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Perspective of Quilombola Communities in Brazil on a Yellow Fever Outbreak and Vaccination

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Abstract. In 2016–2019, Brazil faced the most important yellow fever (YF) outbreak in recent decades. In 2019, cases were concentrated in Ribeira Valley, in the southeast region of Brazil, and largely affected rural Quilombola communities, which can trace their origins to escaped, freed, or abandoned slaves in the mid-1800s, and which traditionally practice subsistence agriculture. We aimed to explore aspects of the YF outbreak and vaccination from the perspective of the Quilombola communities. This was a cross-sectional descriptive study conducted in two Quilombola communities in Ribeira Valley (Sapatu and Nhunguara), using an interviewer-administered questionnaire that included both closed and open-ended questions. Thematic reflective analysis principles were applied for qualitative analysis. We adopted a theoretical domains framework to identify and categorize reported facilitators and barriers to YF vaccination. A total of 226 participants were enrolled: 46% male, median age 44 years. Eighty participants reported acute illness during the outbreak; fever, headache, myalgia, and nausea were the most common symptoms. Only eight participants reported laboratory-confirmed YF. Almost all participants (96.5%) reported YF vaccination. Less than two-thirds of the participants were vaccinated before the first case in the Ribeira Valley; over a third were vaccinated after the death of a community leader. The themes were: concerns about the vaccine, difficulty in accessing healthcare, perception of disease risk, knowledge about disease severity, cultural beliefs, and influence of leaders. The outbreak in the Ribeira Valley may have been averted with an understanding of the vaccination decision-making process, influenced by individual, sociocultural, and contextual factors.

INTRODUCTION

Yellow fever (YF) is a viral hemorrhagic fever endemic in tropical regions of Africa and Americas that affects mainly humans and nonhuman primates (NHP).[1] The disease is caused by the prototype member of the genus Flavivirus (family Flaviviridae), transmitted by mosquitoes.[2] Yellow fever is divided in two forms, sylvatic and urban, which differ in terms of the nature of the vectors, vertebrate hosts, and place of occurrence.[3] The disease ranges from asymptomatic to severe forms. The most serious forms occur in around 15% of those infected, with high death rates.[1,3–5]

Yellow fever vaccine is a powerful tool for controlling epidemics. Despite the existence of a highly efficient vaccine,[6–8] YF has been a recurrent problem in endemic regions of Africa and South America.[9–11] Even in countries that were declared free of YF, reemergence has been observed.[9,10,12] In Brazil, YF virus (YFV) introduction to non-endemic regions caused large sylvatic outbreaks.[13,14]

The YF outbreak that occurred in Brazil from 2016 to 2019 was sylvatic and affected the southeast, northeast, and south regions. It became the most important YF outbreak in recent decades because of the large number of cases and deaths in humans and NHP.[15] In Sao Paulo (SP), the epidemic started in regions with high vaccination coverage, and in less than 6 months spread to areas with low coverage that were previously non-endemic and where the YF vaccine was not recommended.[16]

The State Department of Health of SP identified the priority vaccination areas based on the analysis of virus circulation in NHP at forest fragments,[17] and used fractional doses because of insufficient supply of YF vaccine.[17–19] Despite these strategies, vaccine coverage in high-risk areas was not sufficiently high and YF cases occurred in several regions of SP. Currently, the entire territory of SP is considered an area of risk and, therefore, an area with vaccine recommendations.[16,17]

In January 2018, in response to the YF outbreak in the state of SP, Hospital das Clínicas (HC) was appointed as one of the two reference hospitals for severe YF cases. HC is a 2200-bed, tertiary-care teaching hospital, affiliated with the University of SP.[17,20]

In 2019, YF transmission was predominantly concentrated in the Ribeira Valley, a region characterized by rural Quilombola communities who are situated in areas in which YF vaccination had not been recommended until the outbreak.[15] The area of Ribeira Valley stretches along southeastern SP state and northeastern Paraná state, covering an expansive area of 2.830.666 hectares. It forms a part of the largest continuous area of Atlantic Forest in Brazil, a region recognized by United Nations Educational Scientific and Cultural Organization as a world heritage site. The area includes one of the most extensive and best-preserved continuous remnants of the Atlantic Forest. Access difficulties, because of its geographical characteristics, contribute to its conservation.[21,22]

The Quilombola communities in the Ribeira Valley can trace their origins back to slaves who escaped, were freed, or were abandoned during Brazil's colonial slavery regimen in the mid-18th century.[23] Since their establishment, Quilombola communities have traditionally practiced agriculture for subsistence, more recently on collectively owned land.[24,25] Despite their resilience and cultural richness, the Quilombola

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population continues to face significant vulnerability stemming from the historical process of enslavement. They often exhibit low levels of education, income, and precarious housing conditions, coupled with excessive workloads and challenges in geographical access and transportation. These factors exacerbate their exclusion and discrimination within healthcare,[26,27] making them more susceptible to YF during this period.[16] In this study, we aimed to explore aspects of the YF outbreak and vaccination from the perspective of the Quilombola communities.

MATERIALS AND METHODS

Study design.

This study was a cross-sectional descriptive study, conducted using an interviewer-administered questionnaire that included both closed and open-ended questions (Supplemental Questionnaire 1 and 2). It was part of a project called the Study of Sylvatic YF in the Ribeira Valley (FASVALER). This was a collaboration between Fundação Florestal and HC.

Study setting.

The study was conducted in two Quilombola communities: Quilombo Sapatu (QS) and Quilombo Nhunguara (QN), located in the Ribeira Valley Region, State of SP, Southeast Brazil (Figure 1).

