

“A lack of information keeps us from medicine, well-being, harmony...”: a mixed method study with plaintiffs requesting medicines in administrative cases

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Abstract *The need to request public health managers to ensure the right of access to medicines characterizes an administrative case and the method to do so is called the administrative route. This mixed method study aimed to analyze the perceptions of plaintiffs requesting medications by the administrative route about barriers to access medicines in the Brazilian public health sector. Data were gathered through focus groups and questionnaires. The results point to the interdependence of pharmaceutical services with the interfacing areas to ensure access. The barriers related to individuals reflect the commitment to develop citizenship, justifying the cost of the medicine to motivate the demand. Barriers to service provision include irregular availability of medicines, insufficient resources, and unsatisfactory quality of services. The difficulty in obtaining medical consultations and prescriptions originating in the public sector are barriers to the health sector. The barriers above the health sector are compliance with administrative procedures, corruption, and clientelism. The administrative route intensifies inequities in access to healthcare in Brazil.*

Key words *Pharmaceutical services, Health services accessibility, Health status disparities, Brazil*

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Introduction

Insufficient availability and equity of access to essential medicines¹ has contributed to increasing drug expenditures and hindering the progress of health systems with universal coverage². Brazil is inserted in this context³, has instituted a system (Unified Health System - SUS) which guarantees the population universal, equitable, and comprehensive access to health actions and services⁴.

Although the country has instituted and periodically revised the list of essential medicines, the principle of comprehensiveness is peremptory for the right of access to medicines, even if they are not included in this list. Seeking to make this right effective, many citizens turn directly to the public health service manager to access medicine through administrative cases (from here on referred to as the administrative route)⁵. This practice has become common in Brazil, often seen to alleviate externalities related to judicialization⁵⁻⁷.

A look at the literature on administrative cases or the administrative route against SUS principles enables a better understanding of the subject. This way gives the executive power better management and control of what is being requested, providing opportunities for implementing the public policy of universal access. The principle of universality is infringed by restricting these demands to users with prescriptions issued by the public health sector⁵, since it is legitimate for citizens to claim medicines from the State, regardless of the legal nature of the healthcare provider⁴.

The administrative route has been considered equitable because it meets the demands of lower-income individuals^{5,8}. However, access only occurs to the minority who claim this right. In addition, some situations point to the lack of equity in this route. In general, it is related to personal favoring in granting these requests⁹ and the fluidity of the applicants between public and private care in a complementary way^{5,10}.

By comparing the medications supplied through the administrative route with the lists of essential medicines, studies have shown greater rationality in granting these demands and promoting the principle of comprehensiveness. Thus, a reduction in the deferral of medications with therapeutic alternatives has been reported, as well as an increase in those not included in these lists. In addition, the supply of medications on these lists is observed, portraying the failures in the implementation of public health policy^{5,8,9,11}.

Researches describe the plaintiffs' characteristics and the content of the demands for

medicines through the administrative route⁵⁻¹¹. However, it is still scarce and insufficient to understand the perception of citizens about this route: *What motivates an individual to demand medication through the administrative way? Is the executive way capable of breaking down barriers to access medicines in the public health sector?*

Most studies on access to medicines are dedicated to evaluating the availability of medicines in health services, not only ignoring the other dimensions of access but mainly the interdependence of pharmaceutical care actions with the components of the different levels of the health-care system. There is also a lack of a theoretical framework that sustainably guides qualitative studies on access to medicines. Thus, this study aimed to analyze users' perceptions who used the administrative route on barriers to access medicines in the Brazilian public health sector.

Theoretical-methodological framework

Study design and location

This is a mixed-method study involving a focus group to explore the perception of medicine applicants about barriers to accessing medicines through the administrative route, a questionnaire to outline the profile of the focus group participants, and a description of the medications required.

The study was carried out in a state capital city in the central-west region of Brazil. According to the National Survey on the Access, Use and Promotion of the Rational Use of Medicines (*Pesquisa Nacional de Acesso, Utilização e Promoção do Uso Racional de Medicamentos - PNAUM*) conducted in health services in 2014, the Midwest region had the worst performance at the national level in terms of user satisfaction with pharmaceutical assistance in primary care¹², as well as for the perception of users about total access to medicines in the SUS (46.3%)¹³. In the population-based PNAUM, only 44.8% of adults and older adults in the Midwest region reported full free access to treatment of chronic diseases¹⁴.

The studied municipality has approximately 1.4 million inhabitants and has 79 drug distribution services among 119 basic health units. Of these, only one was destined to meet administrative demands, growing since 2010 after a technical cooperation agreement was signed between the State Public Ministry and the Municipal Health Department to prioritize medicine de-

mands through the administrative route over the judicial¹⁵. Thus, taking advantage of the window of opportunity created by this event, the study was conducted after the municipality consolidated the administrative route.

Participant selection

The selection of participants was based on a survey of all administrative processes filed at the Municipal Health Department from October 2012 to March 2013, totaling 713 processes. Those granted for the supply of medicines and available in the physical collection of the Pharmacy to meet these demands were selected.

Users of the 119 selected processes were contacted by telephone and invited to participate in the study. For users under 18 years of age, a companion aged 18 years or over with knowledge of the therapeutic itinerary was identified.

The representatives of 105 processes were effectively approached for the research, of which 36 accepted the invitation, totaling 41 participants, including users and companions. Representatives of 69 processes who refused the invitation alleging lack of time and interest, impediment due to illness, or change of residence in the municipality were excluded. In addition, representatives of 14 processes not contacted after six attempts on different days and times were excluded.

Data collection

All data were collected in April 2013 at the Pharmacy designed to meet administrative demands. The choice and preparation of the environment were based on guaranteeing the participants' privacy and accommodating those with mobility difficulties, using a room with restricted access to participants and researchers, and without any contact with Pharmacy collaborators and users before or during data collection.

