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Article

The guarantee of the right to health and social security: challenges faced by the quilombola population of the coastal strip of Paraíba

A garantia do direito à saúde e a seguridade social: entraves vivenciados pela população quilombola da faixa litorânea da Paraíba

La garantía del derecho a la salud y la seguridad social: obstáculos vividos por la población quilombola de la franja costera de Paraíba

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Abstract

Objective: To discuss the obstacles faced by the quilombola population in the state of Paraíba in their struggle for effective access to the Unified Health System. **Methodology:** This was an experience report describing the researchers' experiences while developing an extension project based on popular health education, as well as qualitative research and population surveys in the quilombola territories along the coastal area of the state of Paraíba. There are approximately 293 families in the territory. Fieldwork included activities carried out from 2014 to 2021, during which this study was conducted. **Results:** The quilombola territories in the region are threatened by construction and luxury real estate activities, which jeopardize and delay the formal titling of land and also constitute an obstacle to the acquisition of rights reserved for this population, as these depend on legal recognition of the territory as quilombola. Barriers to effective access to the Unified Health System include: deficient infrastructure; scarcity of health professionals; poverty and social exclusion; social security issues; lack of health policies; weak recognition of rights; stigma and discrimination. **Conclusion:** Ensuring access to healthcare for all is a moral and legal imperative that requires the joint action of governments, health professionals, and civil society.
Keywords: Unified Health System; Quilombolas; Right to Health.

Resumo

Objetivo: discutir os obstáculos que a população quilombola do estado da Paraíba vivencia no processo de luta por acesso efetivo ao Sistema Único de Saúde. **Metodologia:** tratou-se de relato de experiência em que se descreve as experiências das pesquisadoras ao desenvolverem projeto de

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extensão, fundamentado na educação popular em saúde, e pesquisa qualitativa e de inquérito populacional, nos territórios quilombolas da faixa litorânea do estado da Paraíba. No território, há cerca de 293 famílias. O trabalho de campo compreendeu atividades que são desenvolvidas desde 2014 até 2021 em que foi desenvolvido o presente estudo. **Resultados:** os territórios quilombolas da região são ameaçados pelas atividades da construção civil e imobiliárias de luxo, o que põe em risco e retarda o alcance da titulação das terras, além de se torna um obstáculo para aquisição de direitos reservados a essa população, visto que estes dependem do reconhecimento legal do território como quilombola. As barreiras para o acesso efetivo ao Sistema Único de Saúde envolvem: infraestrutura deficiente; escassez de profissionais de saúde; pobreza e exclusão social; seguridade social, deficiência de políticas de saúde; fragilidade no reconhecimento dos direitos; estigma e discriminação. **Conclusão:** garantir o acesso à saúde para todos é um imperativo moral e legal que exige a atuação conjunta de governos, profissionais de saúde e a sociedade civil.
Palavras-chave: Sistema único de Saúde; Quilombolas; Direito à Saúde.

Resumen

Objetivo: Analizar los obstáculos que enfrenta la población quilombola del estado de Paraíba en su lucha por el acceso efectivo al Sistema Único de Salud. **Metodología:** Se trató de un relato de experiencia que describe las vivencias de las investigadoras al desarrollar un proyecto de extensión basado en la educación popular en salud, así como investigación cualitativa y encuestas poblacionales en los territorios quilombolas de la franja costera del estado de Paraíba. En el territorio hay aproximadamente 293 familias. El trabajo de campo incluyó actividades desarrolladas desde 2014 hasta 2021, período durante el cual se realizó el presente estudio. **Resultados:** Los territorios quilombolas de la región están amenazados por las actividades de construcción y bienes raíces de lujo, lo que pone en riesgo y retrasa la titulación de las tierras, además de constituir un obstáculo para la adquisición de derechos reservados a esta población, dado que estos dependen del reconocimiento legal del territorio como quilombola. Las barreras para el acceso efectivo al Sistema Único de Salud incluyen: infraestructura deficiente; escasez de profesionales de salud; pobreza y exclusión social; problemas de seguridad social; deficiencia de políticas de salud; débil reconocimiento de derechos; estigma y discriminación. **Conclusión:** Garantizar el acceso a la salud para todos es un imperativo moral y legal que requiere la acción conjunta de gobiernos, profesionales de salud y la sociedad civil.
Palabras clave: Sistema Único de Salud; Quilombolas; Derecho a la Salud.

