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Symbolic sites of belonging and prevention and control of tuberculosis: perceptions and practices of community health workers in Brazil and Ethiopia

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Abstract *This article aims to evaluate the contribution of Community DOTS, Directly Observed Treatment Short-Course, for the prevention and control of Tuberculosis actions in primary care in Brazil and Ethiopia, based on the perceptions and practice of the community health care workers. We employed the Symbolic Sites conceptual-methodological framework, accounting for its three types: Black box, Conceptual box, and Toolbox. The contrasting case study involved triangulating and complementing data collection and analysis from semi-structured interviews with community health workers and health professionals, site observation, and document analysis. The results highlight a sense of commitment as an essential value regarding the activities developed by community health workers in both contexts. The main challenges are the insufficient capacity building and supervision (Conceptual box), and the difficulties related to access (Toolbox), expressed in long geographic distances in the Ethiopian case and barriers related to territory violence, mostly drug trafficking, although not explicit, in the Brazilian context. This implies in a continuous effort for the community health workers to adapt their practices, respecting the cultural values (Black box), in order to direct their actions to overcome these challenges.*

Key words *Evaluation, Tuberculosis, Symbolic sites, Brazil, Ethiopia*

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Introduction

This paper presents an evaluation of TB prevention and control actions at the Primary Health Care (PHC) level, based on the perceptions and practice of Community Health Workers (CHW) in two different contexts, urban and rural, in Brazil and Ethiopia using Zaoual's theory of the sites of belonging[1]. The similarities and differences between the two countries led the authors to describe how global TB policies translate into diverse realities[2].

TB prevention and control actions are organized around the DOTS strategy – *Directly Observed Treatment Short Course* – which was launched by the WHO in 1994 to reduce morbidity, mortality, and the transmission of the disease. The strategy consists of five components: political commitment to the implementation and sustainability of the TB program; diagnosis through bacteriological examinations; directly observed treatment (DOT) aimed at strengthening compliance with treatment and prevention of drug resistance, the supply of medicines, a registration system and case follow-up[3]. Some obstacles have still been identified despite the progress made, especially those related to access in rural and urban areas[4,5]. The WHO and the *International Union Against Tuberculosis and Lung Diseases* have promoted the integration between the National Tuberculosis Programs and primary health care activities. Support was provided to countries with a high TB incidence for the implementation of Community DOTS (CDOTS), led by the CHW. The CHW links the community's daily life to the health services, identifying, through home visits, individuals who are coughing for more than two or three weeks, depending on the country, referring them to the health units to investigate TB (active search), following the medication intake throughout treatment and promoting health education actions[4,6]. Review papers[7,8] indicate that when CDOTS are more effective in controlling the disease when adapted to local contexts. Therefore, decentralized TB actions must be evaluated to verify not only the achievement of results of this strategy but also its *in situ* operationalization[9].

Thus, this paper aims to evaluate the contribution of CDOTS to TB prevention and control actions in Brazil and Ethiopia, through the role played by the CHW, including the approaches to the challenges observed in TB control programs in two places of study.

Why Brazil and Ethiopia?

Both belong to the group of 20 so-called *high-burden* countries for TB according to the World Health Organization[10]. From the geographical viewpoint, they are located on different continents with diverse social, political, and economic contexts. In Brazil, approximately 85% of the population lives in an urban environment[11]. In Ethiopia, 85% of the population live in rural areas[12]. Furthermore, different epidemiological patterns are identified. In Brazil, the incidence rate of TB was 41/100,000 in 2015[10], with disparities among regions. In Ethiopia, TB incidence is 192/100,000, and the infection is spread throughout the country[10]. In the last two decades, significant progress occurred in TB prevention and control, with resources and decentralized PHC actions[13].

Brazil adopted the DOTS strategy in 2003[14], extending its actions to the scope of the CHWs. The Community Health Workers Program (PACS) is part of the Family Health Program (PSF), later called the Family Health Strategy (ESF). The ESF considers the patient in the context of work, housing, family, and community relationships[13]. The TB program acts as an integral part of the public health system, with state and municipal level management structures. The CHW activities would expand access to primary health care units (Basic Health Units and ESF), and is responsible for the development of the TB diagnosis, prevention, and control actions[14-17].

In Ethiopia, TB care is also decentralized from tertiary care institutions to primary care units (DOTS coverage: 95%). The TB program is an integral part of the public health system, with regional and district level management structures. The district health system generally comprises health care units, a health center, and a district hospital. TB treatment is managed in the health centers to which health care units are linked and where the CHWs work. All patients have free access to diagnostic and treatment services in the public health services[18].

Community health workers

In Brazil, CHW started from isolated experiences in the late 1970s. The first professional courses emerged in the 1990s, and the CHW profession was established in 2002. The profile of CHWs has been changing, especially concerning their qualification[15]. Most undertake an introductory course of initial generic training (area

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diagnosis, service portfolio, and primary health care organization), lasting one week and with a 40-hour workload. The number of CHWs must be sufficient to cover 100% of the population registered in the territory, with a maximum of 750 people per CHW and 12 CHWs per Family Health team[13]. The minimum ESF team consists of a doctor, a nurse, a nursing technician, and a CHW. The CHWs receive a salary, and most of them are women[18]. In 2013, there were approximately 240,000 CHWs in Brazil[6].

The *Health Service Extension Program* was created in Ethiopia in 2003, despite earlier initiatives. The *Health Extension Workers* are female professionals who live in the community, have a salary, high school graduation, and are trained for one year in prevention and control activities based on a *16 packages* comprising four areas of expertise: Hygiene and Environmental Sanitation, Disease Control and Prevention, Family Health, Health Education and Communication. The CHWs work in pairs in the health care units of the *kebeles* (smaller administrative units with 5 thousand inhabitants). Other professionals, except for doctors who work primarily in hospitals, work in the health centers. The activities of the CHWs related to TB are primarily health education, respiratory symptoms referral to the health center, and the follow-up of TB treatment[19,20]. By 2014, there were around 34,000 CHWs in Ethiopia[6].

