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Therapeutic itineraries of *quilombola* women in northern Minas Gerais, Brazil

Pâmela Scarlatt Durães Oliveira (https://orcid.org/0000-0001-6084-5011) [1]
Sérgio Vinícius Cardoso de Miranda (https://orcid.org/0000-0002-8482-7560) [1]
Patrícia de Sousa Fernandes Queiroz (https://orcid.org/0000-0002-4616-1593) [1]
Bruna Amorim Santos (https://orcid.org/0000-0002-3372-3390) [1]
João Felício Rodrigues Neto (https://orcid.org/0000-0001-8189-6539) [1]
Cristina Andrade Sampaio (https://orcid.org/0000-0002-9067-4425) [1,2]

Abstract *Quilombolas are ethnic-racial groups, of black ancestry, and had their territories consolidated in Brazil in regions with difficult access and far from large centers. The objective of this study is to know the therapeutic itinerary (IT) adopted by quilombola women in traditional communities located in the North of the state of Minas Gerais. This is a qualitative study with the theoretical model using the Arthur Kleinman health care system. The study scenario was 23 quilombola communities in northern Minas Gerais. Forty quilombola women aged between 25 and 89 years were interviewed. Data analysis was performed following the IT. Units of analysis emerged that were grouped into three categories: quilombola women and the meaning of health and care; the professional care system in quilombola communities; and route of care in situations experienced by women. The therapeutic itinerary of the communities is mainly related to the actions of popular medicine. It was also possible to observe that there are weaknesses in relation to health care due to factors such as difficulty of access to institutionalized services.*

Key words *Ethnic groups, Women's health, Maternal and child health services, comprehensive health care*

[1] Programa de Pós-Graduação em Ciências da Saúde, Universidade Estadual de Montes Claros. Av. Cula Mangabeira 562, Santo Expedito. 39401-002 Montes Claros MG Brasil. pamela-scarlatt@bol.com.br
[2] Departamento de Saúde Mental e Saúde Coletiva, Universidade Estadual de Montes Claros. Montes Claros MG Brasil.

Introduction

The Therapeutic Itinerary (TI) is the search for therapeutic care with the purpose of describing and analyzing individual and sociocultural practices related to the paths taken by individuals in the search for a solution to their health problems[1].

Culture is one of the determinants of TI. The literature describes the existence of a cultural system, called the Health Care System, which includes three interrelated subsystems: popular, folk (informal system) and professional (formal system)[2].

By studying these subsystems, it is possible to identify aspects that contribute to the interpretation of the disease and allow for the development of distinct healing mechanisms that are developed according to the cultural context of each individual and group. The Therapeutic Itinerary is an excellent way of getting to know and studying the practices and strategies of groups in their quest to solve their health problems, especially individuals in the most vulnerable situations, among whom the *quilombolas* stand out[3-4].

Quilombolas are ethnoracial groups of black ancestry whose territories were consolidated in Brazil in peripheral regions, where precarious access to health services is one of the consequences of geographical isolation. The literature is scarce on this subject, especially in relation to women's health[5].

The aim of this study is to find out about the therapeutic itinerary adopted by *quilombola* women in traditional communities located in the north of the state of Minas Gerais.

Methodology

This article is part of the multi-professional research entitled "Health and work situation of rural *quilombola* families".

This study employs a qualitative approach, based on Arthur Kleinman's[2] Health Care System model, which conceives that health, illness, and aspects related to care are articulated as a cultural system that involves the symbolic (consisting of values, meanings, and behavior norms), the religious, and the family, thus requiring the interaction of three subsystems: the popular, the informal (folk), and the professional (formal system).

The setting for the study was the state of Minas Gerais, where, as of 2019, there were 310 *quilombola* communities certified by the Palmares Cultural Foundation, spread over more than 155 municipalities[6]. The northern region of Minas Gerais concentrates the largest number of *quilombola* territories in the state, with 79 communities certified by the Palmares Cultural Foundation and spread over 28 municipalities[7].

Eight micro-regions, 16 municipalities and 23 *quilombola* communities were visited. Data was collected between August 2019 and February 2020 by the researcher. Forty women aged between 18 and 89 were interviewed.

Data production was made possible through meetings in the territory itself, using the Snowball Technique[8], which consists of asking each participant in the research to nominate a next participant until the research objective is reached, thus building a tangle of meanings and experiences. Women from all communities participated in the interviews in order to understand the unique attributes of each location.