These communities were chosen for the study because they had two or more severe cases of laboratory-confirmed YF admitted to HC between December 2018 and February 2019.

Site 1—Quilombo Sapatu (QS).

Its resident population is 137 people, of which 125 are Quilombolas.[28] It is located in the municipality of Eldorado, and its territory comprised 3.711.6257 hectares, with an extensive area occupied by the Ribeira do Iguape river and vegetation. It is crossed by the road that connects the cities of Eldorado and Iporanga (SP-165) and is approximately 33 km from the city center. It is located close to the Caverna do Diabo State Park (PECD), one of the main tourist destinations in Ribeira Valley. Tourism is an important source of income for some residents who work as park guides and environmental monitors.[29]

Site 2—Quilombo Nhunguara (QN).

Its resident population is 415 people, of which 409 are Quilombolas.[28] It is located in two municipalities (Eldorado and Iporanga) and has an official total area of 8.100.98 hectares, of which 91.22% are covered by vegetation, predominantly untouched forests. Access is also via SP-165 road, which connects Eldorado to Iporanga. It is located approximately 40 km from the center of Eldorado and 30 km from the center of Iporanga. Many houses are located along the

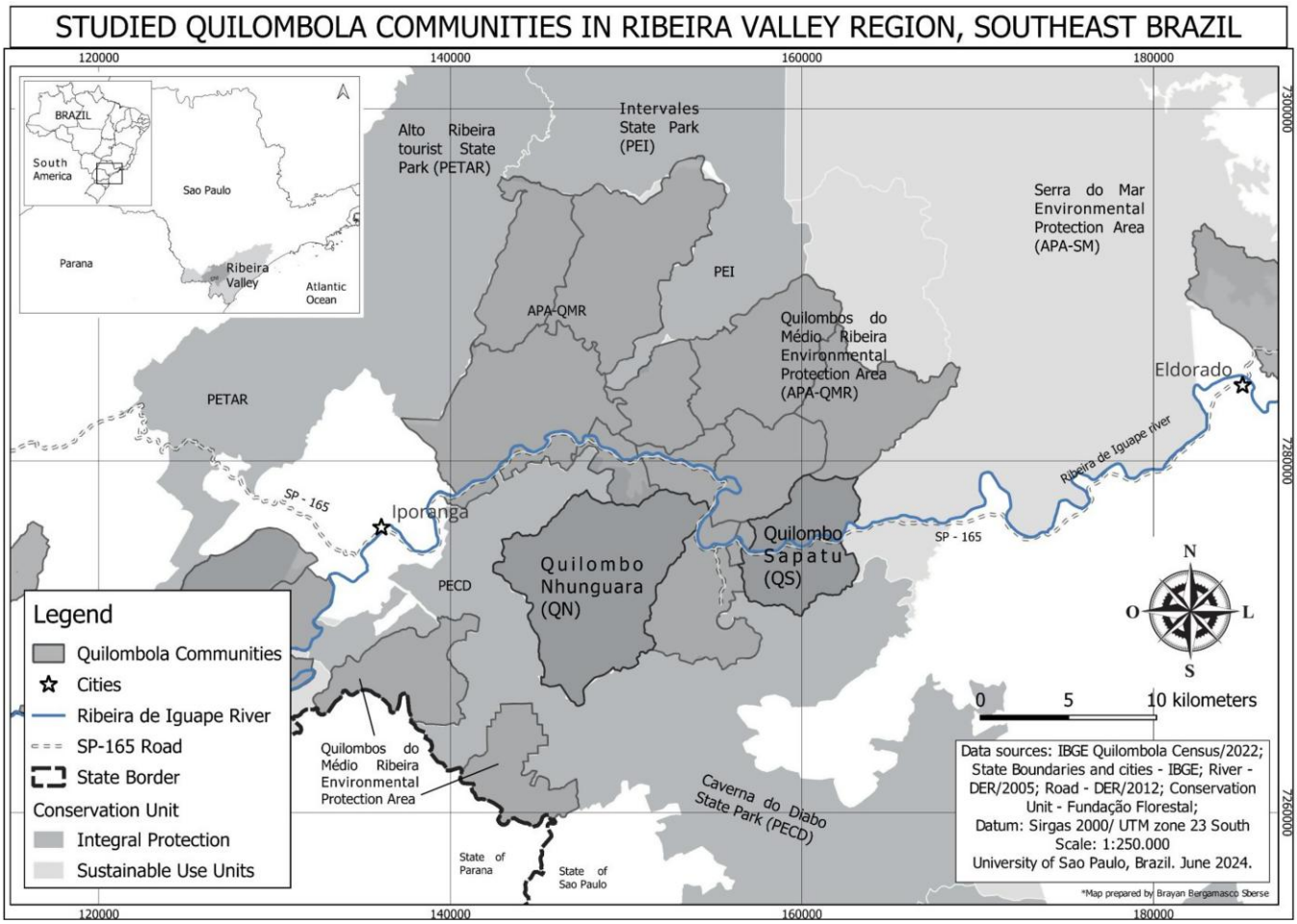

FIGURE 1. Studied Quilombola communities in Ribeira Valley Region, Southeast Brazil.

roads that run through the community; the others are farther away, making access by car impossible because of the poor condition of the roads.[29]

Participants.

Participants included individuals aged 18 years or older residing in QS and QN who agreed to participate in the study. The study used a convenience sample aiming to include as many participants as possible during the researchers' visits.