Two groups were constituted as analysis units: Public-G, consisting of open processes with prescriptions originating in the public health sector; Private-G, comprised of representatives from available processes with prescriptions originating in the private sector. Data collection then took place in five focus group sessions, three for the Public-G, with 14 users and 12 companions, requiring 22 processes, and two sessions for the Private-G, with eight users and seven companions, requiring 14 processes.

The following questions guided the sessions: *How was the experience for you to get the medication? What were the factors which led you to seek this medicine in the public sector? How do you assess access to medication in the public sector? In addition to public services, what are the other factors that can interfere with access to medication?* The same researcher moderator conducted the sessions of approximately 90 minutes and two observers taking notes, who had no prior contact with the participants. All sessions were digitally recorded and stored in a file with restricted access to researchers and transcribed by observers. The moderator made a summary of each session, allowing the participants to add, clarify, or change any information. In the end, the researchers made the relevant entries in the field diary to support the analysis.

The questionnaire to outline the profile of the participants was provided at the beginning and collected at the end of the focus group session, including age, gender, marital status, education, occupation, and family income. The data on the 36 processes included: the prescription origin and the presence on the essential medicines lists^{16,17}.

Data analysis

The focus group analysis was performed in an electronic spreadsheet and based on the theoretical perspectives of the conceptual framework proposed by Bigdeli *et al.*¹⁸, which classifies the barriers to accessing medicines into five levels: individuals, families, and community; provision of health services; health sector; above the health sector/national context; above the health sector/international context.

The interpretive analysis was carried out by the team researchers in a continuous and simultaneous process to data collection, following the steps proposed by Braun & Clarke¹⁹: familiarization with the data, identifying codes, searching for themes, reviewing themes, and defining and naming themes, and producing the report. The definition and naming of thematic nuclei considered the aspects that emerged from the participants' statements within the five levels of the health system described in the adopted conceptual framework¹⁸.

The profile data of the participants and the medicines required were analyzed using descriptive statistics and presented in absolute and relative numbers.

Ethical aspects

The Research Ethics Committee approved the institution's study, where the study was conducted under protocol number 021/12. All participants formally consented to participate in the research through the Free and Informed Consent Form.

Results

The narratives presented throughout the text demonstrate the heterogeneity of the participants' experiences to break down barriers to access medicines required by the administrative route and the complexity and interdependence of this access between the different health system levels.

The results are presented in four thematic areas: barriers related to the individual, the family, and the community; barriers related to the provision of health services; barriers related to the health sector; barriers above the health sector/national and international contexts. Figure 1 illustrates the barriers to access medication through the administrative route perceived by the plaintiffs using the structure proposed by the adopted conceptual framework¹⁸.

Barriers related to the individual, the family, and the community

It was observed that even though some therapeutic itineraries are more frequent among applicants for medication through the administrative route, the barriers to this access are not perceived in the same way and magnitude by the participants. This fact is attributed to each participant's physical, natural, human, and social capital, directly influencing the context of vulnerability to which an individual is inserted and in their interactions with service providers when searching for the medication (Chart 1).

The profile of users and companions contributes to understanding this vulnerability. It was observed that there is a difference between the analyzed groups, with a predominance among users of the Public-G of older adults aged 60 years or more (12; 54.5%), female (14; 63.6%), eight to 11 years of formal education (11; 57.8%), retired/pensioner (10; 52.6%), living with a partner (12; 54.5%), and a mean family income of USD 1,030.26 ± 547.62. In the Private-G, children and adolescents from 0 to 19 years old

predominated (7; 50.0%), male (9; 64.3%), 12 or more years of formal education (5; 41.7%), without paid activity (6; 54.5%), living without a partner (12; 85.7%), and a mean family income of USD 1,921.46 ± 1,813.96. Among the companions in the Public-G, adults aged 20 to 59 years predominated (8; 80.0%), female (7; 58.3%), 4 to 7 years of formal education (6; 54.5%), performing a paid activity (6; 50.0%), and a mean family income of USD 1,005.50 ± 514.56. Among the companions in the Private-G, adults aged 20 to 59 years predominated (6; 85.7%), female (5; 71.4%), 12 or more years of formal education (5; 71.4%), performing a paid activity (4; 57.1%), and a mean family income of USD 2,907.33 ± 3,043.81.

The analysis of physical capital showed that despite the higher mean income among participants in the Private-G, the cost of medicines was the main barrier to access on the demand side for both groups. Thus, the main measures taken by the participants to minimize the commitment of family income with the purchase of medicines until they can obtain them through the *SUS* were: receiving a donation from the family and the community, replacing the medicine of choice with a cheaper alternative, reducing the dose and treatment interruption.

High expenses on medications can interfere with the natural capital of the applicants, especially concerning compromising access to basic needs, such as food.

The heterogeneity between the participants' perceptions about recognizing the right to health is highlighted regarding human and social capital, despite living in a country that adopts a health system based on the principles of universality, comprehensiveness, and equality of access. Difficult access can lead citizens to disregard the system's principles and to defend focalization (their perspective).

Physicians are configured as the primary informants of the administrative route to the participants of this study. Lack of knowledge of this route as an alternative to obtaining medicines is a significant barrier that, when overcome, makes the claimants active agents in disseminating information to health professionals and the community in general.

