Quality of primary health care for quilombolas' Afro-descendant in Brazil: A cross-sectional study

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SUMMARY

OBJECTIVE: The aim of this study was to assess the quality of primary health care services through self-reports by caregivers of children and adolescents living in quilombola communities in Brazil.
METHODS: This is a cross-sectional study in accordance with the STROBE (STrengthening the Reporting of OBservational studies in Epidemiology). Exposure variables included sociodemographic characteristics; and outcome variable was the quality of primary health care offered to quilombola children and adolescents.
RESULTS: A total of 68 individuals participated in the survey. Quilombolas have a low income, a lower level of education, do not work, and receive government benefits. Our results showed that the quality of primary health care, measured by the experience of caregivers of quilombola children and adolescents, generally presents satisfactory values.
CONCLUSION: The quality of primary health care has generally satisfactory values. However, as these results differ from most studies, more research should be conducted.
KEYWORDS: Primary health care. Vulnerable populations. Public health.

INTRODUCTION

Access to health care is a moral imperative for all countries. Equitable distribution of health care is essential to making the gains established by the Sustainable Development Goals (SDG) and contributing to the realization of the right to health. According to the World Health Organization, efforts must be made to strengthen health systems and improve services with an emphasis on universal health coverage. When countries seek universal health coverage, progressive universalism includes vulnerable populations from the beginning, which is the most effective way to reach vulnerable groups in society. Thus, primary health care (PHC) represents one of the most promising avenues for responding to growing health needs, demography, environmental challenges, and emergencies[1].

Brazil, which has undergone several transformations in the past 40 years, instituted universalism through the Unified Health System. The Family Health Program, created in 1994, was a reorientation strategy for the development of primary care that is carried out in the actions of multidisciplinary teams, responsible for the health of a given territory among these territories, we find the quilombolas' communities[2] (has self-attributed ethnic and racial characteristics and a trajectory of black ancestry related to slavery)[3].

In 2004, the Brazil Quilombola Program was launched (Decree 6261); the estimate of the quilombola population in Brazil was 2,14,000 families in 2012 (approximately 1.17 million people)[4]; however, these data are imprecise and underestimated. PHC in quilombola communities is already recognized; however, the investment was reduced in this scenario[5] (e.g., public resources for the quilombola territories in 2017 was almost four times lower compared to the 3 previous years). Health inequality is caused by different impacts, such as wars for ethnic-racial reasons, religious, territorial, radical political-economic changes, and revolutions[6].

Evidence registers inequities in the health services provided to children and adolescents — which become even more evident when these subgroups are from quilombola communities — in which health actions aimed at this vulnerable segment have to consider different needs[7]. A way to protest and to help this population is through scientific evidence; however, there are no studies aimed at the perception of historically excluded groups in PHC.

We believe that improvements in the health and well-being of this population will drive progress toward meeting the SDG health goals; this is the justification for conducting this study. Our aim was to assess the quality of PHC services through self-reports by caregivers of children and adolescents living in quilombola communities in Brazil.

METHODS

Design
This is a cross-sectional study conducted in accordance with the STROBE (STrengthening the Reporting of OBservational studies in Epidemiology). Exposure variables included sociodemographic characteristics; outcome variable was the quality of PHC offered to quilombola children and adolescents.

Setting
The study was carried out between 2015 and 2017 in quilombolas' communities in the state of Tocantins (Brazil); we collect data from clinically set sites in communities. The teams were previously trained, and the collections were monitored by senior researchers who have experience in studies with vulnerable communities.

Participants
Sample is composed of caregivers of children and adolescents up to 17 years of age, residing in five quilombolas' communities in the state of Tocantins/Brazil. Due to the few references on the evaluation of the quality of PHC to quilombola children and adolescents, this is a convenience sampling.

Inclusion criteria were as follows: being the main caregiver of the child/adolescent under the age of 17, being able to answer the questionnaire in question, and knowing the unit used for the research.

Variables
We used the Primary Care Assessment Tool (PCATool — Brazil), child version, developed by the Johns Hopkins Population Care Policy Center[8,9]. We assessed the extent of attributes classified as essential (i.e., first contact access, coordination, longitudinally, comprehensiveness, and coordination of care) and derivatives (i.e., community guidance and family guidance), investigating the "Degree of Affiliation" the regular source of care.

