Barriers to access for interstitial lung diseases care in Colombia

Barreras de acceso en la atención de las enfermedades pulmonares intersticiales en Colombia

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Abstract

There is a growing amount of information regarding the management of interstitial lung diseases in the world. However, barriers in access to health systems affect adherence to treatment standards for these patients. This article aims to explore the perspectives of pulmonologists about the barriers in the diagnosis and treatment of patients with interstitial lung diseases in Colombia. For this purpose, we conducted a qualitative study whose methodological approach was phenomenological. Focus groups were formed with pulmonologists to explore the barriers in access to health services. The data were analyzed using an inductive thematic analysis. The participants expressed the existence of barriers derived from the lack of training in primary care, the lack of integrated services and the scarcity of multidisciplinary discussion groups. Inequality of care is related to structural problems of the Colombian social security system. We concluded that the characteristics of the health system establish most of the barriers to patient care. Greater awareness among medical professionals could avoid delays in access to specialized care.

Keywords: Lung Diseases, Interstitial; Health Services Accessibility; Developing Countries.

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Resumen

Existe una creciente cantidad de información referente al manejo de las enfermedades pulmonares intersticiales en el mundo, sin embargo, las barreras en el acceso a los sistemas de salud afectan la adherencia a los estándares de tratamiento de estos pacientes. Este artículo busca explorar las perspectivas de los médicos neumólogos sobre las barreras en el diagnóstico y tratamiento de los pacientes con enfermedades pulmonares intersticiales en Colombia. Para este fin, realizamos un estudio cualitativo cuya aproximación metodológica fue la fenomenología. Se conformaron grupos focales con médicos neumólogos para explorar las barreras en el acceso a los servicios de salud. Los datos se analizaron usando un análisis temático inductivo. Los participantes manifestaron la existencia de barreras derivadas de la falta de capacitación en atención primaria, de la ausencia de integralidad en los servicios y de la escasez de grupos de discusión multidisciplinaria. La inequidad en la atención se encuentra relacionada con problemas estructurales del sistema de seguridad social colombiano. Como conclusiones identificamos que las características del sistema de salud establecen la mayoría de las barreras para la atención de los pacientes. Una mayor sensibilización al personal médico podría evitar retrasos en el acceso a la atención especializada.

Palabras clave: Enfermedades Pulmonares Intersticiales; Accesibilidad a los Servicios de Salud; Países en Desarrollo.

Introduction

Interstitial lung diseases (ILD) correspond to a heterogeneous group of more than 200 diseases, some of them with known causes (Maher, 2012). Patients with ILD usually complain of dyspnea and cough, and the process for diagnosis and classification requires a detailed medical history and assessment of diagnostic images, pulmonary function tests, and sometimes lung biopsies by multidisciplinary groups integrated into specialized centers (Raghu et al., 2015; Walsh et al., 2016).

Idiopathic pulmonary fibrosis (IPF) can be used as a model of chronic fibrosing ILD, despite its low prevalence worldwide (2.8 to 19 cases per 100,000 population), has a progressive and lethal course, which generates excessive costs to health systems (Olson et al., 2018). In 2011, 37.7% of these patients in the United States required at least one hospitalization, with a total cost of US$ 59,379 per patient, of which about half were due to respiratory complications (Raimundo et al., 2016).

In Colombia there is no prevalence data nor a description of pulmonologists practice regarding IPF and other ILD, so it is necessary to expand local information about this topic. A research documented an average survival of 50 months in patients with IPF from Bogotá (2,640 MAMSL), similar to that documented in sea-level populations (González-García et al., 2014).

In recent years, nintedanib and pirfenidone were approved for treatment of IPF, these therapies reduced the declining of lung function without affecting mortality or quality of life (Raghu et al., 2015). With the advent of these agents, it is now more important than ever that patients be quickly diagnosed and have access to required care, as there is evidence that delays in referral to specialized centers increase the mortality of these patients (Lamas et al., 2011).

In Latin America, barriers to ILD diagnosis were identified due to difficulties in access to diagnostic tests, as well as to specialized evaluation centers (Cherrez-Ojeda et al., 2018; Curbelo, 2013). These problems are common even in developed countries, for example, in France only 56% of the cases have permanent access to a multidisciplinary discussion board (Cottin, 2014). Barriers to access to health services make clinical practice heterogeneous and

limit adherence to management recommendations; a better understanding about them could help adopting service management solutions.