Barriers related to the provision of health services

Barriers to access medicines related to the provision of health services represent one of the

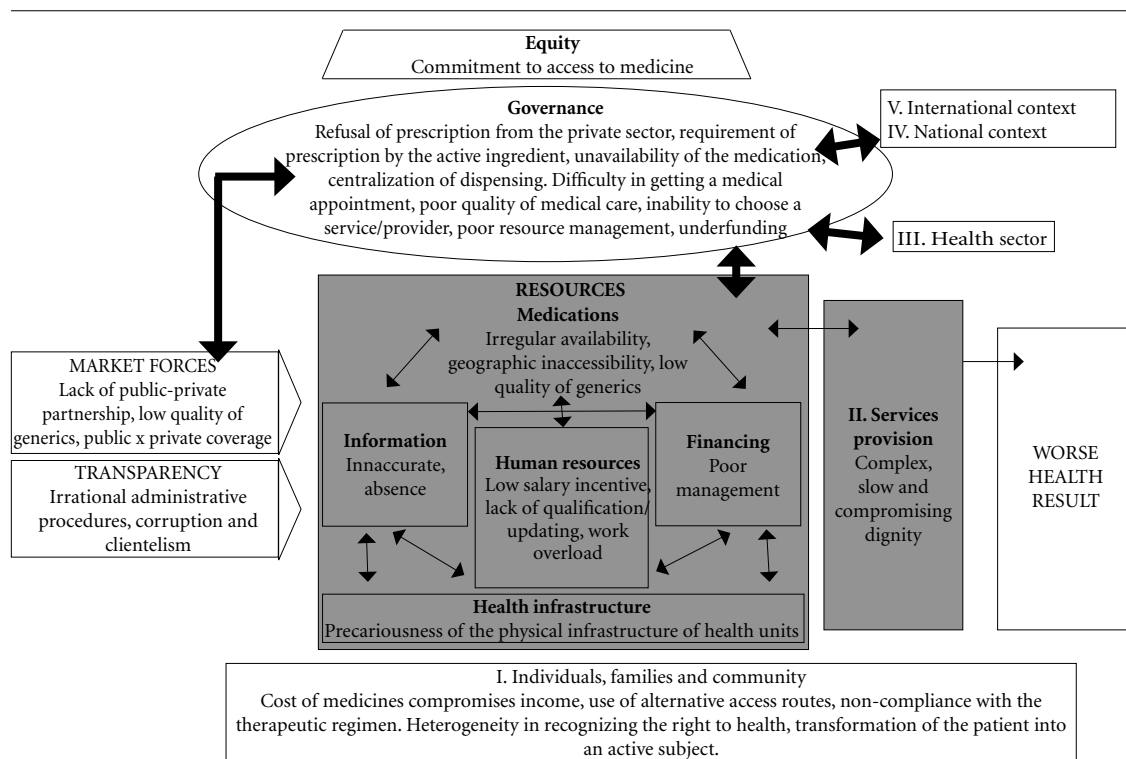


Figure 1. Barriers to access medication through the administrative route perceived by the plaintiffs.

Source: Authors.

levels on the supply side. Regarding the medicines themselves, the participants pointed out irregular availability, geographic inaccessibility, and low quality of generic medicines (Chart 2).

The irregular availability of medicines was perceived in different care points between the two analyzed groups, predominantly referring to medicines from the primary health units by the Public-G participants and to medicines granted administratively by the Private-G participants. The high number of medicines present on the essential medicines lists administratively demanded in this study [Private-G: 18 (72.0%); Public-G: 17 (47.2%)] corroborates this perceived availability.

In addition to medications, barriers related to the resources needed to provide the healthcare service were also pointed out, portraying the interdependence between them so that the quality of the service provided is achieved. These perceptions included poor management of health financing, the precarious physical infrastructure of

the health units, the lack of quality and quantity of professionals to meet the demand, and communication with health professionals. In addition, the participants pointed out the team's lack of knowledge and interest in guiding users about access to medication. Thus, failures related to information were unanimous among the analyzed groups, comprising both the absence and errors in the content about the administrative route and other services.

By perceiving access to medicines as a measure of the quality of health service provision, the participants' itinerary to make this access effective was considered complex and time-consuming and an experience that hurt their dignity principles.

Barriers related to the health sector

Continuing on the supply side, the barriers to access medicines related to the health sector included those associated with the governance of

Chart 1. Narratives regarding barriers to access medicines at the health system level “Individuals, families and community”, Brazil, 2013.

Barriers	Participant narratives
Physical capital	
	<p>“The insulin I use is expensive. If it weren’t for the process, I wouldn’t be able to take it... It’s too expensive.” Public-G</p> <p>“I went to do (the process) for a drug that is not that expensive, but because I will have to take it my whole life, it becomes expensive.” Private-G</p> <p>“Three ml of insulin for R\$90 (US\$55.97)... I use four needles a day... a box of one hundred I now pay R\$60 (US\$ 37.31)... for us it’s difficult ... it’s price research, it’s chasing it, because at that time it’s our money that comes out of our pockets to buy these things...” Private-G</p> <p>“My medicine is expensive, R\$250 (US\$155.47) a box. I kept asking for help from the church, asking friends... I’m asking others because I can’t afford it.” Public-G</p> <p>“The dermatologist: ‘This cream is expensive... 99% I guarantee that (the skin) is normal. But it’s too expensive, you can’t buy it. I’ll give you this one for R\$10. You go there and buy it. I used it and it didn’t help at all.’” Public-G</p> <p>“I thought: instead of taking two pills, I’m going to take one. God will help and won’t let anything happen, because I don’t know if I can get another box.” Public-G</p> <p>“He was without the medication for about four to five months... the last month I got it... it costs R\$130 (US\$ 80.85), the medication only lasts 14 days. I had no way to keep paying for that.” G-Public</p>
Natural capital	
	<p>“I think it’s bad (not getting the medicine through the SUS), because I have to take it from my salary and then sometimes the diet is less. Because people with diabetes have a diet, right? And people say no, but it’s expensive, you have to have a strict diet.” Public-G</p> <p>“We don’t have the natural things, it’s natural for you to have rice, beans, meat, vegetables, clothes, shoes, go out for ice cream, go for a walk. He can’t, because his skin is all wrinkled, understand? It hurts, itches... So like that, he gets troubled.” Public-G</p>
Human and social capital	
	<p>“I think the person should be registered... You have to have control over who needs and who doesn’t, in reality. Because otherwise, I see there, many people arrive in their cars at the door, come to get the medicine here, taking the place of many people.” Public-G</p> <p>“There is no need for the social worker to go to our house... by law, it is the citizen’s right to receive their medication. You can be rich. And there’s no social worker to go to your house to find out if you can afford it or not.” Private-G</p> <p>“That so much stuff... wanting to know how much I pay for energy and how much I pay for water... There’s a law, it’s there, now if you earn a little or a lot it doesn’t matter.” Private-G</p> <p>“If the medicine is for one, it is not just for one, it is not just for the poorest, it is for everyone! And there are resources for that, so we have to charge for it!” Public-G</p> <p>“They talk about the Public Prosecutor’s Office, just like Mom’s doctor... but as I already knew about Dad’s (process), I said: ‘There’s nothing about the Public Ministry, we go straight to the city hall. Dad, Mom, I know what I’m talking about’.” Public-G</p> <p>“I went online and found the number. Because I didn’t even know how to guide myself, the doctor just said that I have to go after it... that it was difficult to achieve.”</p> <p>“It’s common for Brazilians to be uninformed, nobody looks... I’m part of the Health Council of the maternity hospital... See if a mother goes there... help to discuss... see if the population goes.” Private-G</p> <p>“I didn’t even imagine that the municipality provided it, as I found out about it through the psychiatrist... Then... I went to the private doctor. I was the one who told him: ‘Look doctor, it’s on the net’. And he says? I didn’t know!... He started talking to other doctors, other patients... because of me.” Private-G</p> <p>“If I have information, I’ll pass it on, understand?... I’ve seen people complaining in the hospital. I said: ‘Look, you go to the city hall... you’ll get it.’” Public-G</p>

