

## POPULATION HEALTH SURVEY IN QUILOMBOLA COMMUNITIES IN BAHIA STATE: AN EPIDEMIOLOGICAL RESEARCH EXPERIENCE

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**ABSTRACT:** The aim of this article is to report the formative experiences encountered during the preparation and development of an epidemiological survey undertaken with residents of quilombola communities (inhabitants of black communities) in Bahia. Researchers from different fields including the humanities and health sciences were involved in contributing to the construction of the project, selection and adjustment of the instruments, as well as the execution of data collection. In the process, it was possible to perceive the humanistic, professional and scientific maturation of the researchers and academicians involved. In light of this, advances were made and will continue to be made, in the understanding of equitable health care, consolidated through practices that respect the historical and sociocultural characteristics of users and communities supported by health services.

**KEY WORDS:** Health human recourse training; Health surveys; Case reports..

### **INQUÉRITO DE SAÚDE EM POPULAÇÃO QUILOMBOLA BAIANA: RELATO DE UMA EXPERIÊNCIA EM PESQUISA EPIDEMIOLÓGICA**

**RESUMO:** O objetivo deste artigo é relatar as experiências formativas vivenciadas durante a preparação e o desenvolvimento de inquérito epidemiológico desenvolvido em comunidades quilombolas de região geográfica baiana. O envolvimento de pesquisadores de diferentes profissões, das Ciências Humanas e da Saúde, contribuiu na construção do projeto, seleção e ajuste dos instrumentos, bem como na execução da coleta de dados. Ao longo do processo foi percebido amadurecimento humanístico, profissional e científico dos pesquisadores e acadêmicos colaboradores. Neste sentido, ocorreram e ocorrerão avanços na compreensão do cuidado equânime em saúde, consolidadas através de práticas que respeitam os aspectos históricos e socioculturais dos usuários e comunidades atendidas pelo serviço de saúde

**PALAVRAS-CHAVE:** Capacitação de recursos humanos em saúde; Inquéritos epidemiológicos; Relatos de casos.

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## INTRODUCTION

Understanding the issues that affect the health situation of the Brazilian population is a challenge for several research centers, and different ways of planning, executing, teaching and learning about research exist. Obtaining data and analyzing the results of an investigation involves a complex process that is fundamental for an understanding of the issues encountered during the planning and data-collection phases.

It is commonly accepted that scientific research is an important precept and, therefore, should be privileged in the university space. These research activities promote scientific and technical training, and can be considered relevant for honing professional practices. In addition, participation in scientific investigations increases academic satisfaction, providing the perception of more / better development opportunities<sup>1</sup>, whether it be in the personal, professional or social sphere.

Research experiences strengthen academic and professional training, making participants more vigilant and critical of social reality and therefore creating beneficial stakeholders for the development of actions and the implementation of policies in specific populations. It is known that the process of weakening rights and social protection, which in turn stereotypes and weakens the fighting capacity of those who defend them, primarily affects communities in situations of vulnerability, hindering their reaction and resistance<sup>2</sup>.

The aforementioned condition of vulnerability results from the presence of diseases and disabilities, sometimes reinforced by socio-historical relations of domination, intimidation and manipulation<sup>3</sup>. Thus, one of the main practical challenges of epidemiological research with the participation of groups in situations of vulnerability is the structuring necessary for its realization, especially regarding the planning and execution of data collection.

Of the possibilities available, it is known that epidemiological studies are fundamental for collecting information on the frequency of unfavorable outcomes and, also, on the main factors associated with these problems. These surveys allow for an equitable distribution of public health resources, adjusting investments to

reflect the characteristics of different populations, even within the same country<sup>4</sup>. However, interest in critically reporting these experiences, especially those that include difficulties and strategies for coping with them during the course of planning research and obtaining information, does not seem to be widespread.