Although Colombia has a health system based on a principle of solidarity, in which the vulnerable population is subsidized, it is perceived in clinical practice that there are barriers to access to diagnostic tests, specialized medical evaluation, and appropriate treatment, which possibly affect the prognosis of patients and the attention of their individual needs. Considering the mentioned limitations, the objective of this study was to explore and describe the barriers to access to health services in the diagnostic and therapeutic process of ILD in this country.

Methods

Qualitative research methods provide an opportunity to examine the conditions that influence individuals' choices, providing an opportunity to explore limitations to the functioning of health services (Pope; Mays, 1995). This qualitative study was conducted in August 2017 with pulmonologists attending the 17th Colombian Congress of Pneumology and Thoracic Surgery. This was a convenience sample, although attempts were made to represent different areas of the country.

The research was based on phenomenology as a methodological approach, in an interpretative paradigm. The perceptions of health professionals were investigated in order to understand the phenomenon of barriers in the diagnosis and treatment of ILD. In particular, we investigated the dynamics established by the conditions of care of these patients.

The participants were divided into three focus groups in which a thematic guide of open-ended questions was used, developed from the researchers' reflexibility (clinical experiences and review of the literature) and aimed to explore the experience of the participants in the topic of interest. The aspects addressed were barriers to diagnosis, barriers to treatment and patients' perceptions about them (Chart 1). Based on the basic questions, interaction and exchange of opinions among the participants were promoted in order to examine topics not initially included.

Chart 1 – Guide questionnaire for focus groups

Questions Guide – Group 1 (Barriers to diagnosis):
1. How much time do you think is spend between the symptoms presented by the patient and the diagnosis of an ILD?
2. How much time do you think is spend between the symptoms presented by the patient and the diagnosis of a specific etiology of an ILD?
3. What diagnostic tests do you consider essential for a proper diagnostic process?
4. What is the availability of these diagnostic tests in your center?
5. Do you believe that there are differences in the availability of the tests named in other centers or levels of health care?
6. Do you consider the existence of a multidisciplinary discussion important for the evaluation of these cases?
7. Do you have a pathologist and a radiologist with experience in pulmonary diseases to conduct a multidisciplinary discussion of cases?
8. How relevant do you think the participation of other specialties, such as rheumatologist or transplant lung specialists, could be?
9. Considering the above, which aspects do you think have the greatest influence on the delay in the characterization of the disease?
10. What do you think could be encouraged in order to minimize the barriers identified?

continues...

Chart 1 – Continuation

Question guide – Group 2 (Barriers to treatment):
1. How much time do you think is spent between the symptoms presented by the patient and the starting of treatments aimed to an ILD?
2. In your center do you have access to the treatments you believe are necessary for different kinds of ILD?
3. Do you think that in different centers, than the ones where you work in, there are the same facilities to establish an adequate treatment?
4. Do you believe that doctors working as internists could have the knowledge to define a treatment, if they had all the diagnostic methods available?
5. Do you believe that to start immunosuppressive treatment for an ILD associated with autoimmune disorders requires prior assessment by a rheumatologist expert in ILD?
6. Considering the preceding, which aspects do you think have the greatest influence on the delay in the initiation of a therapy for the disease?
7. What actions would you consider should be taken to improve knowledge about the management of these diseases?
Question guide – Group 3 (Patient perceptions about access barriers):
1. What are your patients' complaints regarding the barriers they have in the course of their illness?
2. Concerning diagnosis, did patients refer barriers that have delayed the identification of an ILD?
3. Concerning treatment, did patients report barriers that have delayed the starting of therapies directed at an ILD?
4. Do patients identify barriers in monitoring?
5. Have you perceived if there are differences in the barriers shown by patients living in cities regarding patients coming from the suburbs?
6. Do you believe that patients' perception of barriers to access influences their motivation to learn about the disease and treatment adherence?
7. Considering the above, what do you think could be an objective to improve so that patients present fewer barriers and improve the impression about care in health services?

The focus groups were led by three of the researchers (D.R.S., O.M.G. and J.L.G.). All sessions were digitally recorded, textually transcribed and anonymized. The transcripts were imported for storage and data management into ATLAS.ti (version 8.1.27.0; Scientific Software Development GmbH, Berlin, Germany).