Public-G: group of participants who filed administrative proceedings with prescriptions originated in the public health sector.
Private-G: group of participants who filed administrative proceedings with prescriptions originated in the private sector. US: international dollar using the purchasing power parity conversion factor for 2013 (PPC), which was R\$1,608 for every US\$1,000 (WorldBank, 2013).

Source: Authors.

Chart 2. Narratives regarding barriers to access medicines at the health system level “Provision of health services”, Brazil, 2013.

Barriers	Participant narratives
Medicines	<p>“Many things are lacking in pharmacies... usually they never manage to get them all... there are days when people get there and can’t even get a dipyrone with a prescription from the doctor there, because they say they don’t have it.” Public-G</p> <p>“In my own neighborhood I’ve never been able to get a medicine... because there’s never a medicine there, never, never... every time I go there they say they don’t have it, that it’s finished. Then I go to the pharmacy in Bairro Goiás... When I get there, they have the medication and they provide it for me.” Private-G</p> <p>“I was here yesterday to get my medicine again (through the process)... Lantus was missing... Talking to the girl, I said that last time I didn’t have a needle. She said that they haven’t been delivering needles for over a year.” Private-G</p> <p>“I did a process to get everything and there is a lack of medication.” Private-G</p> <p>“I was able to get Clopidogrel there at SUS Pharmacy, then it was only transferred to the District Pharmacy... For me it is against the grain, because Cais is closer to my house. They should make it easier.” Private-G</p> <p>“They informed me where I’m going to get the meds. It’s not just here, it’s at Cais and I don’t know where anymore... It’s where the medicine is... then it’s complicated... I already get medicine here (by administrative process), so other medicines could be purchased and sent here.” Public-G</p> <p>“The name already speaks, right? Generic! I pray to God when I take the pill.” Public-G</p>
Financial, infrastructure, human and information resources	<p>“Our taxes... had to be better used, reverted to health... there had to be an appreciation of the structure that already exists, improve this structure and the professional who serves, provide training.” Private-G</p> <p>“Whenever I receive those little letters from SUS asking how I think the service is, I respond via the internet saying that it is terrible, that the structure is bad.” Private-G</p> <p>“I think two primary things are missing. First education, I think that wherever you go you have to be well attended... Secondly, I encourage training, I encourage information, I think that the employee who seeks information has to be better paid, they have to be better treated by the government... I think they are the two basic things: education and information because no one knows how to tell you anything.” Private-G</p> <p>“There is a lack of information on the part of the people who file the process, they don’t know anything, they haven’t seen anything, there’s no phone to give us... ‘Oh, I don’t know! I do not know! I don’t know!’ Ah, so what are you doing there my dear? Do you know why? Don’t want to inform? It’s in the wrong place! You have to put a person who likes to talk and communicate... The lack of information takes us away from medicine, well-being, harmony.” Private-G</p> <p>“The doctor enters the Unified Health System and has no training in what happens. He knows that he has to consult and prescribe the medication... they don’t know how to refer you... We get there waiting for them to have information, nobody tells you anything.” Private-G</p> <p>“The place he (the doctor) does not want to work is in the SUS, because it pays less.” Private-G</p> <p>“No doctor wants to work at the SUS, because the salary is not good and the service is too much... there is no time to eat, there is no time for anything.” Public-G</p> <p>“Doctors know that there is no medicine at SUS Pharmacy, how do they give us the prescription? They should get their bearings first.” Public-G</p> <p>“At the pharmacy, they should say ‘There is no such medicine here’ and indicate where they have it... They have to give us an option, not just say they don’t have it and you go away.” Public-G</p> <p>“My doctor gave me the report... He said: ‘There’s medicine here, but it’s not cheap. You’ll have to go through the Public Ministry, you’re going to do something, I don’t know what’... He made a seven-headed thing for me, it seems that the process isn’t even that difficult. I went, talked to the social worker... (Doctor) even told me that by the time I got it, sometimes I had almost died.” Public-G</p> <p>“Oh the difficulty, oh bureaucracy! I went to that office several times and the information was not very correct... the social worker called me for thirty days and made the visit... then there were about sixty days. I called... then they said no, you have to wait... They said they would let you know, but they didn’t. And this thing (medicine) was already here for two weeks or twenty days, already available.” Private-G</p>

It continues

Chart 2. Narratives regarding barriers to access medicines at the health system level “Provision of health services”, Brazil, 2013.