The data collection instruments were: 1) application of a form based on the National Health Survey questionnaire, which made it possible to characterize the profile of the participants; 2) a semi-structured interview lasting approximately 40 minutes, in which the instrument used was a script made up of five guiding questions which dealt with women's lives and experiences regarding issues related to access to health services and care, as well as their journey through social apparatuses, which allowed for the mapping of the therapeutic itinerary by recording the interviews with an electronic recorder; 3) field notebooks; 4) participant observation; 5) photographs showing the way of life and care in the communities, which, in the writing phase of this article, functioned as memorial instruments by helping the researcher to remember and associate the data and images with the reality experienced.

The data was analyzed according to the TIs. Units of analysis emerged and were categorized into three groups: *Quilombola* women and the meaning of health and care; the professional care system in *quilombola* communities; and the care itinerary in the situations experienced by the women. This was divided into three subcategories: The care itinerary of women in situations of acute and chronic illness; The care itinerary of women in urgencies and emergencies; and The care itinerary of women during pregnancy, childbirth, and the postpartum period.

The categories listed were validated by three qualitative methodology researchers (master's and doctoral students), of whom two were nurses and one was a psychologist. Each evaluator had

access to the data analysis spreadsheet prepared by the authors and to the file containing the women's statements, without identification, and so a new stage of data analysis was carried out after this external validation.

The women who agreed to participate in the study signed an informed consent form. The anonymity of the participants was guaranteed through the use of fictitious names. The project was approved by the Ethics and Research Committee of the State University of Montes Claros, under Opinion No. 2.821.454.

Results and discussion

Quilombola women and the meaning of health and care

Forty women between the ages of 18 and 89 participated in the study, thirteen of them aged 60 or over. This data shows a change in the experience of certain situations, such as pregnancy, since the younger generation may have had access to health technology resources, such as ultrasound and laboratory tests.

Twelve of these women completed high school, showing a low level of education. The lack of participation in school education is due to the fact that the communities do not have a high school in their territory, and it is difficult to cross the distance to reach neighboring towns. Half of the interviewees said that they had become mothers when they were under 18, and that they had to devote their time to looking after the house and the children instead of studying. Low levels of schooling can influence the type of occupation women have and, consequently, their family income, and studies indicate that many *Quilombolas* have low levels of schooling[9].

Of those interviewed, 27 were married or in a stable union and worked as housewives. There are many resistance strategies. It must be considered that the African diaspora, with the creation and re-creation of these women's cultural identities, has influenced the role they play in today's *quilombola* society. In African systems, both women and men were providers. While the men hunted, the women managed agriculture and domestic care. These women went from being providers to slaves, subordinated, and belittled mainly because of their phenotype, coupled with the attempt to extirpate their strength and matriarchal power[10]. In the *quilombo*, these women had the opportunity to return to their original roles.

Thirty of the women interviewed receive social benefits, and for some of them it is the only source of income. Low income combined with low schooling makes this minority group vulnerable. The lack of financial resources influences the health of these populations, as it restricts access to other dimensions of life, as well as limiting consumption, production, and cultivation of the land, which is an essential characteristic for *Quilombolas*[9].

Thus, the health and illness of *quilombola* populations must be understood as a biological, individual, social and cultural phenomenon, which implies understanding how these women, in all their diversity, think about and experience their bodies and care. The search for therapeutic care by the individual or family arises from a variety of situations, with morbidity being an objective and subjective phenomenon, with no clear demarcation between variations in health and illness. An individual may feel sicker, leave their daily activities earlier, be absent from work for longer, feel more uncomfortable than another individual with the same objective symptoms[9,11].

Slowly or abruptly, people move from "normality" to "pathology", triggering a complex process in terms of choosing the type of resource to adopt, influenced not only by objective factors, but also by representations that interfere with the meanings of health and illness, in the choice of a certain resource and in the itineraries in search of therapeutic care[12].

This care precedes the moments of illness and is not restricted to the care path, with health promotion and disease prevention being other striking elements in the women's statements:

We're very careful with food, avoiding fat and sweets, pesticides, and eating natural foods. Our means of exercise is the long walk we take from the river to the farm (Iris).

Blessings are very good, I believe in them very much… It's our faith that heals and brings joy (Joana).

Daily lifestyle habits, such as diet, staying active and religiosity, affect the balance of women's health. The care taken with diet and physical activity, seen as important in the culture, in turn, involves a diversified diet, the use of medicinal plants, the consumption of vegetables and fruits characterized as beneficial, reduced sugar, sodium and fat intake, as well as a preference for traditional family foods, associated with walks to tend to their own vegetable gardens and crops[13,14].