Data analysis

Data were processed by deductive thematic analysis, based on literature review, and inductive, from data coding. The transcripts were read and reread by two researchers (O.M.G. and J.L.G.) to achieve the immersion. Initial codes were independently established for abstraction, and integrated to form connections and syntheses of the main themes. After an iterative discussion about the transcripts, codes, emerging relationships and final themes were compared, modified, and agreed upon to be applied to the transcripts.

Demographic information was obtained from the participants in the focus groups. Excerpts from the transcripts are presented to illustrate each topic.

Ethical considerations

The research was approved by the local Ethics Committee. The participation of the professionals was voluntary, their informed consent was obtained verbally prior to the development of the focus groups. Prior to the exercise, the objectives of the study were presented, it was mentioned that the conversations would be subject to audio recording and that the data would be used for academic purposes, guaranteeing their confidentiality and anonymity.

Results

Twelve pulmonologists were included to form the focus groups. Most of the participants worked in tertiary care centers in Bogotá and had an average experience of seven years (Chart 2).

In order to understand the phenomenon around "barriers in the diagnosis and treatment of ILD", the following topics were generated from the analysis and coding of the data (Chart 3).

Chart 2 – Participants' characteristics

Participant	Sex	Origin	Level of health care at which work	Years of experience as a pulmonologist
1	Female	Bogotá	Tertiary	Seven
2	Male	Cali	Tertiary	One
3	Male	Bogotá	Tertiary	Twelve
4	Female	Bucaramanga	Tertiary	Two
5	Female	Bogotá	Secondary	Two
6	Male	Bucaramanga	Tertiary	Three
7	Male	Bogotá	Tertiary	Twenty-seven
8	Female	Pereira	Tertiary	Two
9	Female	Bogotá	Secondary	Three
10	Male	Bogotá	Tertiary	Fifteen
11	Male	Bogotá	Tertiary	Fifteen
12	Male	Cali	Tertiary	One

Chart 3 – Main themes of the focus groups

Lack of training and knowledge about ILD by medical professional.
- Low clinical suspicion and misdiagnosis by primary care doctors.
- Late referral to specialized medical evaluation.
- Inadequate training of specialist doctors (pulmonologists, radiologists and pathologists).
- Inadequate technique of diagnostic tests (images and lung function).
Insurance of patients to the social health system.
- High administrative bureaucracy for the authorization of diagnostic tests and assessment by specialized medicine.
- Late access and monitoring by specialized medical consultation.
- Inequality according to the geographical origin of the patients.
Lack of integral health care.
- High difficulty of access to diagnostic tests.
- Scarce possibility of forming multidisciplinary boards.

Lack of training and knowledge about ILD by medical professionals as a barrier

The participants unanimously reported they observed problems in the diagnostic process of ILD in their experience. Lack of knowledge by primary care doctors was identified as a barrier leading to late diagnosis in most cases. Patients often receive incorrect diagnoses and treatments for months, after they are transferred to specialized centers the diagnoses improve their certainty.

> *If the primary care doctor is unable to identify a patient who may have an interstitial disease, that patient will be labeled as a COPD patient for a long time.* (Participant 5, Bogotá)

Participants perceived a lack of familiarity with these diseases among some of the pulmonologists, including misconceptions about their diagnosis and treatment. In general, they felt that training all health professionals would reduce the time gap between symptom onset and diagnosis. Support from the Colombian respiratory association to strengthen the education of general practitioners and specialists, as well as to develop local management guidelines, was identified as a policy to be established.

> *Somehow* [everyone should be] *aware of the illness to refer cases. If you don't report them, many may even die without a diagnosis.* (Participant 4, Bucaramanga)

On the other hand, although the availability of computed tomography is acceptable in the large and intermediate cities of the country, it is not always carried out with an adequate reconstruction technique, due the lack of knowledge among radiology technicians for its processing.

> *A bad CT* [computerized tomography] *is our worst enemy, because they don't authorize to repeat it. You have a CT scan that is not of high resolution to make a diagnosis, without reaching a biopsy. It's very complicated.* (Participant 7, Bogotá)

The information that patients receive about this kind of diseases is scarce. General practitioners and specialists are not adequately informed to provide patients with sufficient elements to face the disease. The patients' needs are not always satisfied, since the doctor does not prioritize the attention of the symptoms, which tend to be more relevant for the patients than other outcomes.