Barriers	Participant narratives
Quality	<p>“My case took longer, it was even frustrating, because it took me almost a year, or even longer, to get the medications... and there was still an error in my process.” Private-G</p> <p>“You need transport to go to the place to get the medicine, they have to go to the doctor. And it’s not easy to get an appointment... You go to the place several times. Emotional wear... which all generates expenses, physical wear, people get emotionally shaken. So, it’s a series of things that get worse.” Public-G</p> <p>“I also found these processes a little disorganized, as in most public bodies. Bureaucracy makes the process take even longer. So for me it was very frustrating.” Private-G</p> <p>“We already go through the embarrassment of having to ask for the medicine... It is already within us that we are not normal... that we are in need of a little fix... Then we go through the process of asking (the medication by process) and people make light of it, show a lack of respect, indifference.” Private-G</p> <p>“It gets tiring... you’re already so stressed, tired... that the whole process becomes a little humiliating. It feels like you’re begging... the feeling is that they’re doing you a favor by serving you... that you’re annoying because you’re looking for your right, that you’re asking too much.” Private-G</p>

Public-G: group of participants who filed administrative proceedings with prescriptions originated in the public health sector.

Private-G: group of participants who opened administrative proceedings with prescriptions originated in the private sector.

Source: Authors.

both pharmaceutical care and the health sector in general (Chart 3).

The main barrier related to the governance of pharmaceutical care perceived by the participants was the requirement for prescriptions originating in the public sector to guarantee access to medication. This finding demonstrates a lack of coherence and clarification to citizens of the specific regulations for the different access routes to medicines since the origin of the prescription used to open the administrative process was adopted for forming the groups analyzed in this study. However, it is noteworthy that although most users of this study had opened administrative proceedings with prescriptions originating in the public sector, many of these demands initially emerged in the private sector and were later formalized in *SUS* prescriptions to meet the sector’s requirement.

Another inconsistency perceived by the participants was the requirement to adopt the common Brazilian name in the prescription presented for opening the administrative process, as this rule did not apply to all cases.

A need to improve planning to ensure availability on the date scheduled for supply was perceived for the effectiveness of access to the medication granted through the administrative route.

In addition, it was observed that many claimants also use essential medicines provided in primary health units. Thus, a need for all of them to be provided in a single location and a decentralized manner was addressed to rationalize access to medicines, reducing the displacement of users.

The barrier with the most significant impact regarding the governance of the health sector on access to medicines was the difficulty in getting a medical appointment through the *SUS* promptly, especially in a specialized one. Barriers related to the impossibility of the user to choose the health unit and professional to provide care were also perceived, the precarious management of the resources necessary for the provision of health services and the need for health financing which meets the demand of the increasing number of medicines through the administrative route. In addition, the low quality of medical care in the *SUS*, the lack of standardization of services provided, and interventions after formal complaints from users about the quality of service were pointed out.

Thus, participants reported using the public and private health sectors according to their convenience and financial conditions in an attempt to circumvent these barriers. In this public-private mix, the participants preferred to carry out

medical consultations in the private sector and obtain medicines from the public.

Barriers that are above the health sector

Barriers to access medicines above the health sector were perceived in this study only in the national context, considering the health market forces and the transparency of actions (Chart 4).

Participants addressed the possibility of the SUS establishing partnerships to use private sector resources to achieve public health goals about health market forces. In this context, health education services carried out in drugstores and medication supply via the “*Aqui Tem Farmácia Popular*” Program were exemplified. Despite the perception of the benefits of this partnership, the participants recognize failures in the provision of services and distrust the transparency of private sector actions. Another concern was about the quality of generic drugs predominantly being acquired due to their more affordable price.

This study also pointed out a perception that the State attributes low importance to the health sector when applying public resources, failing to meet the real health needs of citizens. Despite this, the importance of the SUS principles was recognized versus the commercial interests of the private sector, which fails to value the needs of individuals to the detriment of the payment power of each individual.

Barriers related to the transparency of actions were perceived as the irrationality of administrative procedures and corruption, demonstrating that the participants know how they are impeding their rights. In this context, the participants pointed out clear signs that there are clientelistic relationships of patronage and deception in the regular care flow, favoring some and delaying the rights of others. More than that, health is an excellent “electoral cable” for professional politicians who take advantage of the precariousness of life, health, and the system’s deficiencies to perpetuate themselves in power.

Chart 3. Narratives regarding barriers to access medicines at the health system level “Health sector”, Brazil, 2013.

Barriers	Participant narratives
Governance of pharmaceutical care	<p>“I filed (the process). A long time passed and they returned the process to me... I had to change (the prescription) for the simple one. There in the office they were not serving private prescriptions and my prescription was from Ipasgo (health plan)... and I already had it here (by administrative process) and I was accredited by Ipasgo. It’s the same doctor, who has never changed... this business of changing the prescription is very difficult. You go, you have to call, make an appointment... and the doctor will only repeat the prescription.” Public-G</p> <p>“This question of prescription I think is impractical. Why?... People go to the Cais, take up space, waste time, waste the doctor’s time... take the place of someone who could be doing that there... wandering often cause such inconvenience to the patient as for the government... If it was modernized, less money would be spent, there would be more doctors.” Private-G</p> <p>“She received it fast... The problem I found was that when she was admitted there, the Ursacol she uses couldn’t be just that name. The prescription had to be changed, it had to be ursacoluso (ursodeoxycholic acid).” Public-G</p> <p>“The drug is for continuous use... it is forever, it’s until you die!... That this record exists, for example, in the units, so that you know that... at the beginning of every month, so-and-so, so-and-so, so-and-so, will be here looking for medication... So be ready! Now send the report!... As soon as you type there... Ok, your medication is here, it’s reserved, almost with your name on the box.” Public-G</p> <p>“If they would make it easier... this distribution, because it’s all in the municipality... For example, here there are times when we can’t get syringes. And there are syringes at the municipal health unit, but they don’t give syringes because I don’t take NPH insulin there... I think it’s so lacking to do everything in one place, to organize, even to save money, save time, save employees.” Private-G</p> <p>“I think it’s wrong for everyone to get (medication) here at this pharmacy. It could make it easier for all patients to transport them to the health posts, pick up at the health posts closest to our residence.” Private-G</p> <p>“They should decentralize this (administrative supply of medication), have more units... We live reasonably close, but there are certainly people who live farther away.” Public-G</p>

it continues

Chart 3. Narratives regarding barriers to access medicines at the health system level “Health sector”, Brazil, 2013.