Introduction

Social security in Brazil is a complex system of social protection, established by the Federal Constitution (FC/88), which aims to guarantee rights to health, social assistance and social security. However, this system faces significant challenges due to demographic, economic and structural factors and is a combination of actions by the government and society to ensure these rights[1]. Historically, the system has undergone several reforms to adapt to legal and social changes[2,3].

The Unified Health System (SUS) in Brazil is based on principles such as universal access and fair treatment. This implies that everyone has the right to health, regardless of their socioeconomic status, and equity seeks to treat the unequal unequally, ensuring that vulnerable groups have access to adequate care[4].

The right to health is a central theme in health law, especially in contexts of vulnerability. This issue involves protecting and promoting the health of groups facing social, economic and cultural disadvantages[5].

The guarantee of the right to health and social security for the Brazilian quilombola population faces several obstacles, reflecting a scenario of historical and social inequality. Quilombola

communities, made up of descendants of enslaved Africans, face significant difficulties in accessing basic health services, despite these rights being constitutionally guaranteed by the SUS[6,7].

The lack of normative and institutional articulation between the Brazilian social security system and public policies aimed at these communities further aggravates the situation, resulting in concrete difficulties in accessing social security benefits and other social rights[8].

In addition, socio-economic factors, such as their geographical location in rural and hard-to-reach areas, contribute to the vulnerability of these populations, negatively impacting their health and quality of life[9,10]. During the COVID-19 pandemic, for example, precarious access to water and basic sanitation became even more evident, exacerbating health risks[9,11].

Ethnic and racial violence, along with the democratic crisis in Brazil, has also negatively influenced the living conditions and rights of quilombola communities, perpetuating a cycle of exclusion and marginalization[12].

The legal framework for quilombola rights goes hand in hand with Brazil's constitutional evolution. Through the Golden Law, the abolition of slavery in 1888, it is understood that quilombola communities became free, but the black population continues to be marginalized, as well as the quilombos, made invisible by the public authorities. Article 68 of the 1988 Federal Constitution recognized the ownership of land by the remnants of quilombola communities[13].

The FC/88 created an obligation for the Brazilian state to formulate public policies to protect quilombolas. Articles 215 and 216 in particular guarantee the full exercise of quilombola communities' cultural and social rights. As a result, quilombolas are recognized as a social organization, based on their own customs and traditions that differentiate them as a population group[14].

The promulgation of FC/88 was a new milestone for the formulation of federal public policies aimed at the black population in Brazil. Since then, the Brazilian state has adopted affirmative action and social inclusion policies to combat structural racism and promote equal opportunities. The main focus of these policies has been to increase access to education, the job market, health and citizenship for this population, with an emphasis on affirmative action in universities and public tenders.

Among the main federal public policies after FC/88, we have the "Affirmative Actions in Higher Education", which, from the 2000s onwards, were implemented to increase the access of the black population to higher education, culminating in Law 12.711/2012, which determined racial quotas in all federal higher education institutions. Currently, the black population has significantly greater access to university, which contributes to and points to the reduction of racial inequalities at this level of education[15].

Law 12.990/2014 instituted quotas for blacks in federal public tenders, with the aim of promoting inclusion in the public service and combating the historical under-representation of the black population in state positions[15]. And, based on the "Promotion of Racial Equality", various federal policies and programs were created to promote racial equality, guarantee rights and combat racism, based on the principle of human dignity, enshrined in FC/88[15].

In 2003, Decree Nº. 4.887 was drawn up, which, in turn, guarantees an improvement in the quality of life of the quilombola population. The document emphasizes the right of access to health, education and sanitation services[16].

It is essential that public policies are re-evaluated and implemented in order to guarantee equity and respect for the human rights of these communities[17]. This experience report on quilombola

territories in the state of Paraíba aims to discuss the obstacles faced by the local quilombola population in their struggle for effective access to the Unified Health System.

Methodology

This is a critical report describing the experiences of the researchers in research/extension activities in quilombola territory, based on personal observations and field diary entries, which highlight the obstacles experienced by the quilombola population of the coastal strip of Paraíba in terms of access to healthcare. The investigation took place in four quilombola communities, called Gurugi, Ipiranga and Mituaçu. The communities are located in the municipalities of Conde and Paratibe, in the city of João Pessoa. In Paraíba, the quilombos along the state's coast comprise around 293 families.