In general, the focus of epidemiologists is on methodological rigor, robust statistical analysis and publication of results in journals. However, in addition to denouncing the conditions of vulnerability, it is essential that the investigations promote knowledge that qualifies professional practices, consistent with the needs and characteristics of the communities<sup>5</sup>, with positive reflexes for effectively equitable health practices.

Thus, it is relevant to present academic productions that, in addition to discussing the epidemiological information itself, focus their attention on the reflexive socialization of the experience of doing and learning to do research in social epidemiology. Considering that this investigative profile is dedicated to understanding the impacts of social characteristics on the health-disease-care process in specific population groups<sup>6</sup>, it should be noted that this type of study provides visibility to information from communities which regularly suffer academic-scientific neglect, with negative consequences for the effectiveness of public policies, equity and access to health services.

Thus, the objective of this article is to report, in a dialogical manner, the formative experiences lived during the preparation and development of an epidemiological survey for quilombola communities in the Bahia geographical region.

## METHODS

This is a critical experience report about the epidemiological research activities entitled "Epidemiological Profile of Quilombolas in Bahia", authorized by the Research Ethics Committee (CEP) of the University of the State of Bahia, number 1,386,019 / 2016, CAAE 49955715.6.0000.0057.

The empirical field of the investigation, initially defined for the State of Bahia, needed to be adjusted for

the geographic micro-region of Guanambi / Bahia, due to the failure to obtain financial support from relevant development institutions. It is worth noting that the activities related to this research, including project development and theoretical-methodological discussion between researchers began at the end of 2014. During the period of field activities, the micro-region in question had 42 certified contemporary quilombos<sup>7</sup>, distributed in ten of the 18 municipalities.

Data collection took place between February and November 2016. At the end of this stage, 850 quilombola adults voluntarily participated in the study activities. The data collection was developed by teams composed of professionals and / or academics in the area of health and human sciences according to their qualifications, all of whom received training for their respective function. These activities started the day before visiting the community participating in the research, and involved the organization of the team, materials and equipment. All communities were located in rural areas, and given the need for blood collection, participants needed to fast overnight. As such, the team met around 4 am, to ensure that activities were started as early as possible in the communities, aiming to generate the least discomfort for the participants.

This article presents, in the form of a reflective report, the issues involved in epidemiological research in quilombola communities in the geographical region of Bahia. Such a study is structured to reflect the reality of the quilombola population, issues of research planning, preparation of the data collection team and recognition of the research field. Then, it proceeds to questions related to contact with the communities, as well as with the subjects and the visits for data collection in the field, before ending with the social / scientific feedback.

For the analysis of the information presented throughout the report, a critical reflection of the issues and perceptions reported by the researchers / authors was produced, in addition to comparing and discussing previous studies in the humanities and health science fields.

## CONTEXTUALIZATION OF EPIDEMIOLOGICAL INVESTIGATIONS IN SOCIALLY VULNERABLE GROUPS: QUILOMBOLA COMMUNITIES

Social acknowledgement and the fight against discrimination waged by minority groups are elements recognized as necessary in the socio-political-cultural structure, for the development of less unfair relations with communities that possess ethnic-racial and cultural specificities<sup>8</sup>. In this way, legal support<sup>9</sup>, given the legitimacy of quilombos in contemporary times, is configured as an important affirmative advance for the black Brazilian population, contributing to the correction of the violence that was historically imposed on them.

It is worth noting that in addition to historical quilombos, contemporary ones have also been instituted. Historical quilombos were founded and inhabited by blacks fleeing the slave regime, while contemporary quilombos, also formed by the black community group, do not necessarily result from the population joining these fugitives from the above regime<sup>10,11</sup>.

These contemporary quilombolas share a different heritage of resistance to violence and oppression arising from racism, besieged by forces far beyond their control, and needing all forms of contribution that could be mobilized to overcome the social negativities present in their daily lives. In this sense, with the support of anthropologists and political action groups, article 68 was inserted in the Brazilian Law, which promised improvements for the quilombo communities in Brazil<sup>12</sup>.