Barriers	Participant narratives
Governance of the health sector	<p>“I need the medical report, but I can’t because there’s no doctor where we live... You have to make an appointment at 0800... If you call from a normal cell phone, you can’t. Look for a pay phone, don’t you think. Understood? We face a lot of difficulty.” Public-G</p> <p>“The girl said I needed a recent prescription and I don’t have it. So I think I won’t be able to get the medicine... it’s going to be very difficult... and that’s where the medicines they gave are gone.” Public-G</p> <p>“If they asked for the prescription, but kept giving the medicine until you brought it, you wouldn’t be without the medicine. Sometimes I make an appointment for my mother in six months. Three months without taking the medicine... she can’t stop taking it for one day!” Public-G</p> <p>“Both the SUS and private prescriptions should be accepted to get medication. Because? Because many times you see your relative, your father dying there and you don’t have the care. You get there to make an appointment, make an appointment for three, four months, a surgery in a year... At the time, everyone pays, the family gets together to pay for a private appointment. Then you get the prescription and you can’t afford to buy a medication.” Private-G</p> <p>“They make it very clear, it has to be a SUS prescription... I think it’s wrong because we often pay for a plan, it’s not because we want to be better than others, it’s because the person really needs it... if (father) get sick and goes to SUS he will die. So we do everything, we give up a lot to be able to have this plan.” Private-G</p> <p>“I used to do my son’s private treatment, but it started to be very expensive. I started and went back to the public network... but it wasn’t as effective as being in private, so we decided to go back again... Not very satisfied, I thought: There must be some way for me to get this treatment for my son... which is borne by the government.” Private-G</p> <p>“If the person pays for a health plan, it is a sign that the Unified System is not working, at least on the part of doctors. Many people prefer to get the drug in the Unified System which, despite taking a long time, you can do it.” Private-G</p> <p>“With this PSF (Family Health Program) business, either you are assisted at that health center or you are not assisted. I think that’s bad, because if a person left one place and is going to another, it’s for practicality, it’s because it’s emptier, because of the education of those who are serving you, because of the quality of the professional who is working there... The government took away this possibility of the person choosing.” Private-G</p> <p>“Here (Pharmacy) there are days when... it’s crowded... there’s no employee... There’s a competition, but they don’t call people. Then there is a lack of employees and they have to split into ten to do everything here. We see that it’s not them... I’ve never been underserved here... I think what’s needed is for the government to invest more. Just like the time it flooded... it’s a place that stores medicine, you have to be more affectionate, because these medicines are very expensive... They have to do their best, but when they try to do it, they don’t have the means. Then it gets hard!” Private-G</p> <p>“My (private) doctor every month... gives a lecture... on a new subject... This week we had a lecture by a dentist talking about what care a diabetic has to take with their mouth. So, it’s something the government has available, there’s a doctor who knows about this, there’s a dentist who knows how to talk about what we have to have... We need to look for the private service.” Private-G</p> <p>“Who owns the money? Us. Who is managing the money that so-and-so and so-and-so come to get these medications every month? Will it cost a hundred thousand? So every month there has to be a hundred thousand for these people, apart from the new ones.” Public-G</p> <p>“We are very abandoned by the government... the doctors’ business, all that stuff, health in general... We watch it on television every day.” Public-G</p> <p>“As much from diabetes as it should have from any other health problem, having the diabetes sector. Where there are people who are giving lectures, bringing knowledge, because one thing is for the mother to say, another thing is for the child to hear from a professional... it is important for us to have quality of life, there would be fewer people who would be sick... problem of gums, speech therapist, cardiovascular has several consequences. People that once a month wouldn’t be difficult, it wouldn’t be any aberration for the government.” Private-G</p>

it continues

Chart 3. Narratives regarding barriers to access medicines at the health system level “Health sector”, Brazil, 2013.

Barriers	Participant narratives
	<p>“The Unified Health System, the program itself, in theory, on paper, it’s very beautiful, in practice it’s not... Doctors won’t work, when you start to create... the bond... disappears, doesn’t gives justification... They disappear with the files... the fault of poorly prepared, rude attendants.” Public-G</p> <p>“Unfortunately, today, things work like this: there are things, there are places you go that work very well and there are places you go that unfortunately I think the government doesn’t look at what’s happening there... I think the big question is that. You see it’s two organs, it’s the same thing and it works completely different. It’s a matter of administration.” Private-G</p> <p>“One question I have is when a patient is underserved by the SUS, that he or she will complain. I never heard that there was a result in that complaint, because if you go, the same doctor is still there today, a thousand people complain about him, but he is still there. I don’t see any improvement, where are our complaints going?” Private-G</p> <p>“I tried calling that 0800 number to complain, who said we can talk? Nobody answered.” Private-G</p>

Public-G: group of participants who filed administrative proceedings with prescriptions originated in the public health sector.
Private-G: group of participants who opened administrative proceedings with prescriptions originated in the private sector.

Source: Authors.

Discussion

The present study demonstrated that although ensuring safe and rational access to medicines is directly related to the actions and services of pharmaceutical care, it should be treated as a challenge to be overcome by the health system and included in the agenda of different areas of the *SUS*. These should, in turn, promote discussion and agreements with the interfacing areas.

Considering that the health concept is related to the absence of disease, access to medication by itself is also incapable of guaranteeing health to the population. However, given its complexity, it became an indicator of the quality and effectiveness of the health system. The United Nations recognizes it as one of the five indicators of progress in guaranteeing the right to health²⁰. Thus, the present study showed in a novel way that although the therapeutic itinerary and the barriers to accessing medicines through the administrative route have their particularities, they have very similar characteristics to those already reported in studies on the judicial way¹⁰, of high-cost medications²¹ and healthcare networks²².