Data sources/ measurement
PCATool — Brazil has Likert-type answers with an interval of 1 to 4 for each attribute (4=definitely yes, 3=probably yes, 2=probably not, 1=definitely not, and 9=do not know/do not remember). The degree of evaluation of the caregiver to the health service was calculated using the structured algorithm according to the different possibilities of the caregiver's response to the three initial questions[9].

Bias
We reduced the information bias by conducting prior training to apply the instruments. Also, we created an electronic data collection form (Epi info 7.2®) to build the database. All data were validated in duplicate (in cases of divergence between data, a third researcher was consulted).

Study size
The communities have about 106 families with 205 children and teenagers up to 17 years old.

Quantitative variables
We calculated the scores of each attribute of PCATool — Brazil, obtained by the average of the items that compose it. All scores for each of the attributes were later transformed into a continuous scale between zero and 10, using the formula: Adjusted score = $[(\text{obtained score}-1)/(4-1)] \times 10$, so that it could be performed the calculation of the "Essential Score" and "General Score" of PHC.

The "Essential Score" was measured by the sum of the average scores of the components belonging to the "Essential Attributes" plus the value attributed to the "Degree of Affiliation" and divided by the number of components. The calculation of the "General Score," in turn, followed the same principle, having added, however, the average scores of the three attributes derived from PHC[8,9] (scores ≥6.6 indicate satisfactory values and adequate presence of the attributes in PHC).

Statistical methods
Statistical analysis was performed using the statistical package STATA, version 18.0, for Windows. We used bivariate statistics (chi-square) and the appropriate tests according to the adherence of the data to the Gaussian distribution (normality verified by the Shapiro-Wilk test).

Ethical principles

All procedures of the present study were previously approved by the research ethics committee (opinion: 3358190).

RESULTS

Participants

We recruited 106 families for the study; only 68 individuals who met the inclusion criteria participated in the survey. A total of 38 participants were excluded, due to the absence after three collection attempts, refusals, and giving up in any of the stages. The greatest loss of data available for analysis occurred with anthropometric data.

Descriptive data

Caregivers were the main informants with low economic status and were dependent on government benefits. Table 1 consolidates the main socioeconomic, demographic, and social support characteristics of caregivers.

Outcome data

Table 2 shows the scores for the quality of PHC, based on the experience of caregivers of children and adolescents who use PHC services in quilombola communities in Tocantins/Brazil. The mean overall score was 7.68 or above the cutoff point for good general primary care (fixed at 6.6). If we break this analysis down by attribute, we will find the reasons for these scores.

In general, the contribution of "affiliation," "utilization," "longitudinally," "services provided," "coordination – information system," and "coordination of care" helped to improve the score; in turn, "ease of access" and "available services" were negative. The highest average scores obtained from caregivers of children and adolescents were affiliation, use, and information system. At the other extreme, the worst overall scores were found in the ease of access, available services, and essential scores.

DISCUSSION

Key results

We describe the quality of care provided by health services through a validated instrument that allows the measurement of caregivers' perception of the quality of these services aimed at the child population.

Our results showed that the quality of PHC, measured by the experience of caregivers of quilombola children and adolescents, generally presents satisfactory values. However, evidence of access and services provided point to inequalities in the access of these vulnerable populations to high-quality health services, so more studies should be conducted.

Table 1. Characteristics of the guardian of quilombolas children/adolescents in relation to health services, Tocantins/Brazil, 2017 (n=68).

Variables	n (%)
Sex (female)	50 (73.53)
Age	
Adult	61 (89.71)
Elderly	7 (10.29)
Economic class (ABEP)	
C1	4 (7.50)
C2	13 (22.50)
DE	39 (70.00)
Receipt of benefit (yes) [a]	41 (50.00)
Sons	
≤ 2	25 (36.76)
> 2	43 (63.24)

ABEP: Brazilian Association of Research Companies. [a] Receipt of benefit: municipal, state or federal government.