Quilombola community engagement.

Initially, the project was presented at a meeting with Quilombola representatives in Eldorado city to obtain permission to conduct research in the affected Quilombola communities. A preliminary phase involving the community was conducted before the beginning of activities, which included establishing methods of collaboration and distributing tasks and responsibilities. Operational activities involving community members, such as organizing meetings and ensuring adherence to the agreed-upon agenda, were facilitated by local leaders.

Field approach.

The study group conducted trips to the Quilombola communities in two stages: Stage 1, trip to QS (June 7–10, 2019); and Stage 2, trip to QN (June 14–19, 2019). During these stages, the researchers presented the project to residents at an open event at the local community center. Community leaders who were familiar with the residents and study sites helped the study group with field access and recruitment of participants. Local leaders helped us to reach residents in remote locations, accessible on foot, especially in QN. To interview people in rural communities, data collection was conducted during the weekend, when residents were closer to their homes and not working on farmlands.

Data collection.

Experienced researchers (male and female) of the study group conducted all interviews. They received additional training, including information on informed consent, interview guidelines, and ethical issues. All interviews were conducted in Portuguese, the native language of both the interviews and the participants; therefore, no language translation was required during the data collection process. Semistructured interviews were conducted face-to-face, in or near the participant's homes. Specifically in Stage 2, part of the interviews were carried out in the community center. Because of the greater number of houses in remote and isolated areas, which are difficult to access, the QN community leader mobilized residents to come to community center. As the community center did not have separate rooms available, we implemented the following strategies to ensure confidentiality: tables and chairs were spaced apart to minimize the likelihood of others overhearing the interviews, and at the beginning of each interview, participants were asked if they felt comfortable with the setup or if they preferred to conduct the interview in a different location. These measures were taken to respect participants' privacy and create a secure environment for their responses. Overall, the interviews were administered only once to each participant, without follow-up, and lasted about 30 minutes. All interviews were transcribed.

An instrument was designed to compile variables of interest, structured to address several topics including identification, residence and travel, medical history, symptoms from December 2018 to February 2019, vaccination, diagnosis of YF, knowledge about YF, and open comments. A database in RedCap was created to store these variables.

STATISTICAL ANALYSES

For statistical analysis, SPSS 20.0 (IBM Corp., Armonk, NY) was used. Thematic reflective analysis principles were applied for qualitative analysis of the content obtained from open-ended interview transcripts. The transcribed interviews were organized, coded, and categorized into related thematic groups. The codes were developed inductively. The coding process was carried out collaboratively by two researchers who performed repeated readings of the transcriptions and developed codes based on the emerging themes. Any discrepancies were resolved through discussion and consensus. Saturation was reached in the answers. The coding process resulted in the identification of 40 initial codes, which were subsequently grouped into six thematic categories.

In addition, we adopted a comprehensive, theory-informed behavior change approach: Theoretical Domains Framework (TDF)[30,31] to systematically identify and categorize reported facilitators and barriers of YF vaccination into TDF themes.

RESULTS

A total of 226 participants were enrolled in this study, which represents 41% of the total population of the two Quilombos (77% of the population of QS and 29% of QN) and an estimated 53% of the adult population; 46% were male. Ages ranged from 18 to 87 years. The majority were rural workers (52.2%) and 118 (52.2%) reported underlying medical conditions (Table 1).

Eighty participants (35%) reported having been acutely ill from December 2018 to February 2019. We analyzed gender differences in symptoms and found no significant differences between men and women. The distribution of symptoms was similar across genders. Fever, headache, myalgia, and nausea were the most commonly reported symptoms (Table 2). Of these, 59 (74%) participants sought healthcare because of the symptoms, and 11 reported having altered laboratory test results, including five with liver abnormalities. Eight were laboratory-confirmed and officially reported to the health authorities (Table 2).

The vast majority (96.5%) of participants reported having been vaccinated for YF, and 73.9% provided proof of vaccination. Of the vaccinated participants, 55.5% received a fractional dose, 68.8% were vaccinated in their local community and 18.3% reported vaccine reactions. Less than two-thirds of the participants were vaccinated in 2018 (Table 3). Fifty-three people were vaccinated on January 14 and 15 of 2019, after the death of a QS community leader well known to residents of both Quilombos. The leader's illness and subsequent death because of YF prompted an increase in demand for vaccination and led to a new immunization campaign in the communities (Figure 2).

At the time of the interview, only eight participants reported not having been vaccinated for YF (Table 4). Three male participants from QS had YF and were hospitalized at HC. Two of them had sought vaccination at the nearest basic health unit before presenting YF symptoms, but the health worker contraindicated the YF vaccine because of their underlying health conditions. In contrast, five female participants did not exhibit signs or symptoms of YF. Three of them disclosed that they did not receive the vaccine because they were

TABLE 1
Sociodemographic and clinical characteristics of participants, by Quilombola community in the Ribeira Valley