Faith also plays a significant role in overcoming the difficulties experienced in the face of care,

as well as in enhancing therapy, as religious rites, devotion to saints and prayers are essential in improving health in general, and in preventing and treating diseases and conditions for *quilombola* women[15,16].

Another element that emerged from the statements was that the majority of the women attributed the meaning of health to being able to carry out the activities they were responsible for within the family and community context.

Health is the most important thing in life, for work, taking care of the family and the house, the vegetable garden and the animals, and taking part in community activities (Tereza).

Getting sick is the worst thing there is, my work is all half done, I work but it's not the same (Lúcia).

Our relatives are the ones who help when we get sick by cooking and feeding the children (Lúcia).

Women do a lot of work every day, as they are responsible for household chores, caring for family members and small animals, as well as organizing and carrying out political and religious activities. Health means being well and able to be productive in their community, and illness is a disorder that limits them from achieving their daily goals and caring for loved ones[17].

Regarding the family subsystem, a primary reference is the kinship network[18]. Mothers and grandmothers are associated with the role of caring for the family and themselves, as well as being providers in the fields, and in the extraction of inputs from nature and small animals, just as originally in the Afro-diasporic matrix and culture. At the time of slavery, these women occupied the roles of ladies-in-waiting, wet nurses, mulattoes, cooks, laundresses, breadwinners, among others, which reduced them to a black body providing care for another who was more important, in this case, their masters[11,19]. Most of them were unable to have a family of their own and devoted themselves to caring for what they felt was important to them, but with the new life that could be achieved by fleeing to a *quilombo*, this became possible and was seen as another reason for strengthening the fight for the right to freedom and land ownership.

Here, the women take care of everyone, and sometimes we take care of ourselves, when there's time (Lúcia).

This account is important because *quilombola* women can neglect themselves, even though they know how important it is to be well in order to carry on with their chores. Caring for others comes to the fore, and this gesture is seen as fundamental to the quality of life and well-being of the family and the community[20].

The close relationship between work and health is highlighted in the statements in this category when they relate serious illnesses to the conditions that prevent them from carrying out their daily activities, with incapacity for work being the main trigger for seeking the professional care system, which we will discuss in the following topic.

The professional care system in *quilombola* communities

Health Care Networks are organizational structures composed of functional units and health interventions of different technological densities which, integrated through logistical, support and management systems, seek to guarantee comprehensive care in the municipalities. These regionalized networks should guarantee responses to users' health needs, since they can be considered the essence of the organization and functioning of the health system. To achieve this, they must eliminate barriers to regional access routes by facilitating entry, ensuring an adequate service supply, and practicing prudent spending[20-21].

The services offered in these networks can be divided into levels of complexity, and at the primary level are the Primary Health Care (PHC) services, comprised of health centers, health posts and Family Health Units. The secondary level, which includes referral centers, outpatient clinics and general hospitals, and the tertiary level, which includes specialized hospitals and outpatient clinics that provide highly complex services.

All the municipalities had outpatient clinics and small general hospitals in the urban area, as well as PHC services. Rural areas had 'support points,' simplified spaces that enabled healthcare services for remote populations. Some rural communities do not have a health center in their territory, and care is provided by health professionals from the reference city, according to schedules pre-defined by the health manager. In these communities, residents have to travel several kilometers to a neighboring area to get health care.

When you get really sick, the only place here to get help is the 'postinho' (Vitória).

The communities that have health services are concentrated in the Family Health Strategy (ESF) units, called "*postinhos*" by the residents,

and they offer medical and nursing consultations, medicine distribution and cervical cancer prevention (PCCU) for women, and a few teams have a dentist. The infrastructure of the ESFs is considered inadequate, as they lack basic materials and supplies to carry out some health procedures.

It's hard to get a doctor here, they come to the association every two months and there's always a different one, they change all the time (Carla).

The women report a high turnover of health professionals in these ESFs, which poses a problem for the residents since it impacts ongoing treatment and care for the population. Long distances and unpaved roads are the reasons most often given to explain the frequent change of higher education professionals.

It's a good thing there's a health worker who's my neighbor, and sometimes she manages to bring a technician to take my blood pressure (Sebastiana).