It is recognized that the quilombola population, after years of struggle, is constitutionally supported by the National Policy for the Comprehensive Health of the Black Population, necessary due to the issues related to health-disease that need to be considered in the socio-cultural context in which subjects / communities are inserted, given that their culture includes diverse symbols, norms, values and practices, including those related to health.

However, unfortunately, these population groups still suffer from a limited guarantee of the right to health due to the continuing neglect of quilombola health demands, as asserted by recommendation number 030/2012 of the National Health Council<sup>13</sup>.

Race and ethnicity are social categories, rather than biological, referring to groups that share a cultural heritage<sup>14</sup>. The difference between them is that ethnicity expresses a cultural reality shared by a particular ethnic group. Race refers to the attributes given to people who share common biological traits. Thus, racism represents an agent that generates social vulnerability, resulting from the recurrent violence imposed on the black population throughout Brazilian history<sup>15</sup>, which transcends biological representation and assumes a segregating role.

The 'quilombolas' theme is characteristic of Brazilian communities, which partially explains the scarcity of studies with this population in the area of health in national and international journals. This knowledge gap can make it difficult to provide adequate health services according to the population profile since, to achieve this, the availability of information from the communities served is essential, especially regarding exposure to diseases and their respective risk factors<sup>16</sup>. In the same sense, this gap also implies difficulties in the equal qualification of the services provided.

Another issue detrimental to the improvement of quilombola health is the limited availability and, consequently, difficult access to health services. For historical reasons linked to slavery and the construction of a racist society, quilombola communities, in general, were founded and remained in rural spaces, regularly without the presence of health facilities nearby. This situation, in which it is difficult to access health services, associated with socioeconomic inequality and poor living conditions can favor the high frequency of chronic diseases in this population<sup>17</sup>.

#### PLANNING AND ORGANIZATION OF AN EPIDEMIOLOGICAL RESEARCH IN BAHIA QUILOMBOS: PATHS TO SCIENTIFIC EVIDENCE

The planning of the research, with methodological rigor and adequate design, is an essential requirement for the success of any epidemiological investigation. However, it is necessary to strengthen the pre-study contact with the communities to be researched, in order to clarify, together with participants, what the procedures of the activity will be and how they will be carried out, in

addition to recognizing aspects of the local reality, so as to adjust the execution logistics. This stage consisted of selecting and structuring the instruments, preparing the team and taking action in loco for data collection, as well as presenting the results to the investigated population.

After one year of discussions about the proposal, containing techniques related to the application of interviews, anthropometric measurements, blood pressure checks and blood collection, it was forwarded to the CEP in November 2015. In response to the project sent, the CEP requested ethical adjustments related to appropriate disposal procedures after blood analysis, in addition to simplifying language in the Free and Informed Consent Form, thus making it more accessible to participants.

In January 2016, the survey was approved by the Ethics Committee and, in February, visits to obtain information from quilombola communities began. By the end of the last visit in November of the same year, 850 quilombola adults had voluntarily participated in the study activities, which were developed by teams composed of qualified professionals and academics in the field of health and human sciences, after training for their respective tasks

The team consisted of researchers from different areas of knowledge: physical education, nursing, physiotherapy, history, geography, biology, pharmacy and dentistry. Thus, it should be emphasized that the epistemological diversity in the constitution of the group allows for a broader understanding of the issues investigated<sup>18</sup>, a perspective aligned with the objectives of the Brazilian health system in place since the 1980s<sup>19</sup>, which aims to increase the analyzes of the health-disease-care process from an interdisciplinary and multiprofessional perspective.

The data collection also included the participation of students from bachelor's degrees in nursing and physical education. In this sense, the participation of students in community actions contributed to their citizen training, linked to the demands of society and capable of improving their theoretical-practical learning<sup>20</sup>. Such opportunities can be considered as attitudes that confront and question the reproduction of prejudiced and dehumanized models for these communities.