Variables	Quilombo Sapatu		Quilombo Nhunguara		Total		P
	n = 105		n = 121		N = 226		
Age (years)							
Median (min–max)	46	19–87	42	18–87	44	18–87	0.156
Gender (n %)							
Female	57	54.3	65	53.7	122	54	0.932
Male	48	45.7	56	46.3	104	46	
Occupation (n %)							
Rural worker	48	45.7	70	57.9	118	52.2	0.068
Domestic worker	34	32.4	35	28.9	69	30.5	0.574
Environmental monitor	6	5.7	0	0	6	2.7	0.008
Other occupation	32	30.5	28	23.1	60	26.5	0.213
Commuting to work (n %)							
No need to travel	25 of 94	26.6	21 of 108	19.4	46 of 202	22.8	0.227
Up to 1 km	33 of 94	35.1	42 of 108	38.9	75 of 202	37.1	0.579
>1 km–5 km	23 of 94	24.5	33 of 108	30.6	56 of 202	27.8	0.335
>5 km	13 of 94	13.8	12 of 108	11.1	25 of 202	12.4	0.558
Other itineraries (n %)							
Usually enters forest areas	60	57.1	74	61.2	134	59.3	0.173
Lifestyle habits (n %)							
Alcohol consumption	27	25.7	26	21.5	53	23.5	0.497
Tabacco use	7	6.7	13	10.7	20	8.8	0.283
Medical history (n %)							
Underlying medical condition	55	52.4	63	52.1	118	52.2	0.962
Hypertension	26	9.5	33	27.3	59	26.1	0.524
Diabetes	9	8.6	15	12.4	24	10.6	0.356

pregnant during the vaccination campaign period. They were breastfeeding at the time of the interview.

Almost all participants (92.9%) reported having knowledge about YF disease. Approximately half had known about it before January 2019; 21.9% became aware from the news of the 2016 outbreak in the states of Minas Gerais and SP. The majority of participants knew about the transmission of YF to humans (76.5%) and knew that monkeys also get sick (88.5%).

More than half of the participants reported that they often walk on the community forest trails for various purposes, including access to agricultural lands and natural resources. Of these, 43.2% used to see monkeys on the trails. The majority (73.6%) of the participants observed that monkeys had stopped appearing or making noise; of these, 28% noticed this in December 2018, 47.1% in January 2019, 5.1% between February and June 2019, and 19.7% in another period before December 2018. Only 4.5% of the participants encountered monkeys that appeared sick, with the main locations described in the fields and on trails in PECD; and 9.9% found some dead monkeys, with the main locations described inside the communities or surrounding areas, on trails, forested areas, and in PECD.

TABLE 2
Reported acute illness from December 2018 to February 2019, and signs and symptoms, by Quilombola community in the Ribeira Valley

Variables	Quilombo Sapatu		Quilombo Nhunguara		Total	
	n = 105		n = 121		N = 226	
Acute illness (n %)	35	33.3	45	37.2	80	35.4
Signs and symptoms (n %)						
Fever	21 of 35	60	22 of 45	48.9	43 of 80	53.8
Headache	25 of 35	71.4	29 of 45	64.4	54 of 80	67.5
Myalgia	21 of 35	60	25 of 45	55,5	46 of 80	57.5
Nausea	20 of 35	57.1	25 of 45	55.5	45 of 80	56.3
Vomiting	8 of 35	22.9	19 of 45	42.2	27 of 80	33.8
Abdominal pain	18 of 35	51.4	19 of 45	42.2	37 of 80	46.3
Jaundice	5 of 35	14.3	3 of 45	6.6	8 of 80	10
Arthralgia	14 of 35	40	23 of 45	51.1	37 of 80	46.3
Hiccups	1 of 35	2.9	6 of 45	13.3	7 of 80	8.8
Drowsiness	15 of 35	42.9	15 of 45	33.3	30 of 80	37.5
Seizures	1 of 35	2.9	2 of 45	4.4	3 of 80	3.8
Oliguria	5 of 35	14.3	2 of 45	4.4	7 of 80	8.8
Coluria	2 of 35	5.7	3 of 45	6.6	5 of 80	6.3
Hemorrhagic manifestations	4 of 35	11.4	2 of 45	4.4	6 of 80	7.5
Gingivorrhagia	4 of 35	11.4	2 of 45	4.4	6 of 80	7.5
Epistaxis	1 of 35	2.9	0 of 45	0	1 of 80	1.3
Petechiae	1 of 35	2.9	1 of 45	2.2	2 of 80	2.5
Melena	3 of 35	8.6	2 of 45	4.4	5 of 80	6.3
Laboratory-confirmed yellow fever case (n %)	6	5.7	2	1.7	8	3.5
Officially reported yellow fever case (n %)	6	5.7	2	1.7	8	3.5

TABLE 3
Reported yellow fever vaccination of participants, by Quilombola community in the Ribeira Valley

	Quilombo Sapatu		Quilombo Nhunguara		Total	
Variables	*n* = 105		*n* = 121		*N* = 226	
Yellow fever vaccination (*n* %)						
Yes	101	96.2	117	96.7	218	96.5
Proof of vaccination (*n* %)						
Yes	81 of 101	80.2	86 of 117	73.5	167 of 218	76.6
Date of first dose of vaccine (*n* %)						
Before 2018	5 of 101	4.9	4 of 117	3.4	9 of 218	4.1
January–June 2018	46 of 101	45.5	68 of 117	58.1	114 of 218	52.3
July–December 2018	9 of 101	8.9	4 of 117	3.4	13 of 218	6
January–June 2019	38 of 101	37.6	35 of 117	29.9	73 of 218	33.5
No information	3 of 101	2.9	6 of 117	5.1	9 of 218	4.1
Used fractional dose (*n* %)						
Yes	54 of 101	53.5	67 of 117	24.8	50 of 218	22.9
Reported vaccine adverse reactions (*n* %)						
Yes	21 of 101	20.8	19 of 117	16.2	40 of 218	18.3
Place of vaccination (*n* %)						
Local community	55 of 101	54.5	95 of 117	81.2	150 of 218	68.8
Eldorado city center	24 of 101	23.8	2 of 117	1.7	26 of 218	11.9
Another place	12 of 101	11.9	9 of 117	7.7	21 of 218	9.6
No information	0 of 101	0	1 of 117	0.9	1 of 218	0.5

Thematic analysis.