Table 2. Average score based on self-report of guardians of quilombola children/adolescents in relation to PHC in the State of Tocantins/Brazil, 2017 (n=68).

PHC attributes	Mean (standard deviation)	95%CI
Essential attributes		
Degree of affiliation	10 (0)	
Use	8.45 (0.39)	7.63–9.26
Accessibility	6.01 (0.42)	5.13–6.88
Longitudinally	7.25 (0.34)	6.54–7.95
Care integration	7.39 (0.52)	6.33–8.45
Information system	8.24 (0.36)	7.49–8.99
Available services	6.57 (0.31)	5.93–7.21
Services provided	7.93 (0.41)	7.09–8.78
Derived attributes		
Family orientation	7.93 (0.49)	6.53–8.55
Community orientation	7.54 (0.34)	6.72–8.12
General evaluation		
PHC essential score	4.42 (0.20)	4.00–4.84
General score	7.68 (0.21)	7.24–8.12

PHC: primary health care; CI: confidence interval.

Limitations

We made several attempts to collect data from all caregivers in the communities, but there were some data losses that reduced the sample size. This small sample size may have been a limitation with regard to the ability to extrapolate the results found in this study. However, this study is the first to assess the quality of PHC in five quilombola communities from different locations in Tocantins, using an internationally developed and validated tool in Brazil, which makes this an important parameter for similar studies, as well as strengthening the goals of SDGs related to the inclusion of vulnerable populations.

Interpretation

Main socioeconomic demographic characteristics of quilombolas have lower income, less education, do not work, and receive government benefits (i.e., they are poorer and have lower purchasing power, greatly affecting the child population). This corroborates evidence from other studies[7,10] that have shown that population groups like this are less likely to access and use health services.

Similar studies[11,12] report that the identification and use of PHC as a regular source of care are directly related to social vulnerabilities (belonging to groups with a historical profile of exclusion/discrimination — quilombolas[5], indigenous[13,14], and populations with disabilities)[15]. Equitable distribution of high-quality health care is essential to achieving the goals set out in the SDGs and contributing to the realization of the right to health.

Our results demonstrate that overall satisfaction was well evaluated, possibly influenced by a number of other factors, including social, economic, and demographic aspects; this may explain some literacy-related findings (e.g., satisfaction is often high for demonstrably low-quality services, particularly for users with less education or less experience in high-quality health services)[16,17].

An Internet survey of 12 countries showed contradictory evidence between educational level and satisfaction. People with primary (or less) education consistently rated their user experience as worse than people with secondary and/or higher education. In numbers, 34% of respondents reported that the staff had treated them poorly because of their identity; 10% attributed this to their poverty[18]. Improving health literacy can reduce this mismatch, although user satisfaction provides an important perspective, other measures should be considered. These can include trust in the health system and the quality of interpersonal care provided by health professionals[19].

Scores observed for the degree of affiliation and use (i.e., the recognition and use of the health service) demonstrate that those responsible identify the PHC as a reference service for their child/adolescent and is related to the characteristics of quilombola communities such as geographic isolation, large distances from other health services, transportation difficulties, and low income[20,21] — model of the universal health system in Brazil[22] — it is also a variable that explains the good performance found.

Universal access to health is essential to comply with the SDG; however, the urgency to expand essential services to the population at any cost, without a focus on quality, does more harm than good[18,23]. Concern with heritage implies access to a minimum level of quality guaranteed for everyone; two reasons that support this hypothesis are as follows: ethical achievement of health outcomes (increased access will not translate into better health outcomes for disadvantaged people unless all people have access to high-quality services) and efficient use of resources (spending scarce resources to expand access without quality is wasteful and inefficient).

Low scores found in the accessibility sub-item show the disadvantages of health services in quilombolas' communities and portray how poverty and vulnerability increase inequalities. A study carried out in Kenya[24] showed that poor quality of maternal care was substantially more prevalent for the poor than for the richer people. Likewise, in Brazil, poor communities receive poor quality care[25].