> *Another complaint from patients* [is that] *sometimes you don't speak the same language as them, because for me the most important thing is the improvement in the reduction of hospitalizations, in getting vaccinated, because I know that it helps. But for the patient it doesn't solve his symptoms.* (Participant 9, Bogotá)

Insurance of patients to the social health system as a barrier

Professionals emphasized that the social security system imposes multiple barriers to patient care. Insurance companies that provide patient care usually establish an important bureaucracy that the patient faces in the care process, which varies depending on the insurance the patient is registered. They prioritize costs over quality, without articulating the service to the individual needs. Since nintedanib and pirfenidone were released in the Colombian health system, the authorization and dispatch of these medications have been difficult because of their high cost.

> *The patient suffers a series of administrative refusals, with diagnoses that are not clear, handled in primary care.* (Participant 6, Bucaramanga)

> *Clinicians have a health care model in our minds and about the responsibility in terms of diagnosis, but the HPE* [Health Promoting Entity] *is interested in the economic model that revolves around medical care, if it is cost-effective or not.* (Participant 12, Cali)

The type of patient insurance affects unequal treatment. Patients with subsidized insurance are less likely to have access to diagnostic procedures or

receive specialized care than those with contributory insurance, because subsidized insurance has fewer contracts with institutions that provide necessary services for patients with ILD.

> *Unfortunately it depends a lot on the type of social security that the patient has* [...] *A patient on a contributory regimen must be delayed between the presentation of symptoms and being referred to pneumology for about three or four months* [...] *there are patients on the subsidized regimen that can easily last one year.* (Participant 5, Bogotá)

Health services are not always adequately staffed with specialists in pneumology, radiology or pathology, so the timing of care is often late. Some participants felt that the consultation time, adjusted to the productivity needs of health care institutions, is short and makes it difficult to instruct patients about their condition.

> *If you have twenty minutes per patient you can't even explain well what it's an interstitial disease* [...] [I] *work in a place where I have twenty minutes and in another one where I have half hour, I think the attention to those who stay for half hour is better.* (Participant 9, Bogotá)

The place of origin of the patients establishes a barrier for the access to the services, since the majority of the specialists are concentrated in the capitals and big cities. Diagnostic methods are also not easily found in small cities, where people with fewer resources to make transfers to specialized centers tend to live. The use of telemedicine was suggested as an alternative to care for patients living in peripheral areas.

> *If in Bogotá there we have administrative obstacles, in small cities or intermediate cities the access is more complex.* (Participant 5, Bogotá)

Lack of integral health care as a barrier

Participants reported that it is infrequent to have availability of all diagnostic necessary tests for the management of these patients in the same institution. The provision of health services is usually contracted by insurers with third parties that fragment and offer a bad healthcare. Patients are treated in different institutions with a consequent greater investment of money and time.

> *That is why it takes a little longer for these patients to be authorised for medical examinations, because not all institutions have, for example, lung function tests. So, until they authorize the tests, and the patients do them* [...] *it limits a lot the treatment of patients.* (Participant 2, Cali)

On the other hand, as insurance companies contract medical services in different institutions, it is not possible to provide integral care or to conform multidisciplinary discussion groups. Contracts may vary according the insurers, making it difficult for cases to have a continuous monitoring. When there are models in which insurers contract all services with a single center, better experiences are obtained in patient care.

> *A problem not only for interstitial disease, but also for our health system, is the non-integrality. We have patients who have spent a long time being treated in different places because of the way the pneumology service is contracted.* (Participant 11, Bogotá)