In the context of social policies, the direct relationship between barriers to accessing medicines and physical, natural, human, and social capital observed in this study reflects the commitment to the development of Brazilian citizenship. This is because access to medicines, as part of the right to health, is associated with oth-

er social rights: education, food, work, housing, leisure, security, social security, maternity and childhood protection, and care provided to the destitute²³. The historical failures in delivering these goods and services by the State have made the citizen assume the provision of their own needs. This scenario justifies the cost of medicines being the primary motivator of demands through the administrative route, evidencing the ingrained position in society of using the State as a last resort, failing to seek their rights as a praxis of Brazilian citizenship.

The legitimate desire to obtain quality medicine, available close to home, in an environment with an attractive design and empathetic employees, generates an expectation of experience with the service. When perceiving the barriers related to the provision of health services, the citizen tends to exclusively use the essential services to activate the administrative route, especially for those with private health insurance. As a result, the patient experience in the *SUS* is superficial, taking away the opportunity for the citizen to create a link with the services, recognize the importance of this system for society, and claim the integrality of their rights.

Private health insurance coverage and the financial system proved to be an alternative for users to overcome barriers related to the health sector, streamlining prescriptions to maintain a regular supply of medicines in the public sector. This type of arrangement distorts the *SUS* when

Chart 4. Narratives regarding barriers to access medicines at the health system level “above the health sector – national context”, Brazil, 2013.

Barriers	Participant narratives
Market forces	<p>“The city hall there (where I previously lived, in another state) partnered with the pharmacy... a group, a large company. They could partner there to give lectures... They also provide samples for people who cannot afford it... The pharmacy also profits from this, because medication for diabetics is expensive... The Health Department there also goes to schools... So everything is important. When you have this partnership, it even favors the Health Department, fewer people will look for it... to be able to receive medication... There are other means that can help...” Private-G</p> <p>“Of course, the bureaucracy is less in the Popular Pharmacy. You get there with the prescription, with the document, take it out, get it. These days it was a little more complicated... But, even so, much faster, much more practical.” Public-G</p> <p>“Sometimes I need simvastatin and diamicon, they charge a fee at the pharmacy (Popular). Do they really have the right to charge this fee?... Sometimes they don’t have it in the network and we go because we need the drug and they charge a fee.” Private-G</p> <p>“The drug Losartana... I use 120 pills, but I only get 50 (from the Popular Pharmacy). The other part I have to supplement, I have to buy, because they only give 60 pills. And if you go there before 30 days, you don’t have to go... I think it’s bad because I have to take it out of my salary.” Public-G</p> <p>“I’m already afraid to buy generics. But... lately I bought it because it’s cheaper. God knows if it’s going to be good. But to do what?” Public-G</p> <p>“Did the doctor prescribe it? It’s what the doctor prescribed! Our taxes are there, for that, and not for them to mess around in the squares... in traffic... advertising with our money. It’s to use and revert to our benefit!... But we have to charge! The right is ours! Public-G</p> <p>The private service does not charge devices that its SUS provides, does not charge for the medicines that SUS provides. SUS is excellent... it helps a lot of people, it helps us. The private service has a certain surgery, they say they don’t cover it, they don’t provide the medicines we use. So is the private service good? Yeah, how profitable is it for them... So is the SUS good? It’s good, it could be better.” Private-G</p>
Transparency (price, source and quality of medicines acquired)	<p>“Bureaucracy is a methodology to avoid fraud and corruption, but it has become a problem for us... First, we have to avoid excessive bureaucracy. And second, informing about the standards... Everyone has to be aware, those directly involved, the attendants, the doctors, the pharmacists, they have to know and know how to transmit it to us, otherwise it’s one way, another time is from another.” Public-G</p> <p>“You have better care at SUS if you have an influence. The father of a student of my mother was an orthopedist in the private service... He called a SUS doctor: ‘I have a patient here who will need surgery, can you find a place for him?’. The other doctor said: ‘You can come tomorrow and I’ll admit you’. I was hospitalized the other day and had a very complicated surgery... If you don’t have someone you know, it’s very difficult for the Unified Health System.” Private-G</p> <p>“It was very fast... Here it took a while because of the bidding process... I have knowledge there with the supplier. I called a friend of mine there and said ‘Help me, I have my son’s process to get medicine, are you the city hall’s medicine supplier?’ I gave the process number... He ordered it delivered, the other day I came and got it. ...For me it was fast.” Private-G</p> <p>“We pay a lot for our taxes... but the problem is the amount of embezzlement, theft, so much dirt that it doesn’t let the money be used well... Goiás is an emerging state... but public health is chaos.” Private-G</p> <p>“They say that there is a law there, that you must go through the doctor. But you go through the doctor in “quotation marks”... they informed me that they get paid for the consultations... They don’t even look at you or anything, they just ask if everything’s ok, ok, you sign and leave. I even think it’s ridiculous.” Public-G</p> <p>“In the election year it is good because there is no lack of medicine in the pharmacy. You arrive and get everything on time.” Private-G</p>

Public-G: group of participants who filed administrative proceedings with prescriptions originated in the public health sector.

Private-G: group of participants who opened administrative proceedings with prescriptions originated in the private sector.

Source: Authors.

used in a complementary way to private services, infringing the principle of comprehensive care and introducing ethical and equity implications. By privileging the private sector user through a double entrance to the system, often cutting a waiting list to which exclusive *SUS* users are submitted, this public-private mix intensifies inequalities in access to medicines. The use of the *SUS* in a complementary way to the private sector was addressed by Vargas-Pelaez²⁴ by judicial claims in Brazil and Argentina. In Brazil, Chagas *et al.*⁵ observed that the public-private mix is more common among judicial than administrative claims. In this same study, the authors clarify that opening administrative proceedings with a prescription from the *SUS* is a requirement that does not prevent the demand from having been initially generated in the private sector, as observed in this study.