Six main themes emerged from the analysis: concerns about the YF vaccine, difficulty in accessing healthcare, perception of the risk of the disease, knowledge about the severity of the disease, cultural beliefs, and influence of leaders (Table 5).

Concerns about the YF vaccine.

These concerns were largely centered around the worry that the vaccine would cause more harm than benefit. The interviews also expressed concerns that the vaccine was risky for elderly individuals and those with comorbidities. Apprehension about serious adverse events was also noted, reinforced by descriptions of fake news that were disseminated to some participants through social media.

The elderly population was afraid to take the vaccine. Some participants with comorbidities such as hypertension reported that healthcare professionals advised seeing a specialist before taking the vaccine. As a result, they were afraid and did not take the vaccine initially in 2018. One elderly participant reported being one of the last to get vaccinated

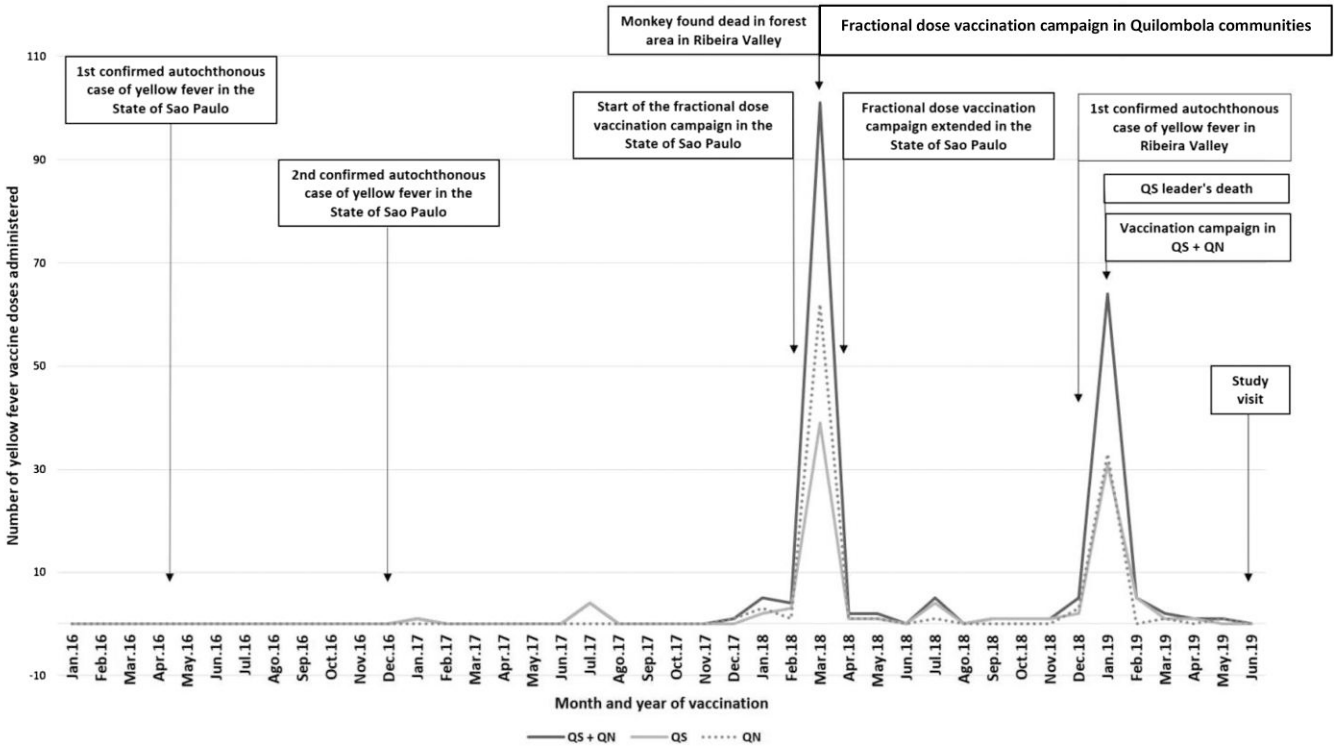

FIGURE 2. Number of yellow fever vaccine doses administered, by month and year of vaccination.

TABLE 4
Characteristics of participants who reported having not been vaccinated for yellow fever in two Quilombola communities in the Ribeira Valley, Brazil (June 2019)

Quilombola Community	Age (years)	Gender	Laboratory-Confirmed Yellow Fever	Underlying Medical Condition	Reason to Not Vaccinate for Yellow Fever
Sapatu	44	Male	Yes	Respiratory disease	Thought he did not need it—he never gets sick
Sapatu	48	Male	Yes	Neurologic disease	Medical history—epilepsy (contraindicated by local HW)
Sapatu	58	Male	Yes	Infectious disease	Medical history—leprosy (contraindicated by local HW)
Sapatu	24	Female	No	None	Pregnancy and/or breastfeeding in 2018/2019
Nhunguara	33	Female	No	Respiratory disease	Pregnancy and/or breastfeeding in 2018/2019
Nhunguara	27	Female	No	Infectious disease	Pregnancy and/or breastfeeding in 2018/2019
Nhunguara	22	Female	No	None	No specific reason
Nhunguara	70	Female	No	Cardiovascular disease	Difficulty of access because of geographic isolation

HW = health worker.