Longitudinally implies a therapeutic relationship, characterized by the responsibility of health professionals and the patient's trust[26]; for this to be effective, the bond or affiliation between the child's family and the health service must occur. However, despite the good results found in this study, bonds in quilombolas' communities are often established with community health agents (and not with doctors and nurses). In Brazil[27], as in other countries[28,29], community health workers operate within their own community and are more likely to behave as expected by community members (establish trusting relationships with caregivers).

Our findings are similar to those of Nanyonjo et al.[30], in which continuity of longitudinal care for children under 5 years of age — treated for malaria, pneumonia, and diarrhea, continuity of longitudinal care — was greater for Community Health Workers than for professionals from the health care unit. If professionals know the child's health history and develop a family bond, this strengthens the longitudinally and quality of the service and increases user satisfaction with the health service (and, of course, the professionals involved in the work performed).

Integrality is the measure in which health services are provided and available in a complementary and coherent way[26].

Services provided component obtained a satisfactory score, demonstrating that professionals guide caregivers[31,32] on how to maintain health, growth, development, and child/adolescent safety. However, the available services component scored below ideal — this indicates inadequate facilities, lack of diagnostic and treatment tools needed for high-quality care — these are important and sensitive services (e.g., for disease management noncommunicable and other chronic conditions more common in children and adolescents)[33], as they refer to the early detection of infections such as HIV, which require continuous support from the patient.

Despite the significant decline in the incidence of vaccine-preventable diseases, several countries report delayed vaccination of children and adolescents in Asia, Eastern Europe, Africa, and South and Central America[34] (mainly in relation to socioeconomic conditions and characteristics of the health system)[35]. Formative surveys at eight facilities in Zambia revealed that only 46% of patients are on stable HIV treatment; in Brazil, the population group between 13 and 19 years old continues to show increasing incidence rates of this infection[36], despite being a national policy for patients in these countries. Similarly, lapses in tracking test results have also been reported and pose serious challenges for HIV[37,38].

It is important to highlight the need for health units to provide more services to meet the population's basic health needs (including supplies such as vaccines and medicines). Another warning to professionals about the low quality of care in health care. Research has revealed that individuals in low- and middle-income countries do not receive appropriate treatment during consultations — including preventive interventions during childcare, oral rehydration therapy for children with diarrhea, or antibiotics for those with symptoms of pneumonia[18].

Competent systems provide individuals and communities with timely health promotion and disease prevention. People have the right to rely on their conditions being detected and managed in an integrated manner. Assistance coordination presented a satisfactory assessment, which may be due to the perception of the need to combine the basic care network and the specialized services that are absent in the quilombolas' communities. Inadequate integration of the Health Care Network generates weak referral systems and undermines the ability of health systems to take care of complex and emerging conditions[39].

In spite of a new design for the coordination of care for PHC, it will be used in the past four decades as a key for health care for all[40], the continuity of two care in this way requires that the maintenance of the quality be incorporated into the DNA of all health systems. Among the actions of succession include adhering to a policy and a national quality strategy, building management capacity in all the new health systems, strengthening the regulation and provision of bills, and collecting and learning the data of the health system[41].

Thus, the coordination of care must be focused on the user, with a system that is easy to access and navigate, especially for the most vulnerable subpopulations that, in addition to communication barriers in health services, are common even among the most enlightened (who do not recognize, for example, the place right for the service)[39], face barriers of prejudice, discrimination, and exclusion in the various PHC services[42,43].

Among other essential challenges in care coordination, robust information systems for all health care platforms represent a key area for innovation. However, the use of electronic records to produce a coherent view of indicators needs to evolve into technical organizational arrangements (single information systems) that maximize quality at the system level.

Evidence shows that health system data collection is often expensive, uncoordinated, and disconnected from decision-making. Data quality in routine health information systems is poor, with vertical program evaluations often identifying a high prevalence of missing or inaccurate data[44]. Tools and indicators are fragmented by disease and source of funding, with inadequate harmonization and few plans coordination and use of data[45]. Inadequate integration between platforms and weak referral systems hampers the ability of health systems to address complex and emerging conditions. Poorly organized health systems lose lives, waste scarce resources, and the goodwill of populations.