The perception of the barriers above the health sector was a differential of the present study, demonstrating the existence of a fragile health system permeated by historical, structural, and endemic problems in a developing country. This situation contributes to the maintenance of a public sector which suffers from a distorted and negative image, discrediting the *SUS* and what is public in Brazil. In a study to identify why the middle class refuses to use the public services of primary healthcare, Reigada and Romano²⁵ pointed out the stigma of the population associated with the use of *SUS* and the lack of appropriation of it as a right. This perception was also identified in this study, despite the participants' acknowledgment that the public sector is the only alternative for access to healthcare for most citizens. Therefore, it is paradoxically defended and attacked, although the importance of the *SUS* for its users is evident in all the statements.

In this context, it is clear that the administrative route is used to meet the needs not met by other means and not by claiming the right to health, as already shown for the judicial way by Leite *et al.*¹⁰. It must be considered that the administrative route can be more empowering than the judicial one since users assume a more active role in this trajectory, which is the responsibility of lawyers and prosecutors in the judicial route¹⁰. However, this situation is not effective enough for citizens to use and demand comprehensive quality care, abstaining from this right and perpetuating the financing and rise of the private health sector in Brazil.

The mismatch between what is expected from the *SUS* and how citizens use the system

was evidenced in the criticisms and judgments of politicians and public administrators as corrupt, while scams are narrated to the recommended flows with the aim of personal favoritism.

The perception of a bloated, inefficient and bureaucratic health system pointed out in this study fosters proposals for the privatization of public health services, proposing easier access based on reduced bureaucracy in the system. This is the same justification used in the 1990s to subsidize the creation of social organizations, private companies supposedly capable of managing State financing more efficiently²⁶. However, this program has been responsible for the deregulation of health protocols and democratic processes essential to maintaining public policies, removing the role of the State in inspection, and guaranteeing its safety. Evidence²⁷⁻³⁰ demonstrates that health publicity is a process of disguised privatization and questions the non-profit nature of these organizations, the efficiency in applying public resources, and the promotion of *SUS* principles and guidelines.

The interdependence between the different health system levels was demonstrated in this study using what is called system software¹⁸. The empowerment of participants at the individual and community level regarding administrative procedures and their social role in disseminating information to the community can be highlighted. At the health service provision level, it is worth mentioning the importance of information about the different access routes to medicines and the clarity of the rules to avoid rework and delays in the administrative process. At the level of the health sector, it is evident that the requirement of a prescription every 90 days for a prescription originating in the *SUS* ignores the inability of the public sector to meet the demands for medical appointments, especially specialized ones, as already demonstrated by Rover *et al.*²¹. In the national context above the health sector, the need to comply with administrative procedures and cases of corruption generates a negative image of the public sector, reduces the efficiency of the *SUS*, and marginalizes the most vulnerable groups of the population.

The legitimacy of flaws in the system's software can be seen with the increase in the number of medical professionals in primary healthcare³¹ and the flexibility in choosing the professional who provides care in primary healthcare³². However, there are still many ways to go: the difficulties in using health services among the most vulnerable segments of the population³³; low

prioritization of budget and supply logistics to avoid shortages of essential medicines³⁴; the lack of specialized medical consultations³⁵; and the expansion of family and community medicine³⁶.

The health team's routine approach to patients is essential to break their barriers to access medicines and integrate the different health system levels, comprising at a minimum: the feasibility of using more accessible (and occasionally less efficient) therapeutic alternatives; the availability to pay for prescribed drugs with their resources (considering the commitment of family income and not just the cost of the drug); and the knowledge and interest in activating alternative ways of accessing medicines, such as administrative. The inefficiency of this dialogue, especially on the part of the physician, harms the patient's health condition since access to medication is not immediate even if the administrative route is used.

The prospects for overcoming barriers to access to medicines in Brazil are becoming more and more intangible with the freezing of the federal budget for 20 years. The tendency is to overload the system due to the national situation

of scarcity, intensifying the barriers to accessing health services^{37,38} and increasing the demand for medicines through the judicial³⁹ and administrative channels, as this is an alternative. Thus, the commitment of collective needs will be devastating for these individual demands to be fulfilled, putting the sustainability of the Brazilian public health policy to the test.

Therefore, it is concluded that the plaintiffs perceive the administrative route as a mechanism for the citizen to access medicines that considerably compromise the family income and are unavailable in public health services. However, this route is incapable of breaking through systemic barriers to access medicines and promotes meeting the demands of a minority who often uses the public sector in a complementary way to the private sector as a mere supplier of medications. Thus, given the current Brazilian scenario with the discrediting of the *SUS* and the overvaluation of the private sector, the new fiscal regime, and the freeze on health financing, the administrative route intensifies the inequities in health access in Brazil.

Collaborations

AQ Soares: Conception and project; collection, analysis and interpretation of data; writing of the manuscript or relevant critical review of the intellectual content; approval of the version to be published; responsible for all aspects of the study to ensure the accuracy and integrity of any part of the study. MA Melo: Collection, analysis and interpretation of data; writing of the manuscript or relevant critical review of the intellectual content; approval of the version to be published. PI Silva: Collection, analysis and interpretation of data; writing of the manuscript or relevant critical review of the intellectual content; approval of the version to be published. VO Chagas: Collection, analysis and interpretation of data; writing of the manuscript or relevant critical review of the intellectual content; approval of the version to be published. MP Provin: Conception and project; collection, analysis and interpretation of data; writing of the manuscript or relevant critical review of the intellectual content; approval of the version to be published. MM Silva: Analysis and interpretation of data; writing of the manuscript or relevant critical review of the intellectual content; approval of the version to be published. VSC Vila: Collection, analysis and interpretation of data; writing of the manuscript or relevant critical review of the intellectual content; approval of the version to be published. RG Amaral: Conception and project; collection, analysis and interpretation of data; writing of the manuscript or relevant critical review of the intellectual content; approval of the version to be published.

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