(in March 2019) because she was afraid of having a reaction because of heart problems. Another elderly participant reported taking the vaccine only on the third occasion it was offered in the community and had a reaction. One participant reported that her mother did not get vaccinated because she was elderly (86 years old), had been diagnosed with diabetes, and was afraid of the vaccine's reaction.

The spread of fake news appeared in statements where participants reported that the population received messages through social media.

Example of social media report:

- "*The vaccine does more harm than the disease."* – female, 49 years old, QN;
- "*The vaccine transmits HIV*. *The injection kills, the disease does not."* – male, 29 years old, QN.

The fact that the vaccine offered in the first campaign was the fractional dose raised questions about its effectiveness and duration of protection.

Example of typical report:

- "*People were somewhat afraid to vaccinate. I think they thought it wouldn't be effective.*" – female, 23 years old, QS.

Difficulty in accessing healthcare.

The participants live in rural areas, some of which are geographically isolated and difficult to access, making it challenging to reach healthcare services. Because of the live virus nature of the YF vaccine, certain precautions were taken for elderly individuals and those with comorbidities. Local health agents were uncertain about recommending the vaccine and advised residents to obtain a medical report from a specialist, such as a cardiologist. However, to see a specialist, residents had to travel to larger towns, often facing long waits for appointments. As a result, many missed the opportunity to be vaccinated. In addition, remote areas, particularly in QN, made it difficult for health agents to reach some households, further hindering access to vaccination.

TABLE 5
Themes categorized by TDF, barriers and enablers to YF vaccination

Themes	TDF Domains	Barriers	Enablers
Concerns about YF vaccine	Knowledge	Lack of knowledge about efficacy or side effects of the vaccine	Perception about vaccine benefits after outbreak
	Beliefs about consequences	Perception that vaccine is not effective	Perception that first cases were not vaccinated
		Distrust of YF vaccine safety	
		Perception that fractioned dose is weak	
	Emotion	Fear of side effects	Fear of YF disease after outbreak
		Absence of concern about YF	Fear of death after outbreak
Perception of disease risk	Knowledge	Lack of knowledge about risk of YF	Health education about YF
	Beliefs about consequences	Misconceptions about YF transmission	Perception that monkeys had died of YF
Knowledge about disease severity	Knowledge	Lack of knowledge about YF lethality	Knowledge about disease severity after outbreak
	Beliefs about consequences	Perception that vaccination campaign was an exaggeration	Perception about vaccine need after outbreak
Difficulty accessing healthcare	Environmental context and resources	Lack/shortage of vaccine supply	Free-of-charge yellow fever vaccination
		Presence of other health conditions	Clear guideline to local healthcare workers
		Poor accessibility to health services	Vaccination strategies home to home
		Challenges in geographical access	Vaccination in target community places
	Social role and identity	Unequal access of healthcare by Quilombola communities	Health authorities' visit after outbreak
Cultural beliefs	Social role and identity	Structural racism	Cultural humility in vaccination strategies
		Religious beliefs	
		Traditional use of medicinal plants	
Influence of leaders	Social influences	Negative experiences of close contacts	Encouragement from local leaders
		Lack of encouragement from family and local leaders	Local leaders' participation in vaccination strategies
	Social role and identity	Lack of social role to stimulate the community to be protected	Community involvement in vaccination after outbreak

TDF = Theoretical Domains Framework; YF = yellow fever.

Example of common report:

- *"The local doctors advised that I should see a cardiologist before taking the YF vaccine. So, I was afraid to get vaccinated. The diabetes diagnosis, 19 years ago, was difficult for local doctors."* – male, 69 years old, QS.

Example of participant residing in a forest isolated area of QN:

- *"I was very worried because one was going to the doctor, another was dying. When I heard about the vaccine (in 2018), they had already left and I didn't take it (I live very far away)."* – female, 67 years old, QN.

Perception of disease risk.

In several speeches, participants mentioned that they did not think the disease would reach their community and that the YF vaccination at that time (2018) was an exaggeration.

Examples of common reports:

- *"At first, I didn't know what was happening. Later, I found out that people had died of YF. During the campaign (March 2018), I didn't get vaccinated. I thought it was an exaggeration, that the disease wouldn't come here."* – female, 24 years old, QN.
- *"In 2018, there was movement for vaccination. There was movement in Registro city. We thought it only happened to others. We thought the disease was in SP and wouldn't reach here."* – male, 46 years old, QS.

Knowledge about disease severity.

Some comments indicated a lack of knowledge about the severity of the disease. For example, some participants saw YF as a mild illness; therefore, interest in vaccination was low in the first vaccine campaign (March 2018).

Examples of common reports:

- *"I thought YF made people yellow, it wasn't that big deal."* – female, 42 years old, QN.
- *"People didn't believe that YF was a serious illness*." – male, 69 years old, QS.

Cultural beliefs.

Cultural beliefs were present in some reports of study participants, such as religion, values, and traditional practices, like the use of medicinal plants.

Example of typical report:

- *"I was afraid of taking the YF vaccine. I know I will die when God wants."* – male, 36 years old, QN.

Example of report from YF vaccine campaign health worker participant (March 2018):

- *"People think they were being discriminated against, because YF is known as monkey disease and they are Quilombolas. I feel somewhat responsible and at the same time powerless because I tried everything and yet people did not get vaccinated in the campaign."* – female, 50 years old, QS.

Influence of leaders.

There were some reports of distrust in relation to the YF vaccine resulting from some community leaders not taking the vaccine in 2018. Others mentioned vaccination after the death of community leaders because of YF.