Dialogue with local leaders, through visits to the population and participation in community activities, began in 2014 and continued until 2021, under the leadership of the main author. However, the link with the communities continues through the creation of other extension projects that followed the example of the initial proposal, with links to the children's ministry and through the practice of research. This continuity allowed the researcher to observe and become socially involved at various times in the communities.

The fieldwork was carried out by the university extension and adopted the Popular Education methodology, developed by students from health courses, and was later redesigned in both extension and research; and the Freirean character of the activities continued.

A participatory methodology was adopted, because it considers that participating means “taking part in the process; following up in a qualified way during the project and at the end of it the activities generated through collective decisions; and it also involves sharing the results”[18]. For the authors of this methodology, participating implies relating, which may require rules of coexistence and sharing, as well as the ability to listen.

Participatory methodologies are also based on Freire’s conception, for whom[19]” [...] proposing to the people, through certain basic contradictions, their existential, concrete, present situation, as a problem which, in turn, challenges them and thus demands a response, not only at the intellectual level, but at the level of action”.

According to Pedro Demo[20]According to Pedro Demo[20], this is an approach designed to reach subjects, events and different temporalities, so the experience report intertwines different types of knowledge and processes, connecting to forms of scientific production that are more sensitive to the relevance of narrative skills. In a context marked by mistrust, political tensions and criticism of universalizing discourses, the narrative emerges as a legitimate way of expressing and validating knowledge about singularities, assuming the status of a competent scientific narrative. The account reveals trajectories, stories and highlights the importance of multiple voices in telling them[20].

The fieldwork, over time, included activities carried out in the territories, such as home visits, monitoring the community’s social activities, and the participation of the researcher in health education activities based on activating changes in the territory. It was structured in partnership with the community leaders of the communities and the community health agents who were called in played an active role in carrying out the fieldwork, identifying homes, choosing the best routes to take in the territory and introducing the researcher to the families.

Questionnaires were administered regarding the socio-economic profile of the families, the health/morbidity profile of the children aged 0 to 10 and the food security profile of the families. The data was stored on the RedCap platform and analyzed using Stata software.

With regard to ethical aspects, the study was approved by the Research Ethics Committee of the Aggeu Magalhães Research Institute - FIOCRUZ/PE, under CAAE: 35329120.2.0000.8807.

Results and discussion

Study site

The state of Paraíba covers an area of 56,467.239 km², divided into four mesoregions (Mata Atlântica, Brejo, Agreste and Sertão), with an estimated population of 4,018,127 people, a population density of 66.7 inhabitants/km² and a human development index (HDI) of 0.658[21].

According to official data, there are currently 42 quilombola communities in the state, recognized by the federal government. There are a total of 3,050 families, with an approximate number of 15,250 quilombolas. The last census carried out in the state in 2012 registered only 7,095 individuals with a household situation distributed between the urban area (15.2%) and the rural area (84.8%). Around 29.8% of the entire census population is distributed in the Paraíba hinterland[22].

Table 1. Main characteristics of quilombola communities in the coastal region of the state of Paraíba, 2021

Community	Municipality	Geographic area (km²)	Total number of residents
Paratibe	João Pessoa	2,67	297
Gurugi I	Conde	1,49	199
Ipiranga	Conde	0,34	153
Mituaçu	Conde	5,85	386
Total		**10,35**	**1035**

Source: the authors.

The quilombola population is understood to be in a situation of vulnerability, due to the exploitative and discriminatory process they have suffered. The recognition of communities as quilombolas is intrinsically related to the identification and titling of their territories. For these groups, the ancestral connection with the land is the basis of their history, cultural identity, religious manifestations, forms of leisure, economic and subsistence activities, as well as their family relationships[23]. Therefore, to recognize oneself as a quilombola is to be connected historically and ancestrally to a territory.

