word "cancer": *"how we say it? That thing in the lung... (...) the words escape me" (E1); "when I heard those words..." (E4); "I already had it in my mind, that I already had that problem" (E3).*

People refer to cancer as "this disease," "disease" or "problem," which shows the stigma that still surrounds the topic, probably due to the high mortality rate. According to the literature, anxiety, fear of death, uncertainty about the cure or health improvement are constant feelings in the process of cancer diagnosis and treatment, especially in the terminal phase²³. The patient begins to perceive death as much closer, since, in a generalist and pessimistic view of society, the cure is considered rare and difficult to occur²⁴.

The diagnosis of cancer, the complex treatment and the challenges of survival intensify the psychological symptoms, impairing the patients' adaptation to the disease²⁵. From this perspective, hope is the most important psychological factor after diagnosis is confirmed. It is the feeling that most contributes to maintaining quality of life, and can be stimulated by professionals²⁶. Family members, who become caregivers, generally have

a lower level of hope, due to the pressure of day-to-day care²⁷. It is also necessary, therefore, to prioritize interventions that avoid hopelessness among caregivers²⁶.

Informing the diagnosis is a difficult task. The moment is delicate and requires communication skills: *"The doctor, she was shaking, two doctors talked to me. The day before, they already knew it and didn't have the courage to tell me. Then she called my husband and arranged for us to go to a private room at the hospital. And it was kind of difficult, even though the doctors are well prepared" (E1).*

The lethality of lung cancer, usually with late diagnosis, raises feelings of impotence and failure. In another study with cancer patients, there was a consensus on the importance of communication, which can alleviate symptoms, reduce anxieties and bring calm, comfort and balance to patients. Inadequate communication, in turn, brings anguish, fear and anxiety. Thus, professionals must position themselves properly when faced with the patients' and family members' pain²⁸.

Communication difficulties are common when it comes to issues involving illness and death. To refer to these difficulties, the term "bad news" was used: any information that radically and definitively affects the prospects for the future of the recipient²⁹. More recently, however, the term was replaced by "difficult news": information that, directly or indirectly, has negative results in the patients' and families' lives³⁰.

In the case of cancer, it is clear that, in addition to the stigma that the word carries, there are the professionals' limitations regarding the preparation to communicate the diagnosis³¹. For this reason, protocols to communicate difficult news have been elaborated³⁰. Such protocols indicate that the professional must consider how the news will affect the patient's well-being, from an emotional, physical and social point of view. Thus, there must be flexibility in revealing the truth, depending on what and how much each one wants to know³².

Search for treatment: barriers

This category describes the course of treatment and the difficulties experienced. As with the diagnosis, also in the treatment, the participants reported (financial, geographical, structural) barriers

generated by problems in the work process and by the fragmentation of the SUS network. One of the interviewees said: *“It was very difficult to get here. Today I am more experienced (...). I know how to look for [service]. But in my city it’s awful”* (E2).

At the treatment stage, there also seems to be failures in communication to inform patients’ rights. The participants’ learning took place over a long and painful journey, full of difficulties. It should be noted, on this point, that Ordinance 876/2013 33 establishes in its article 3 a period of 60 days, counting from the diagnosis and registration in the medical record, to start SUS cancer treatment, whether in surgical, chemotherapy or radiotherapy modalities³³.

Financial and geographic barriers

One of the difficulties in seeking treatment is the displacement from rural areas and other municipalities to health services – an arduous journey, coupled with large expenses. Even though chemotherapy is entirely covered by SUS, there are significant expenses with transportation: *“sometimes we can’t buy anything, because all the money is spent on travelling”* (E4). Another expense concerns the prescribed diet, such as special types of milk to control weight and strengthen the body, in order to withstand the strong medications: *“the doctor sent a report, the health department gives two cans. (...) The consumption is ten cans a month”* (E4).

Social and economic inequalities exacerbate disparities in treatment and access to care. There is a clear relationship between lower socioeconomic status and lower likelihood of receiving treatment for lung cancer³⁴, and it is important that qualitative studies explore the reasons for this correlation, since inequality interferes with patient survival.

Geographical barriers stand out in the reports of patients from rural areas, where misinformation seems to be greater. Patients and family members were unaware of the fact that the municipality provides a car to take users to the reference hospital: *“We live in the countryside, we are disconnected from everything. Only later we’ve learned that the car is available for the oncology patient”* (E4).

The lack of information on how the SUS network works may be due to the scarcity of health services in some municipalities. A study carried out in Rio Grande do Norte, Brazil, found challenging

peculiarities and lack of a basic health unit in small municipalities in the rural area of the state. There are locations 100% covered by the Family Health Strategy, but with lack of service to users due to turnover. Therefore, there are care gaps in more remote municipalities³⁵, which hinders obtaining adequate information about the functioning of SUS oncology services.