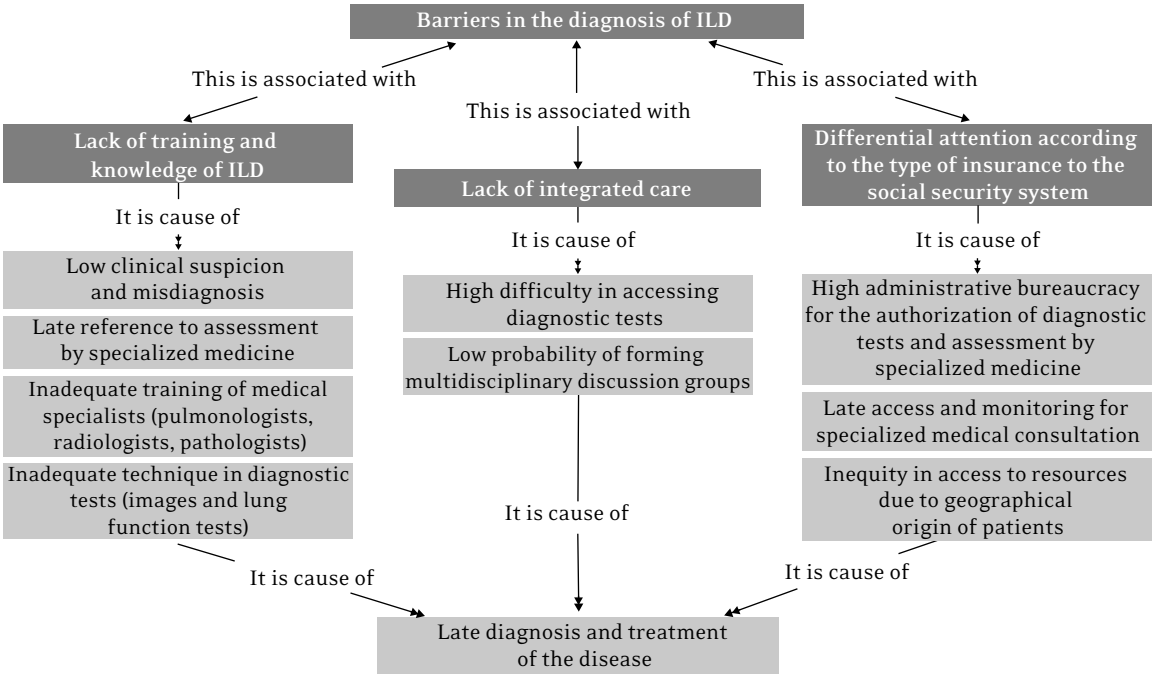
The usefulness of multidisciplinary teams and the establishment of medical boards for the diagnostic and therapeutic discussion of cases was emphasized. The need for these boards to include radiologists and pathologists with expertise in ILD, as well as rheumatologists, was recognized. However, these specialists are not always available or, if they are available, they do not always have sufficient expertise or time.

> *The problem is that not all institutions have the means or staff to make a multidisciplinary board. For example, in my institution we are two pulmonologists, we don't have a rheumatologist, we don't have an expert pathologist, and* [regarding the] *radiologist we have some limitations.* (Participant 2, Cali)

As a final comment, the barriers are presented at multiple levels of the system: the lack of knowledge of doctors about these diseases, the scarce availability of diagnostic tests and specialists, and the delays imposed by insurers for the authorization of services. The sum of these barriers establishes a complex network that makes the care of patients with ILD late and far from any recommendation based on the available evidence (Figure 1).

That is a set, I could not say it is only the lack of access to the medicine or the lack of access to the specialist, because in our environment there are many places where you don't have everything at the same time. So, it will always be the access by the HPE, [or] *access to the authorization of medications,* [or] *they don't have available consultations for pneumology.* (Participant 5, Bogotá)

Figure 1 – Thematic network of the phenomenon barriers in the diagnosis and treatment of ILD



Discussion

This study shows a variety of gaps in the care of patients with ILD limiting the possibility of obtaining an accurate diagnosis and timely treatment in each case. This is the first initiative to explore the perceptions of health professionals concerning the barriers and needs in the care of these patients within the socio-political context of the Colombian health system. This kind of study may contribute to expanding the provision of resources for the management of these diseases by the parties responsible for improving the access and quality of the health services.

Although for the researchers the aspects of health insurance are evident from clinical practice as critical in decision making, the participants identified a lack of integrality of the health system common to the entire territory. For the participants, the lack of integrality is significant, since patients must carry out a large number of procedures to receive care. From the experience of the interviewees, it is possible to conclude that the characteristics of the Colombian health system constitute the main barrier to patient care.