The ESF is the main gateway to the professional care system in *quilombola* communities, and its work is mostly concentrated on home visits and monthly monitoring by Community Health Agents (ACS). During these visits, the ACSs give advice on preventing illnesses and diseases, and offer to schedule appointments for women, such as the PCCU test, monitoring hypertensive and diabetic patients, and inviting them to the rare educational groups they reported having attended at the unit. Women sometimes report that they have already had their blood pressure taken by ESF nursing technicians during home visits.

Six municipalities where the *quilombola* communities were situated had Family Health Support Centers (NASF), along with the Health Academy Program, with social workers, physiotherapists, speech therapists, pharmacists, nutritionists, and psychologists in conjunction with the School Health Program (PSE) and the *Bolsa Família* Program. The women indicated that there is a long waiting time for appointments with these professionals, and appointments are frequently not scheduled. They also said that to go to appointments, they would need to travel to the seat of the municipality where they live, and that they don't have the means of transportation or the financial means to do so.

I had cancer, I had to take the 'health bus' to the city for treatment, the association's car took me to the pick-up point, I was out all day (Dolores).

For highly complex treatments, such as some types of cancer, surgeries and imaging tests, the reference is Montes Claros, the largest city in the north of Minas Gerais, and Belo Horizonte. Most of the specialized services offered was concentrated in the seat of the municipalities where the regions were based. Services such as hemodialysis, chemotherapy, and radiotherapy are carried out in Montes Claros, and patients are taken by health transport, such as municipal buses. There was an agreement regarding the limited availability of specialized services, with one of the alternatives being the Intermunicipal Health Consortia, funded by the municipalities.

When resorting to paying for specialized consultations and exams due to access difficulties or to expedite treatment, women relied on family members, assistance from politicians (councillors), friends, and bank loans. In addition to financial aid, the informal system was very present in the care pathways through the professional system for referring professionals, scheduling exams/consultations and accompanying the women. Support was also identified from a charity (a support home for people with cancer) in the host municipality.

Care itinerary in situations experienced by women

The care itinerary of women who are acutely and chronically ill

The analysis of the TI of chronically ill women revealed two patterns of care-seeking: one focused on the care offered by the professional system and the other focused on a plural search for care, contemplating the informal, popular and professional systems in different combinations and situations.

For the illnesses classified as serious, the manifestations required professional care; for the symptoms and conditions they considered simple, they were remedied by the informal and popular system. The care offered by the informal system is made up of family, friends, teas, among others, and the popular system, by blessers, healers, priests, pastors and other religious leaders, and this result is similar to that of other studies[11,22].

Other TI research also points to the existence of the classification of illnesses as serious or simple as a guide to care practices. In these itineraries, the first choice of care for simple conditions was the informal sector, through self-medication; if the symptoms didn't ease, the professional sector was called in, followed by the popular sector. In the case of illnesses considered to be serious, the first choice was always the professional sector, a fact evidenced by the following statements:

When I see something serious that bothers me, I go straight for a consultation, and quickly make some remedy (Carla).

If the illness is simple, we make ourselves some tea, a blessing or take a medicine, and it'll go away (Deia).

In addition to home remedies, there is a link with beliefs in the search for a cure, so you have to take the medicine and believe in its effect[22,23]. This dynamic based on popular medicine was identified in the interviews, as well as the belief in curing acute illnesses through the power of religion and the subject's faith. Another important element in the case of acute illnesses was the accessing of the family support network, through the women, neighbors and friends, according to the following statements:

The blessings are also very good, I believe in them a lot, you know? My neighbor is the one who performs them (Ana).

Whenever grandma sees us coughing, she makes tea, and a pennyroyal syrup to make it better (Clarissa).

In the case of chronic illnesses, the main ones reported during the interviews were heart problems such as Chagas disease, systemic arterial hypertension and diabetes. Control of these diseases is achieved through medication prescribed, for the most part, by ESF professionals and through lifestyle changes, ranging from a balanced diet to walks in the community. Tests are rarely part of disease control. The vast majority of women interviewed said that it was difficult to access the professional system in these follow-up cases, according to the following statements:

When an illness like blood pressure gets out of control, it's too difficult to see a doctor, so I end up waiting for it to heal at home (Rosa).

I can't get things like check-ups through SUS. For us at the quilombo, everything is more difficult (Glória).

In most cases, women have to travel to nearby cities to get tests and consultations with health professionals. There are also other political and socio-economic factors that interfere with the use of health services, such as the lack of health professionals working regularly in the area[19,23,24].