In the countryside *“it’s very complicated, because it’s seven kilometers from my house to the bus stop. From the bus stop to the city, it’s 77 kilometers. (...) I have to pay to use a motorcycle taxi. And then I pay to take the bus. Then, I get off the bus and have to pay for another motorcycle taxi to go to my sister’s house. It’s difficult. Even more [for] a person who sometimes does not feel well”* (E2). In the same sense, another patient reported: *“We have the benefit of using the Health Department’s car, but until I get there I have to pay 40 reais for a taxi. Forty [reais] to get to the city and forty to go home”* (E4).

In addition to costs, time is another factor pointed out by the participants: *“We get up (...) four o’clock in the morning to get there”* (E4). And the difficulties become even more intense in the rainy season: *“The car doesn’t reach the door, it gets stuck. We have to walk a bit”* (E4). Finally, there is still the complication of bureaucracy in the exam procedures: *“You have to register it! Then, a week goes by, as we live in the countryside. They request the others [exams] (...), and, then, more expenses”* (E2).

The results of this study are in line with the literature, which also points out difficulties in moving from the residence to the specialized service, long periods of absence from home, financial difficulties, fear of the unknown and insecurity, lack of information about the clinical condition and changes in life habits as a result of the treatment³⁶.

It is important to understand the health demands of different social groups in different territories. The health of users in rural areas must be evaluated more broadly, beyond the disease. Among the challenges of public policies, we find: improve the quality of life of residents of remote areas by offering services and generating income, boosting education and providing adequate conditions for housing and basic sanitation. All these challenges determine access to health services³⁷.

SUS structural and work process barriers

The speeches also reveal SUS network structural and work process weaknesses. As already mentioned, deficiencies in the system led patients to resort to private healthcare. Broken equipment is an example of an infrastructure issue: *“CT scans (...), broken equipment. (...) Scintigraphy, I had to pay for a private exam. Every three months we undergo exams. And when the doctor request them (...) there is no equipment”* (E1). Sometimes, there is also lack of medication: *“Then you have to wait, go back, or come back the next day”* (E1).

Another study showed that the time for the patient to be referred to the specialized sector is very long, often leading to lack of cancer treatment³⁸. Fragmented systems are organized by isolated points of care, to the detriment of continuous care to people's health. Thus, primary care does not have fluid communication with secondary care and, therefore, these two levels also do not communicate with the tertiary level or with support points of the system. As a result of this fragmentation, primary health care does not fulfill the role it should play, as a coordinating center of care³⁹.

The request for exams is frequent and increases the barrier: *“[for those who] live on a salary, four CT scans at once is a lot! I looked for one, looked for another, I wrote down people's names, until we managed to do them. Then the doctor said: ‘But they should have been done on that date, it is impossible to evaluate them properly’”* (E2). SUS does not offer structural conditions for comprehensive treatment, exams and other necessary resources. The lack of integration delays exams, requiring new requests to assess the patient's current condition. This fragmentation is highlighted by another study, which indicates the access to medium-complexity services as one of the challenges to achieve comprehensive care⁴⁰. To overcome this obstacle, the computerization of services in isolation is not enough. It is necessary to propose articulated actions in health, organize services and their work processes at SUS different levels⁴⁰.

Also with regard to access barriers, city halls do not provide all exams, as they deplete the monthly quota: *“There isn't that quota, because the quota is closed now”* (E4). With this monthly limit, even simple tests, such as blood tests, end up being performed by patients in the private sector:

“If you are going to the oncology [sector] tomorrow, you have to get the blood test done today. Every time I go [to look for approval], there is no quota” (E4). *“In my city, they schedule consultations once a month for the whole month (...) who wants [a consultation] has to pay for it”* (E2).

One must reflect on SUS complex regulation, which is not limited to the technological incorporation of computerization and hospitalization centers, consultations and examinations. The regulation involves managers, service providers and users, with different interests, and deals with actions that enable access to care, with a view to comprehensiveness and resoluteness⁴¹.

Another point highlighted in the speeches was the inadequacy of the hospital's physical structure: *“There is no room for a companion there. (...) You have to keep going in and out, because stay there standing [is not good]”* (E1); *“it's very tight and you need a companion (...) you go to the bathroom alone when you're taking the medicine, you get dizzy”* (E4). Caregivers even take benches from home, which goes against the National Humanization Policy regarding the ambiance. SUS services must provide healthy spaces, which welcome patients with comfort and privacy¹⁷.