In addition, experience from different qualifications and areas contributes to the creation of professionals with an interdisciplinary view, perception of expanded reality and who can reflect on their performance in different spaces, moments and places, fostering the construction of relevant knowledge to support academic-science actions for society.

-Data collection instruments: what should be investigated?

It is understood that epidemiological science is based on the principle that human life consists of multiple factors that directly impact the condition of morbidity and mortality, with the assumption that understanding the various events related to the health-disease-care process is fundamental for the qualification of scientific evidence directed to disease prevention and health promotion, especially in populations in vulnerable situations. From this perspective, the adequate choice of the data collection instrument is essential if the information is to contribute to the elucidation of the predisposing issues related to the health situation of a given population.

Thus, in the investigation reported, firstly, a broad search of previous studies was carried out in order to identify instruments developed and / or validated for research in quilombola communities. However, none were found for investigations with this population profile. Only one study carried out the process of verifying and adapting the language of the National Health Survey form for the quilombola population<sup>21</sup>.

Given this theoretical-methodological framework, the researchers chose to track instruments validated in Brazilian adults that cover different health issues and methods that are widely used in health sciences. Then, a selection was made, giving priority to the most experienced researchers, in order to enhance the selection of instruments with a language more accessible to the quilombola population, and that best represented the research proposal and permitted the practical use of the information gathered by this study. As such, avoiding difficulty in understanding and embarrassment of the participants, in addition to optimizing the data collection stage.

Thus, the final instrument structured by the team of researchers encompassed issues related to sociodemographic characteristics, housing conditions, work, disabilities, diagnosed chronic diseases, health services, oral health, economic situation, mental health and lifestyle.

After the first activity of data collection, with the participation of 28 subjects residing in a community, the researchers thoroughly evaluated each item proposed in the questionnaire, which consisted of correcting questions that were interpreted with difficulty during its application, so as to improve the final form of this instrument.

Anthropometric information and the body fat percentage were also collected using a bioimpedance scale. Systolic blood pressure was obtained using semi-automatic equipment. Finally, blood samples were collected and subsequently analyzed by the automated colorimetric enzymatic method in an accredited laboratory.

- Training of the executing team: sensitizing researchers

The preparation of the team for data collection in epidemiological research requires special care, being more critical than technical. As in health work, it is clear that the harmonious encounter between research subjects and researchers allows for space-time problems, of a merely technical nature, to be overcome during the meeting itself<sup>19</sup>.

Research involving the participation of communities with special characteristics requires that those responsible for the collection understand the important interaction of objective questions (the information to be obtained) and subjective questions (who is the subject of the research, their values, their desires and their fears). Researchers must be careful and sensitive to the subjects, using simple language, close to the local reality, so that obtaining the information occurs in a comfortable and safe way for the participants. This attitude is consistent with the proposal to train critical health professionals, capable of proposing and sensibly applying intercultural criteria to improve the health indicators of specific populations<sup>22</sup>.

In this sense, workshops were held with the research team to adjust the dialogue to the needs of the subjects, including consensus and standardization of language, clarification of doubts, as well as the alignment of understandings about the questions presented in the data collection instrument. Then, after a random selection, there was a visit to the first quilombola community, which was authorized by the residents' association, and a pilot study was applied so as to make the final language adjustments to the instruments.

During the workshop stage, the training of health professionals qualified for blood collection was carried out, since biochemical tests were included in the research to assess various events related to the health-disease-care condition of people residing in these communities. This stage had the support of an experienced researcher to make appropriate adjustments in the collection, storage and transport of this biological material.

Due to the extension of the period for the complete development of data collection, an increasing physical strain in team members was observed. As a result, the researchers decided to hold two more workshops for training students. This action allowed alternation in the composition of the groups, especially among undergraduate students, reducing the risk of stress and fatigue in the collectors. After this stage, the attitudes of researchers and logistics for structuring the collection in the communities were reflexively reassessed.