> Quilombola communities are part of a context in which their definition is based on criteria of self-attribution, their own historical trajectory and specific territorial ties , where they are generally located in rural areas. Difficulties of access interfere with the health and education of this group, who tend to suffer from high illiteracy rates, precarious living conditions, housing, basic sanitation and access to health services.[24]

Racial inequalities and health indicators

The presence of racial inequalities has harmful consequences for the health indicators of this population, which has a higher incidence rate of various diseases. Recent studies show that the quilombola population in Brazil has some of the worst health indicators, with high rates of infectious and chronic diseases and conditions associated with social vulnerability. Hypertension, diabetes, heart disease and kidney disease are highly prevalent, especially among the elderly and Quilombola women. Multimorbidity (≥2 chronic diseases) reaches 52.9% of the elderly, with a higher incidence in women and older age groups[25,26,27,28].

In the context of infectious and parasitic diseases, there is, for example, the seroprevalence of toxocariasis, which showed a prevalence of 82.7% in quilombola communities in southern Brazil, the highest ever recorded in the country, associated with poverty, contact with contaminated soil and lack of basic sanitation[29,30]. In addition, the prevalence of common mental disorders reaches 38.7%, with a higher risk among women, people with low schooling, low income and who have suffered discrimination in health services[30].

With regard to oral health, there are high rates of edentulism, carious lesions and periodontal diseases, which are attributed to lack of sanitation, limited access to health services and consumption of cariogenic foods[31,32]. With regard to malnutrition and cardiovascular risk, among the elderly, there is a high prevalence of underweight, loss of muscle mass and cardiovascular risk, especially in women and older people[26].

Elderly quilombolas have a low average life expectancy score, reflecting the adverse conditions faced by this population. In addition, the quality of life of quilombolas is impaired by factors such as low income, low level of education, difficulties in accessing health care and unfavorable environmental conditions, which contributes to greater vulnerability and, consequently, lower life expectancy[33,34]. The presence of chronic diseases, such as hypertension and diabetes, is high among quilombolas, further aggravating the health situation and reducing longevity[33].

Despite the intensification of social and political actions with leaders within the communities, the human development indicators in these places are unequal and characterized as inferior compared to other groups[35]. Access to health care is hampered by geographical isolation and the poor quality of the services available, resulting in worse health conditions, especially among women[33].

Studies in different Brazilian states show that most quilombola families live on up to one minimum wage, often supplemented by social programs such as Bolsa Família. Access to basic sanitation and electricity is still insufficient in many communities, as pointed out in an analysis of living conditions in quilombola communities in Tocantins and in a study of morbidities in quilombos in the Amazon region[10,36]. Dietary diversity and quality are limited, especially among children, and are associated with socio-economic factors such as income, schooling and the number of people in the household[37].

In the Brazilian context, social inequalities arising from ethnic-racial issues are reflected in the living conditions and health of the black, brown and indigenous populations, who have lower health indicators when compared to the white population[38].

Health records are strategic and fundamental for understanding the morbidity and mortality conditions of populations and for decision-making. When studies/lives are planned in quilombola territories, they must be aware of and respect the historical process and construction of each territory,

so that they can make a contribution in line with territorial needs and ways of doing things, working together with the community, activating autonomy and self-recognition.

Challenges reported by the quilombola population in accessing health services

According to the experience of the researchers in research/extension activities in the quilombola territory, and as allowed by the bond developed with the communities, for the quilombola population to access targeted and specific public policies, the declaration (officialization) of the territory as quilombola and the concrete move towards recognition is essential. This has been these communities' biggest obstacle to achieving affirmative rights, due to territorial disputes with farmers, real estate agents and the government's slow recognition process.

There is a constant dispute over the quilombola territories in the region, which are threatened by construction activities and luxury real estate, which jeopardizes and delays the achievement of land titling, as well as becoming an obstacle to the acquisition of rights reserved for this population, since these depend on the legal recognition of the territory as quilombola.

Among the rights that are becoming more distant is health care according to their needs and specificities. According to the National Comprehensive Health Policy for the Black Population[39] due to the context of historical vulnerability to which the black population has been subjected, it is essential that strategies are implemented to mitigate health inequalities in the different life cycles. Among these strategies, the place of care/health attention must be within the community, close to the people, where life happens, i.e. residents' associations, spaces where religious and cultural activities take place.