High scores for longitudinally were also accompanied by higher scores for the attribute of family orientation. Considering that child health care presupposes greater interaction with the family, the results suggest that the Estratégia Saúde da Família/Family Health Strategy (ESF/FHS) tends to provide, in fact, a change in the care model, which starts to value the context of people's lives more (people-centered model) and the insertion of the subject in the family and in the community.

This second aspect is notably highlighted by the children's caregivers, who attributed better scores for the attribute of community guide to the family health strategy teams. Similar evidence was described, highlighting some factors that seem to be related to the better effectiveness of community guidance in care[28,29], much as the actions of home visits carried out by all professionals, but mainly by community health workers, which facilitates health surveillance and monitoring of families in quilombolas communities.

Appropriate counseling and health education are essential elements for family and community guidance, quality indicators, and derived attributes, evaluated in this study with

satisfactory scores. Similar results were observed by children assisted in PHC, showing improvements in some health indicators, such as the reduction in the number of deaths from diarrheal disease and respiratory tract infection in the postneonatal period[46]. Respiratory infections in children showed a reduction in mortality in approximately 80% in the past two decades, a fact strongly attributed to increased access to health services[47].

However, in observation of consultations of sick children in 17 countries, only 43% of professionals informed caregivers about the diagnosis of their children. Counseling is particularly important for the management of diseases characteristic of health particularities in this stage of life characterized by the greater volume of acute conditions[48]. Another shows that 2 million deaths from neonatal diseases and tuberculosis, which are amenable to health care, 56% occurred in people who used the health system but did not receive good quality care[49].

The low overall assessment of the essential score (4.42), similar to other studies[50], represents the reality of many vulnerable populations in relation to high-quality access in different countries. One explanation for this scenario would be the conceptual application of the Reverse Care Law[51], as the availability of good medical care tends to vary inversely with the need to provide it in the population served — there is evidence of this reverse care law in many health systems — for example, tuberculosis has a strong socioeconomic gradient across countries, within countries, and within communities[52].

The equitable distribution of high-quality health care is essential to reducing systematic health disparities, especially among socially disadvantaged groups such as quilombolas. Primary care is one of the main determinants of health, and equitable access to the system is, therefore, important to ensure positive results, especially those aimed at by the SDG, ultimately contributing to the realization of the right to health.

The results of our study do not allow us to ensure that the child population has received the best possible care. Health units suggest a precarious structure to provide basic clinical care and deficiencies in health promotion, disease prevention, and continuity of care. A diverse range of movements must be accommodated under the umbrella of PHC. These movements include intersectoral actions to ensure the health agenda of vulnerable populations on the agenda of all policies, governing with quality, investing in infrastructure, transforming strength, and educating community residents, especially caregivers and leaders, about rights, responsibilities, and fighting for them.

Finally, it is highlighted that the results must be interpreted considering some limitations. The lack of national studies on the subject, especially among quilombola populations, points to the need for new similar assessments. Although the scope and scope of the study portray the perception of five communities, it is difficult to draw conclusions about how generalizable these strategies are.

However, it should be noted that the same socioeconomic reality and the same history of segregation and abandonment are present in many communities in the national and international Canary Islands. We emphasize that the registered perception did not include all social actors, and the perspectives of managers and service providers must also be known, in order to better face the situation.

More broadly, the successful development of shared vision, policies, strategies, coordination, and implementation with vulnerable populations is necessary to design a care architecture that directs patients and professionals to the proper performance of PHC services.

CONCLUSIONS

Quality of PHC has generally satisfactory values. However, as these results differ from most studies, more research should be conducted.

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AUTHORS' CONTRIBUTIONS

FRPQ: Conceptualization, Data curation, Formal Analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Supervision, Validation, Visualization, Writing – original draft, and Writing – review & editing. **ESM:** Conceptualization, Data curation, Formal Analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Supervision, Validation, Visualization, Writing – original draft, and Writing – review & editing. **FA:** Conceptualization, Data curation, Formal Analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Supervision, Validation, Visualization, Writing – original draft, and Writing – review & editing. **AMB:** Validation, Visualization, Writing – original draft, and Writing – review & editing. **AP-S:** Validation, Visualization, Writing – original draft, and Writing – review & editing. **FLAF:** Visualization, Writing – original draft, and Writing – review & editing.

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