- Recognizing the territory: visiting quilombola communities

All quilombola communities in the Guanambi / Bahia region, recognized by the Palmares foundation up to 2016<sup>7</sup>, were listed as potential participants in the research. Initially, the communities were randomly classified in ascending order and selected. Subsequently, contact was made with the community through people living in the quilombos. It is important to note that this approach was enhanced through the collaboration of professors and students at the University, so that researchers could establish communication with the social representatives of this population group. In addition, it should be mentioned that the University

provided extensive institutional support for structuring and executing data collection, even though the research group did not have funding to carry out the investigation.

After this selection, there was good acceptance by the communities. Of a total of 17 quilombos contacted, 14 allowed visitations for research purposes. It is worth mentioning that some leaders of communities that were not selected made contact with the researchers, demonstrating their interest in participating in the present investigation, mainly after talking with residents of communities that were involved in some research activity, but, unfortunately, as they were not selected, they were not able to be part of the survey. This voluntary action to request participation can be a result of the recognition of the positive impact of studies in the field of health in solving social problems<sup>23</sup>, such as the permanence of insufficient coverage of services in the face of community demands<sup>24</sup>.

However, it is noteworthy that despite working well most of the time, the process for inclusion of the communities in this investigation was fallible, for several reasons. Contact with one of the communities was hindered by the way the intermediation was carried out by an individual from the University. Despite his proximity to the quilombo and providing a phone contact to a representative of the residents' association, the quilombolas said they were unaware of the existence of the study, generating distrust and, consequently, the community's refusal to participate in the research. In another community, it was not possible to contact the president or any other person responsible for the residents' association, which made the research process unfeasible.

Furthermore, there was also a community whose initial authorization for visitation given by the residents' association was withdrawn, as it was claimed that it is common to develop studies without any return for the community. Community representatives did not allow the development of activities even after clarification that the present research would have immediate and individual answers for the participants (explanation of the results and guidelines for correcting the identified risks), as well as scientific feedback (publications that would strengthen the debate on health issues in the black population)

and community feedback (production report sent to communities and bodies responsible for health services provided to communities in the region), which would enable a specific and substantiated base from which to make demands of health units and bodies responsible for organizing, implementing and expanding health services provided to communities in the region.

It should be noted that, during the visitation process, there were some problems that deserve attention. In one of the communities there was a rumor that people were visiting the communities to spread diseases, which generated an important index of refusals among quilombolas, and which were subsequently removed in accordance with the ethical procedures that had been clarified previously. Another relevant aspect was the difficulty of access to some quilombos, located in the rural space, far from the urban space - where the headquarters of the respective municipalities are located, and with access roads in precarious conditions of conservation.

#### - Data collection: understanding the role of researchers

It was noticed, with the advance of the study interventions, that the accumulation of experiences made researchers (teachers and students) more empowered, with beneficial changes in their speech, postures and practices of interaction among themselves and, principally, with the subjects, making them better able to understand their own study object in their *praxis*. The decrease in power relations among researchers was also noticed, given the evolution in the acquisition of responsibilities among the less experienced researchers. Throughout the process, the researchers achieved a greater degree of autonomy, becoming freer to act and decide, assuming an empowered role in their respective activities<sup>19</sup>, which demonstrated the importance of participation in research for training aimed at technical-humanistic proactivity.

These facts corroborate the understanding that research favors the appropriation and production of health knowledge, as well as the researcher's self-recognition<sup>25</sup>. In addition, participation in research expands the perception of confidence, a more humanized professional attitude and the development

of autonomous and reflective behavior, which should be fostered throughout academic life.

Two participants had problems during data collection, due to fainting and high blood pressure. However, the team was prepared to deal with these atypical situations and the volunteers were assisted immediately and directed to the nearest health service. None of the participants had adverse health consequences or outcomes and the events were not related to the data collection process itself, but to the lack of administration of medications for continuous use, such as antihypertensives.