An important community member in QS had mobilized people in the first vaccine campaign in March 2018; but he did not take the vaccine himself and died of YF on January 13 2019. Several participants had been directly affected by leaders having severe cases or even dying from YF.

Examples of typical reports:

- *"When the vaccine came, people didn't really believe it. It seemed like a story, no one had seen it. My father (community leader) took everyone to get vaccinated, but he didn't take it himself, he was afraid. On the day of his funeral, about 60 people got vaccinated. I think 70% of the neighborhood hadn't been vaccinated."* – female, 26 years old, QS.

Also, in Site 2 (QN), some participants vaccinated for YF only after the influent local leader's death:

- *"I got vaccinated on January 14, 2019. On January 15, I started to have symptoms. I thought it could have been a natural disaster, a reaction of nature. But it hadńt happened here. We never think it will happen to us. When the community leader died, I attended the burial on Sunday, vaccination was on Monday, and then it happened very quickly."* – male, 29 years old, QN, hospitalized at HC with severe YF in January 2019.

Some participants highlighted the role of local religious leaders.

An example of a minority report:

- *"Many people didn't get vaccinated because they were told the vaccine would transmit disease; people only went to get vaccinated after evangelical pastors helped break the taboo."* – female, 57 years old, QN.

In summary, the individual decision-making process regarding vaccination is complex and multidimensional. Barriers to YF vaccination have been identified, as well as the broader sociocultural issues of the context in which these barriers are rooted.

DISCUSSION

In this study, we analyzed 226 individuals residing in two Quilombola communities from Ribeira Valley, a region that had laboratory-confirmed cases admitted to HC. During the period of the YF epidemic, more than one-third reported having been acutely ill, although diagnostic testing was not available. Although YF vaccination was available at the beginning of 2018, an important proportion of the Quilombola population (>40%) did not adhere; thus, when the epidemic reached the region, there was a significant susceptible population. The potential explanations involve lack of knowledge, poor training of health workers, misconceptions about the vaccine and the disease, the spread of fake news, the involvement/not involvement of local leaders, and the short period during which the vaccination was offered locally before the epidemic. Once a local leader died of YF, the population sought the vaccine actively and the authorities made an effort to extend coverage, offering vaccination even at the leader's wake.

Initially, we conducted a demographic data analysis indicating homogeneity between QS and QN groups, especially by gender and age. The Quilombola population in Brazil is 1,330,186 people, corresponding to 0.66% of the population; the Southeast Region concentrates 182,427 Quilombolas (14%). The analysis of the age structure of the Quilombola

population, in comparison with the structure by gender and age in Brazil, highlights differences in the composition of this traditional and specific population group. The Quilombola population has more men than women, especially in the younger age groups.[32] In Brazil, YF has historically been documented mainly among rural workers and male individuals aged between 14 and 35 years. That prevalence profile is because of greater exposure and not greater susceptibility to the virus.[33] The recent reemergence of YFV also showed that the majority of the population affected by YF (>80% during 2016–2019) were male.[34] This population is in an economically active age range and is composed of rural areas residents, probably because of work activities and proximity to forest sites, factors that contribute to the exposure of these individuals to the vectors.[33,35,36]

We found in our study that all participants with laboratory-confirmed and officially reported YF were male, aged 25 to 58 years, and 75% were rural workers. All cases of death by YF (related by the participants and officially reported to health authorities) were in male individuals in both communities (QS and QN). Although no environmental monitors were confirmed as cases in our study, they were also likely at higher risk because of their frequent entry into high-risk locations, such as forest trails within the PECD, where dead monkeys were encountered. Furthermore, official reports include a case of YF-related death in a male environmental monitor from the Ribeira Valley region, highlighting the occupational risk.[16]

Our study was done only 6 months after the beginning of the YF outbreak. This short interval was important to reduce recall bias in the study. Eighty participants (35.4%) reported acute illness compatible with YF from December 2018 to February 2019. Of these symptomatic participants, only eight had officially been reported to health authorities. All were severe cases, admitted to hospitals. We estimate that only severe cases of YF were informed to the health authorities and that patients with mild symptoms were missed.

Brazilian Quilombola population has a significant territorial diversity, being present in different geographical situations, in urban and rural spaces.[32] Both the studied communities (QS and QN) are located in rural areas of Ribeira Valley, surrounded by Atlantic Forest vegetation. Every month, a considerable number of residents in both QN and QS travel to Eldorado or Iporanga to shop and access public services, such as banks, health centers, and hospitals.[29]

Rural Quilombola populations are relatively invisible when considering disease indicators and thus are not adequately considered in public health policies. It is difficult for the Quilombolas to access health services because of their relative geographical remoteness and the low supply of health services close to their territory.[37–40] Isolation, low access to healthcare, and underreporting of cases are the main obstacles to continued YF population-based surveillance.[41] In our study, the theme of difficulty accessing healthcare emerged in the content analysis, also as a barrier to YF vaccination.