The Colombian social security system is based on a model of regulated competition in which health

insurers compete in terms of quality, organizing an offer of services that attracts members, and efficiency, reducing their operating costs, to access the resources of the system directed to each member (Vargas, 2009). Insurance is related to the employment status of people, those employed by independent or labor ties are covered by the contributory regime, while those who do not have the capacity to pay belong to the subsidized regime (Vargas, 2009). The degree of coverage and financial support is inequitable in relation to the type of insurance, since the availability of resources and technologies varies according to the insurance, with the subsidized population being the less favored despite being the most vulnerable (Luján, 2010).

The system has a market-based approach in which insurers do not usually design services to satisfy the needs demanded by patients, they seem to be articulated exclusively to business dynamics seeking to invest the lowest possible amount of resources in their services at the expense of quality (Hernández; Rubiano; Barona, 2015). The contracting of providers and services in a fragmented manner constitutes part of the barriers to access, as patients are subjected to a greater number of trips, procedures and costs (OPS; OMS, 2017). These findings have been validated in other studies that have analyzed the barriers of the Colombian social security system in the care of chronic and preventable diseases (Luján, 2010).

From an administrative point of view, it would be useful to offer patient-centered services, with quality diagnostic tools and specialists for comprehensive case evaluation. Multidisciplinary care in ILD has a positive impact on patient prognosis, especially when performed in specialized academic centers (Flaherty et al., 2007; Walsh et al., 2016). However, the opportunity for care by specialists and delays in authorizing procedures are some of the most commonly reported barriers in the system (Ayala, 2014).

There are important differences in the meet needs of patients with ILD by region of origin. Areas further away from large cities tend to have fewer resources, a greater lack of medical professionals, diagnostic and therapeutic tools (Hernández; Rubiano; Barona, 2015). Poverty and social exclusion in Latin America are reflected in the coverage and integration of health services (Vargas, 2009). Colombia has around two hundred pulmonologists, most of them distributed in big cities, so integral care and monitoring of patients with ILD is not a reality throughout the country. Alternative models, such as telemedicine, are needed to allocate human resources to peripheral areas. The impact of these types of strategies need further exploration in the future.

Apart from the structural problems of the Colombian health system, better training of primary care doctors could reduce the delay in diagnosis. Although primary care doctors should have a better knowledge of more prevalent diseases, it is necessary to give them sufficient elements to identify ILD cases in a timely manner. The lack of information reflects the absence of educational strategies in undergraduate, graduate, and continuing medical education; the time and quality of education related to ILD are often deficient, even in the training of pulmonologists (Bonella et al., 2016; Sharp et al., 2015). In this sense, a greater participation of scientific societies is called for in order to update medical professionals and to establish clinical practice guidelines involving primary care and adapted to the needs of the country.

This study had some limitations that should be considered when interpreting the results. First, there may be a selection bias as only specialist doctors perceptions were included for analysis, and they do not reflect the full complexity and reality of the healthcare system, nor the patients' needs. Involving patient organizations and primary care doctors is essential for future researches and policy formulation regarding standards of care in ILD. A qualitative study conducted with patient advocacy groups regarding the care of IPF in 11 European countries identified inequalities and unsolved needs for integral care in this region, with this information a roadmap was designed in the European Parliament for the establishment of health policies for the care of these cases (Bonella et al., 2016). Second, it is possible that, due to the sample of specialists selected, this experience does not fully represent the individual situation of each one of the country's regions. Third, the principal investigators are

pulmonologists and their own experience could bias the analysis of the information obtained. Fourth, there is likely to be an information bias due to each participant's tendency to selectively recall events that they consider relevant to their particular interest.

This study includes different perspectives and provides useful information about the panorama of ILD care in Colombia. This experience is specific to the Colombian context; however, the conclusions can be transferred to scenarios with similar health systems and sociocultural characteristics. Articulating the medical evidence to the limitations and needs of each country would guarantee achieving optimal care goals that reduce the complications derived from inappropriate managements.

In conclusion, our findings suggest that the Colombian health system establishes most of the barriers to care for patients with ILD. Dynamics should be generated from universities and academic societies to train medical personnel about the relevance of ILD and from government agencies to promote policies that make the care of these patients homogeneous.

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Authors' contribution

Galindo and García Morales managed the project and contributed to the methodology. All authors contributed to the design of the project, analysis and interpretation of data, as well as to the writing and reading of the document, and to the approval of the final manuscript for its presentation.

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