Moreover, procedures were carried out in response to special cases so that these episodes would not be repeated, such as seeking medication for continuous use in the participants' homes for those who remained on a complete fast for blood collection.

#### - Data collection: availability of infrastructure and community participation

Even though ten years had passed since the Quilombola Social Agenda was decreed<sup>26</sup> in 2007, during the execution of this research, in 2016, the participating communities still did not have a space for health care. The situation found in communities in the Bahia region corroborates the lack of public investments in the development of infrastructure in rural communities<sup>10,27,28</sup>, and results in a negative impact on the provision of health services<sup>29,30</sup> and, consequently, influences the condition and life quality of residents.

Therefore, in order to better develop the activities presented by the researchers to the communities, the residents' associations provided locations, such as their respective headquarters, schools and / or churches, to carry out data collections. All were sufficient for the different activities to be conducted with care, respect, comfort and safety for residents and researchers.

It is noteworthy that the continuous contributions of community leaders and residents in general in offering the best working conditions for the research team, such as in the organization and cleaning of the spaces, contributed to overcoming infrastructure limitations.

Another aspect that could have impacted on the survey was the inaccuracy in the number of residents in the communities. As there was no guarantee that the resident association or health service registers were up to date, community leaders went to the field of study to update the list and invite those over the age of 18 to participate after scheduling the days of activities. This situation, although demonstrating the support of the community, also confirms the permanence of the imprecision of information about the quilombola population, which hinders the planning and execution of public policies<sup>31</sup>.

In a complementary manner, it is valid to note that some quilombos presented population seasonality, mainly of the male sex, in periods of more intense drought associated with the harvest period in other regions. These situations make the search for auxiliary or complementary alternative income necessary to provide for the economic sufficiency of the subjects and families.

- Results: immediate and medium-term return for quilombos and the academic community

No later than two weeks after completion of the research in each community, researchers returned to the site to give the results (laboratory tests and health indicators), with the recommendation to seek a primary health care service when necessary. Individual care was provided by health professionals prepared for this stage. The guidelines focused on improving quality of life, with an emphasis on greater access to health services, the role of the community agent and the practice of healthy living habits.

In addition, reports and scientific articles were prepared to pass on the findings to the scientific community. Manuscripts have already been published in journals<sup>32-39</sup> and papers presented at congresses<sup>40-44</sup>. In this perspective, it is evident that participation in research activities contributes in a differentiated manner to the training of participants, providing opportunities for the production of knowledge on a specific theme<sup>45</sup>.

## FINAL CONSIDERATIONS

Research activity in epidemiology seeks to understand the innately complex conditions of illness, requiring researchers (professionals and students) to understand the specific characteristics of subjects and demanding that knowledge and representations be shared about the difficulties faced and characteristics noted during the process of obtaining the analyzed information.

More than the data generated, this investigative activity allowed, in a concrete way, for the growth of researchers from different areas of epidemiology that value the social aspects of academic investigations, as well as providing unintended experiences connected to the relationships between members of the research team and quilombolas. The interactions between students and teachers of different qualifications and areas of knowledge enabled a broader reflection on the socio-historical reality, and, as such, training actions that overcome technical-disciplinary issues.

This study from the perspective of social epidemiology contributed to the construction of the citizenship of the subjects involved and can be considered a successful experience, due to the scientific and cultural enrichment that the researchers acquired through contact with participating communities. Thus, the social interaction that brought academia and the community together in research was optimized, extrapolating the phases of a scientific method that often disregards such an outlook in these types of studies.

The professionals were given the opportunity to continue their training in research, while for the students, it may represent a unique experience involving approximation and knowledge about the living and health conditions of quilombola communities, which are regularly in a situation of socioeconomic vulnerability. Thus, it can be affirmed that professional / student participation will have an important positive influence on their future professional and / or academic choices.



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