Over the years of activities in the quilombos of the coastal strip of the state of Paraíba, we have identified limitations in access to the local health service, mainly in its dimensions: availability and adequacy. Each quilombola community in the coastal strip of the state of Paraíba has its own health unit of reference, but not all families are covered by a community health agent, which, added to the distance and lack of transportation, makes it difficult to access information about the service and to monitor families' health and/or illnesses.

Each quilombola community on the coast of the state of Paraíba has a health unit that covers its respective territory, but the structure of the integrated health units means that some localities are geographically distant from each other, bringing together three or four family health teams in the same unit. Therefore, the location privileges some families over others, an organization that benefits the municipality's structural management and financing process, promoting the containment of institutional expenses, but which leads some population groups to live with the geographical distance to the health service.

While for some groups the service is a two-minute walk away, for others it becomes a 30/40 minute walk, since private transportation is not available to families and public transportation is deficient. This is the reality of the quilombola population of Paratibe, in the municipality of João Pessoa.

In this way, there is the majority of experience that reports the distance of the integrated health unit from the territory, an aspect that makes it difficult for users who most need to go to this place of health care, such as pregnant women, infants, the elderly and people with disabilities.

According to a cross-sectional study of 91,000 quilombolas included in the Ministry of Social Development database, it was found that the factors associated with the lack of access to health services in the country by quilombolas are age, ethnicity and the region where they live. These factors directly

interfere with government actions, which fail to respond to the specific needs of these populations. Although there are promising initiatives, they are not able to reduce the inequalities experienced by this population[7].

According to Costa et al.[40] in a survey that analyzed the socio-economic and health conditions of elderly people living in 11 quilombola communities in Maranhão, Brazil, it was found that the majority of individuals lived in a situation of socio-economic and health poverty, as well as low scores in all health dimensions and limitations in carrying out daily activities. It therefore points to the need to tackle poor social and health conditions, combined with the lack of investment in public health policies aimed at this population.

In January 2016, Conduct Adjustment Commitment Term (TAC) Nº. 001/2016[41] was signed. in which the municipal administration of João Pessoa, the municipality where the urban quilombola community of Paratibe is located, undertook to revitalize the Rio do Padre, set up the Quilombola Cultural Centre, set up the Social Assistance Reference Centre (CRAS) and the Family Health Programme (PSF) within the quilombola territory. Among some of the things achieved, the community was able to have the Family Health team in the community's cultural shed.

We verified the strategy of bringing the family health professionals into the community, so that the visits would be weekly, as this would cushion the demand, but it is still not enough; since the time and day allocated to the service are unfeasible for some residents. The structure of the Family Health Program has not yet been built within the community, which does not make it possible to adjust the Term of Commitment. Thus, we see the persistence of the geographical obstacle, the distance between the community and the health service.

This scenario is compounded by low vaccination coverage[42] and a drop in prenatal care coverage[43,44]; either due to the geographical distance to the service, the lack of supplies or the lack of health education; the absence of basic sanitation and garbage collection and the alarming prevalence of food insecurity. Add to this the lack of resources, the need to train professionals who are trained to deal with cultural and social diversity, and the resistance of some parts of society to recognizing the right to health as a universal human right. On the other hand, growing awareness of the importance of public health and social mobilization in favour of rights can create opportunities for significant advances in guaranteeing the right to health.

Experiencing the quilombola context allows us to observe and understand the particularities of this population group, the need to promote equity in the distribution of public health resources and to reallocate investments according to the needs of each territory[45].

Final Considerations

This study sought to describe the viewpoint of the researchers in the experience developed in doing research and extension in quilombola population groups. This type of study promotes the visibility of information from the communities, which regularly suffer from scientific and academic neglect, which has a negative impact on the effectiveness of public policies and access to health services.

Despite the progress made with the 1988 Constitution, social security and the guarantee of the right to health for the quilombola population is still very fragile, and little has been achieved. This makes the vulnerability of these populations more acute in the contemporary context.

In order to build a fairer and healthier society, it is essential to tackle vulnerabilities. Guaranteeing access to health for all, especially those in disadvantaged situations, is a moral and legal imperative that requires joint action by governments, health professionals and civil society.

Conflict of interest
The authors declare that there is no conflict of interest.

Authors' contributions
Da Cunha RD contributed to the conception/design of the article, data analysis and interpretation, writing and approval of the final version. Lyra TM contributed to the critical review of the content and approval of the final version of the article.

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