Another problem is that the professionals who assist them don't consider the methods and tools that these communities commonly employ in their care practices. This is a failure to comply with the principles that guide the proposal of the Unified Health System (SUS), such as universality, integrality and equity, affecting the way these people access their right to health[25].

Collins[26] discusses the concept of a matrix of domination to reflect on the intersection of social markers, in which the same person can find themselves in different positions in society depending on their characteristics. Thus, this definition of the identity of black *quilombola* women and the space they occupy in the world is based on the intertwining of gender, race, class and generation, without one element taking precedence over the other[16]. Another point that reinforces the situation of vulnerability of *quilombola* communities is the fact that public health provision, in addition to being concentrated in municipal centers, occurs according to the demand of professionals and managers, rather than users[28].

As in other studies, the decisive points for women not seeking or gaining access to the professional system were the delay in receiving care, the lack of forms and the time and day of service that didn't match their needs. They pointed out that the existence of basic units in rural communities could effectively contribute to promoting the health of the population living there.

The care itinerary for women in urgencies and emergencies

Urgencies are those situations in which there is an acute clinical or surgical process without imminent risk to life, and emergencies are those where there is an imminent risk to life[29]. In the *quilombos*, women report that PHC is responsible for tending to all users and addressing their needs, including urgencies and emergencies, holding equal importance and responsibility during service provision. Professionals must provide first aid to critically ill patients in an adequate and resolute manner, as their performance significantly affects the patient's prognosis[30].

It is from this element of the care network that all the other components usually start, such as the Mobile Emergency Care Service (SAMU), specialized care and hospitalizations, among others, in an attempt to ensure comprehensive care[31].

It's worth pointing out that most *quilombola* communities are located in isolated places that are difficult to access, even for SAMU ambulances. This means that the population has to find the nearest health service by driving themselves or by making use of any vehicle available in the community where they reside.

The starting point for TI in cases of serious illness in the communities under study was the care provided in the family system, translated into the assistance provided, such as caregiving, which is mostly carried out by women, since they are the

ones who struggle with the activities of daily living, dealing with pain and the existence of health problems, including the most complex ones[32].

The need for help from family members and neighbors when faced with serious health situations was highlighted. Considering the difficulty of accessing and transporting to a medium/high complexity service, reports emerged that nearby individuals were the most viable reference to attempt to solve the problem in the first moment, as indicated by the statements below:

We don't have a car here, so when people get sick it's the Association that comes with the car (Marisa).

My husband threw me on the back of his bicycle, and we went to the city so that I could have the boy (Dolores).

Authors[33] debate the importance of the family connection, pointing out in their studies the significance of the family's presence in illness situations and how it can contribute to the individual's prognosis. The statements highlight the difficulty they face in going straight to the city for more complex cases, and how accountability and responsibility for healthcare is placed on individuals and their families. In these communities, the lack of infrastructure and social determinants of health highlight the fragile role of the state in guaranteeing such rights. Through efficient and specific public policies for rural black populations, it needs to consider and ensure their right to access health and services, in accordance with the principles of SUS[23,24].

The care itinerary for women during pregnancy, childbirth, and the postpartum period

In this category, one of the primary highlights is how ancestral *quilombola* knowledge assists in the care process for these women during pregnancy, childbirth, and the postpartum period. Promotion, prevention, and treatment are influenced by beliefs and rituals that have been accumulated over time and are present within the popular system of these communities. It is important to actively consider the knowledge possessed by therapeutic practitioners in these areas (blessers, midwives) in the handling of medicinal herbs found within the communities' surroundings, and their utilization for women's health maintenance[34-35].

Additionally, there is a noticeable lack of seeking institutionalized healthcare, which can be attributed to the challenges these women face when attempting to schedule appointments and tests within primary health care facilities, a common practice during pregnancy, due to the existing backlog. Women expressed dissatisfaction with the healthcare they receive. Among these women, the majority did not receive adequate prenatal monitoring from the healthcare team, as illustrated in the following statements:

I received prenatal care for some pregnancies, while for others, I didn't. I managed to have blood tests and ultrasounds for the ones I did receive care for. Those I saw if they were boys or girls before they were born (Lurdes).

There are no doctors here for prenatal care, we have to leave here when we feel very ill during pregnancy… (Maria).

Prenatal care occurs irregularly, mainly due to the lack of resources for traveling to urban areas. Pregnancy monitoring becomes subpar, reaching a point where basic tests such as obstetric ultrasounds are neglected. Proper prenatal care for women is essential for early identification of diseases in both the mother and fetus, enabling a healthy gestational development and subsequent reduction in risks during the childbirth and postpartum processes, leading to decreased maternal and child morbidity and mortality[34].