Another problem highlighted concerns queues. Patients, even those who live in the hospital's city, reported the need to wake up very early to get care: *“We wake up at four in the morning. There's no way to do it that day if you don't get there early. Then, it is the next day. And it is not good for those who are from another city”* (E1). For patients from rural areas or from other cities, there is also the difficulty of planning a stay in the city, with more expenses: *“If the appointment is tomorrow, we sleep here, depart at five in the morning. Stand in line”* (E4). There are users who spend all day in the hospital for consultation and chemotherapy: *“You have to arrive at five in the morning, and leave at five, six in the afternoon! Why? (...) It's the crowd, right, because there are a lot of people there.”*

It is perceived, therefore, that access to health services is unequal, and more difficult for residents of rural areas, due to greater social vulnerability, added to difficulties such as mobility³⁷. However, Ordinance 4.279/2010⁴² establishes guidelines for the organization of the Health Care Network respecting

the diversity of regional and socioeconomic contexts and health demands. For full access, there can be no geographic, financial, organizational, sociocultural, ethnic or gender barriers.

Access can be analyzed by availability (attention to the user), convenience (waiting for service, convenience of schedules, ease of scheduling and contact with professionals, comfort of environments) and acceptability (satisfaction with the location, service, service and professionals). Therefore, the availability of human and physical resources is an important factor for the Health Care Network⁴² to materialize access to services.

Thus, without failing to recognize SUS advances in a country with marked heterogeneity and inequalities, it is still necessary to organize it as proposed in the legislation. Fragmentation has not yet been overcome, and the system has followed a different direction from that initially established in the Constitution. Understanding this is important to correct directions⁴³. It is also worth pointing out that the current context of political crisis, with constant threats of dismantling the State and constitutional social rights, hinders the fight against inequalities⁴⁴.

Thus, there is a need for changes in favor of effective, efficient and safe responses, with the development of care models for both acute and chronic conditions. This point is important as health systems have been developed with a greater focus on acute conditions and events. When the coherence between the health situation and the care system is broken, there is a crisis that has also occurred in other countries whose systems are predominantly focused on diseases and acute events or on the exacerbation of chronic diseases³⁹.

The scarcity of resources in public health requires an equitable distribution that includes vulnerable populations. A broad discussion that favors social control should take place within the municipal health councils⁴⁵. It is also necessary for the population to demand the State to fulfill its protective role⁴⁶, supporting citizens in adverse situations⁴⁷. As the Universal Declaration on Bioethics and Human Rights points out, health is a fundamental right for everyone, regardless of social or economic status⁴⁸. Thus, populations in a situation of social vulnerability need to have their rights guaranteed by the State throughout

the course of the oncological therapeutic itinerary, which starts even before the diagnosis⁴⁸.

A possible limitation of the results presented here is the memory bias, since the reported delay between the search for a diagnosis and the start of treatment may have led participants to forget details of their itinerary. However, to prevent or minimize the problem, a family member or caregiver was invited to the focus group, in addition to the patients. It is also worth pointing out that other factors that could favor the understanding of the theme were not addressed, such as social network and care relationships. Despite this, we believe that the therapeutic itineraries reported here may be similar to those of many other patients, since they deal with the weaknesses and fragmentation of a national public health system.

Final considerations

This study found weaknesses and difficulties that permeate the care pathway of lung cancer patients in the public service network. Barriers of different natures were identified, which appear in the period of perception of the symptoms and signs of the disease and extend to the first consultations, in the search for diagnosis and treatment of the disease.

Participants reported problems throughout the care pathway, such as: difficulty in accessing medication and exams; queues and long wait for service; delay in diagnosis; fragmentation of service at different levels of care; dehumanization of care environments; and failure in communicating to clarify patients' rights, legally established, related to access to health care.

The different barriers, together, create difficulties in the care pathway, making it difficult and painful for patients and families. The data show the need for constant bioethical reflection on public health and the struggle to make the ideal SUS a reality, without obstacles and offering quality, comprehensive and humanized services. This fight must face the vulnerabilities caused by social inequalities, seeking to guarantee access to health care in different geographic territories, including rural areas.

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Rafael Turano Mota – Master – rafaelturano@yahoo.com.br

 0000-0001-7215-1818

Érika Ferreira Martins – Undergraduate student – erikinhafmartins@yahoo.com.br

 0000-0002-3062-6800

Maria Aparecida Vieira – PhD – di.vieira49@gmail.com

 0000-0002-7921-4049

Simone de Melo Costa – PhD – smelocosta@gmail.com

 0000-0002-0266-018X

Correspondence

Rafael Turano Mota – Avenida Maria das Dores Barreto, nº 100, Ibituruna
CEP 39401-330. Montes Claros/MG, Brazil.

Authors' participation

Rafael Turano Mota, Maria Aparecida Vieira and Simone de Melo Costa participated in all stages of the research, article writing and final version approval. Érika Ferreira Martins contributed to article writing and approval of the final text.

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