The use of YF vaccine fractional doses was adopted to control recent outbreaks in Brazil and was appropriate to the emergency as a temporary solution to vaccine shortages.[42,43] From February to March 2018, plans were made to vaccinate around 20 million people from 76 municipalities in the States of SP, Rio de Janeiro, and Bahia.[44] With global vaccine stocks depleted and experiencing substantial shortages, dose fractionation was a valuable strategy to expand vaccine coverage to reach all at-risk communities.[14,45,46]

The first YF vaccination campaign in Quilombola communities of the Ribeira Valley occurred in March 2018. It was triggered because on February 19, 2018, a 50-year-old man, resident of a nearby municipality (Miracatu), died because of YF; and on March 2, 2018, a monkey was found dead in a forest area of the same region (Pedro de Toledo). The Ribeira Valley is 4 hours away from the capital, SP, and there are few hospitals in the area. Community health agents worked intensely, visiting and vaccinating Quilombola communities in March 2018. At this time, the fractional vaccine was used in the state.[17]

Despite extensive campaigns for YF vaccine, we found that information reaching the studied Quilombola communities varied widely. Hence, only 101 participants (39 from QS and 62 from QN) were vaccinated for YF in March 2018. In our study, two themes emerged from the content analysis as barriers to vaccination: concerns about the YF vaccine, especially fear of side effects and mistrust of the fractional dose; and perception of disease risk, with lack of knowledge about the risk of YF and misconceptions about YFV transmission.

According to the National Immunization Program Information System,[47] 69,657 doses of YF vaccine were administered in the Ribeira Valley in March 2018; YF vaccination coverage was 48.51% in the State of SP in 2018, and 10.91% and 58.22% in Iporanga and Eldorado, respectively. For experts from Brazilian health agencies, the low adherence could be a consequence of fake news, which attributed deaths from YF to the vaccine itself, and misinformation among health teams about the protective effect of the fractional doses (the idea that the smaller dose would not have the same effect as the full one).[17]

In a recent review,[48] false information on immunobiological agents, inadequate knowledge, negative attitudes toward vaccination, beliefs (religious or on the vaccine's efficacy), lack of time for vaccination, and difficulty accessing vaccination hubs were the factors that contributed most to YF vaccine hesitancy. Furthermore, other negative factors were: risk perception in terms of disease versus vaccine, concerns regarding vaccine safety and adverse events, age, and time spent in the country in the case of travelers. The cost of immunization was an important factor influencing vaccine hesitancy, which is not applicable to Brazil where YF vaccine is made available free of charge.

Brazilian qualitative research[49] analyzed fake news about vaccines published on national news checking websites in different years, from 2010 to 2019. In this study, greater dissemination of fake news was observed in 2018, representing 55% of total news, 63% of which referred to the YF vaccine. Other factors that may have interfered with YF vaccination coverage include: lack of well-functioning immunization system, knowledge and attitudes about vaccination, and lack of communication and information.[41]

In our study, after the outbreak initiation in Ribeira Valley, with illness and death of a known Quilombola leader, 64 (31 from QS and 33 from QN) participants took the YF vaccine in January 2019, during a new campaign (Figure 2). We identified the themes: knowledge of the disease severity and the influence of leaders as enablers to YF vaccination.

Our study showed that eight participants reported not having been vaccinated (Table 3). There were different reasons

among participants who opposed the YF vaccine; for example, contraindication by the health workers because of medical history, or pregnancy and/or breastfeeding in 2018/2019. YF is preventable by a live attenuated vaccine, which is classically contraindicated during pregnancy because of concerns of harming the fetus.[50] Except in the case of an outbreak emergency, the contraindication of the YF vaccine in pregnant and lactating women is because of the risk of vertical transmission of the vaccine virus.[10,51–54] Despite this, WHO recommendations indicate that a risk–benefit assessment should be made during outbreaks and when living in an YF-endemic region, as the benefits of vaccination may outweigh the risk of transmission of the attenuated virus to the fetus.[10,43,53–55] A qualitative study showed that conflicting information about vaccine safety led to concern about miscarriage in pregnant women; and that health officials were unaware of the WHO recommendation that pregnant women can be vaccinated for YF during outbreaks.[56] Other recent studies[57] explored perceptions of YF vaccination in Uganda among vulnerable groups (people over 65 years and pregnant women) and most respondents had no knowledge of the vaccine, and the lack of information reinforced mistrust of YF vaccines.

In our study, cultural beliefs were identified as barriers to YF vaccination. Adopting cultural humility is essential to build trust with Quilombola communities and develop partnerships founded on reciprocal respect to improve vaccination strategies. In the medical context, cultural humility may be defined as a process of being aware of how people's culture can impact their health behaviors, and in turn, using this awareness to cultivate sensitive approaches.[58] Other studies also indicate the need to provide culturally tailored health education and vaccination initiatives, focused on cultural humility.[59,60]

Our study has some limitations. First, we only visited two Quilombola communities in Ribeira Valley. It must be taken into account that other Quilombola communities may have different sociodemographic and geographic characteristics, therefore the data may not be generalizable. Second, the use of a recorder was not possible in the site fields. So, the interviews were not audio recorded and information collected in the open-ended section of the questionnaire was transcribed directly from notes during the interviews. We emphasize that the study group was trained in conducting interviews to ensure data quality. Third, we did not include the totality of residents of the two communities. This would have been challenging, because we conducted our data collection in remote rural areas. Despite that, we included a considerable proportion of the community members. Furthermore, 23.19% of the Quilombola population of the state of SP is aged between 0 and 14,[32] and we only included people starting at 18 years old. Therefore, the percentage of the adult population included in our study was even larger.

CONCLUSION

In conclusion, the outbreak in the Ribeira Valley may have been averted with a proper understanding of the decision-making process regarding vaccination that is influenced by several individual, sociocultural, and contextual factors. Barriers and enablers to vaccination identified in this study highlight the need for targeted interventions addressing misinformation, improving access to healthcare, and addressing community-specific concerns to enhance vaccination uptake and control of the disease in communities.

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