The process of childbirth has been adapted over time and is usually supported by midwives, a group of women who have acquired knowledge about childbirth from previous generations and are integral to the informal healthcare system. Midwives are women equipped with the appropriate knowledge to understand the intimate nature of childbirth, across various regions of Brazil. They also possess knowledge regarding care related to pregnancy and the postpartum period (miscarriages, confinement, and care for the newborn)[35].

The midwife plays a crucial role in encouraging and caring for pregnant women throughout the childbirth process. While most of the interviewees currently give birth in hospitals, some, particularly the elderly, received assistance from these caregivers during childbirth and hold a great deal of respect and affection for this role:

I gave birth to some children with the midwife's assistance, and some by myself. I gave birth, held them, and wrapped them in cloth… (Luci).

The child was born, but it was difficult; he came out all bruised, crying very little. If it weren't for the midwife, who was incredibly skilled, he might have died (Cida).

The midwives we had here were excellent; they took care of us, provided support, and we weren't afraid when giving birth (Railda).

The therapeutic care delivered by midwives in these communities has proven to be invaluable. In extreme cases when there isn't enough time to travel to hospitals to receive assistance during childbirth, midwives play an indispensable role, aiding the mother during the expulsion of the baby. Their contribution within the informal system is not confined solely to childbirth assistance; these caregivers are equipped with a range of responsibilities, from maintaining maternal and infant health during gestation to postpartum care.

According to authors[35], midwives, drawing from their traditional knowledge of medicinal herbs, created a variety of teas and infusions to provide comfort to parturient women during labor, alleviating pain. To provide comprehensive care, they remain at the woman's residence until the umbilical cord stump falls off.

The work of midwives or other female figures within the family extends to postpartum care for both the mother and newborn. This includes the use of plants and herbs to make teas and sitz baths in an attempt to prevent postpartum hemorrhage and infections[35]. During the postpartum period, informal and popular systems are the most commonly accessed for health care actions.

We breastfed the baby and gave them herbal medicine to cleanse them from the inside, and we took it too (Q9).

The children were all born; the midwife caught them, administered bitter medicine, the blesser removed evil eye, and we quickly recovered after giving birth (Q7).

The use of teas, baths, and prayers during pregnancy, childbirth, and the postpartum period reflects the culture of *quilombola* women – the culture of a people and their memory, highlighting the connection between their way of life, the environment, and care[36].

This knowledge remains present in contemporary times and in the practices of women belonging to *quilombola* communities. From this perspective, folk medicine is a shared practice within the *quilombola* community – among relatives, friends, and neighbors who share the same worldview, offering practical solutions to health problems[36,37].

It's evident that the TI of *quilombola* women centers around popular knowledge and the support of midwives, family members, and the broader community. Many women report challenges in accessing institutionalized healthcare. These findings underscore the need to reevaluate healthcare strategies for *quilombola* communities, considering their unique social, cultural, and epidemiological characteristics, particularly their predominantly rural location. Consequently, inclusive actions and more effective equity-promoting strategies are crucial to mitigate the recurring impact of institutional racism on *quilombola* communities[18,38].

Final remarks

We have gained insight into the interviewees' Therapeutic Itinerary, the significance they attribute to health, and the existing barriers to accessing healthcare services.

Understanding these meanings, obstacles, and pathways is pivotal for reconsidering strategies and public policies involving *quilombola* communities. Our exploration has shed light on popular health practices, underscoring the necessity for healthcare professionals not only to comprehend these practices, but also to incorporate them into their caregiving endeavors within this population. This approach bolsters community involvement throughout the entirety of the care process.

It is worth reinforcing that, despite the advancements made by SUS (Brazil's Unified Health System), there remains a need for actions that genuinely provide this community with services rooted in the principles underpinning the healthcare system, such as universality, comprehensiveness, and equity. By doing so, services can be offered that effectively address the authentic needs of this population.

Collaborations

PSD Oliveira, SVC Miranda, PSF Queiroz, BA Santos participated in the conception and design of the work, performed the bibliographic survey, the fieldwork, analyzed and discussed the results and wrote the manuscript. CA Sampaio and JF Rodrigues Neto guided the research, participated in the analysis of the interviews and the discussion of the results, performed the critical review of the content and approved the final version of the article.

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