The theory of sites of belonging

This reference aims at a cultural analysis of social practices, based on the concept of a symbolic site of belonging. Sites are not empty geometric spaces, but they make up a material and immaterial entity of shared sense, where social codes and local customs are common[1]. This signalizes the impossibility of mechanically transposing models from one site to another, as in the thesis of globalization, where one can perceive the expansion of a standardizing hegemonic model in the scientific, economic and financial fields[21]. The model of the sites of belonging would be able to produce differentiated effects according to the places, moments, contexts, organizations, and activities. If, on the one hand, we would observe an excess of uniformity, standardization, and regulation, on the other hand, we see the return to the site, sustainable and creative in every way. Therefore, it is crucial to consider the actors' responses in coding and recoding resources, both material and immaterial, that come to them, considering the models and organizations of the contexts to which they are linked. According to Zaoual[1], abstract constructions would succumb to the "exuberance of the factual world". The classical models of rationality would be limited in their ability to read individuals' local practices, being "mostly static, deterministic, mono-disciplinary, and mono-cultural" from the perspective of Panhuys[21], without, thus, favoring the world view of actors within the decision-making process. Situated rationality would not be limited to mere technical adequacy, but would consider the rationality of beliefs and actions in the sites[1].

Thus, the acceptance of a "standard" such as the CDOTS guidelines is different from the domain of the standard. The incorporation in the local setting becomes possible if it integrates particularities of the reception sites, requiring recombination of the incoming values within a given local cosmovision and its "invisible borders "[1], which will facilitate or not the implementation processes. In this case, the CDOTS would have to give meaning to local and concrete actions and interactions, with the need for a monitoring pedagogy, in which action and reflection would go hand in hand with this process. To this end, the processes would have to flow in a flexible, dynamic way built *in situ*. Thinking from this perspective, we ask ourselves, "How is the CDOTS rationality presented in places/sites as diverse as Brazil and Ethiopia from the perspective of the CHWs? How are CHW practices organized and managed on the day-to-day basis of the sites?"

Methods

A contrasting case study was carried out employing the *Rapid Evaluation Method (REM)*[22] .

In Rio de Janeiro, a Health Center (HC) and a Family Health Strategy Unit located in a slum, in an urban area were selected. In Ethiopia, a HC coupled with its five Health Care units were selected in the rural area of the village of Agaro.

Data collection included different techniques and sources of evidence: semi-structured interviews with the CHW and health professionals, direct observation of health facilities, and the review of TB patients' follow-up books, as to check the pertinence and validity of the information (triangulation and complementarity)[23] . Data collection occurred in 2012 by two research assistants, one in Brazil and the other in Ethiopia, accompanied by the principal researcher.

A thematic content analysis was carried out employing Zaoual's box typology[1]: conceptual,

tool, and black boxes. The *conceptual box* encompasses the empirical or theoretical knowledge, designated as social knowledge accumulated by the different actors' courses. Actors also operate with a *toolbox* that contains the know-how, techniques, and modes of organization, and context-specific behavior models. In this conceptual framework, the black box describes the myths, beliefs, experiences, and values that give sense and direction to the sites' actors. It is usually the often-hidden symbolic aspect of local practices that alludes to complicity, uniqueness, and openness to the new. The analysis viewed the convergences and divergences between the Brazilian and Ethiopian contexts.

For the quantitative analysis, a descriptive statistic of the variables gender, age, marital status, level of schooling, professional category, and working time in the unit were included.

The study was approved by the Research Ethics Committees of Health Secretariat of the city of Rio de Janeiro and Jimma University.

Results

The case of Rio de Janeiro, Brazil

The city of Rio de Janeiro (RJ) has a population of 6.5 million inhabitants. The HC is located in an area with high levels of violence, mainly due to drug trafficking. The HC is broad, and the Health Family unit is placed inside it. The TB program functions on the first floor of the HC, occupying four rooms, two for medical appointments, and two for nursing. The waiting room is located in an open space, being exclusively for TB patients. We interviewed 11 CHWs and seven health professionals (2 nurses, 2 nursing technicians, 1 physician, 1 pharmacist, and 1 adult program manager). Concerning the CHWs interviewed, 10 were female, with a mean age of 30 years. Most of them had completed High School, being predominantly married, with diverse religious options (Catholic, Protestant, and Spiritist).

The case of Agaro Town, Ethiopia

The village of Agaro has a population of 26,000 inhabitants, and lies in the region of Oromia, southwest of Ethiopia. The region is known for its coffee plantations, with Agaro being a market place for this product. The HC is large and located in the village center, and has five rural health care units, each with two CHWs. Patients wait for care in an open, external area. There are no doctors on the HC. Nurses and *health officers* (professionals trained in management and nursing) are qualified to examine, diagnose, and prescribe treatments. The health care units are within a distance from 2 to 15 km. Each unit is staffed with at least two CHWs. Eight CHWs were interviewed, with a mean of 22 years, all with complete High School level, and most were single, Muslim women. Six health professionals were interviewed at the HC, including one nurse, one pharmacy dispensary, one laboratory technician, one laboratory technologist, one pharmacist, one health administrator, and one *health officer*.

Analysis

Conceptual box: CHW empirical and theoretical knowledge

CHWs in Ethiopia undertake a one-year training course. All eight CHWs respondents describe in detail the scope of the activities carried out under the denominated "16 Packages", which includes 80% of prevention activities and 20% of control and treatment.

My activities are based on the 16 packages: maternal and child health, anti-natal care, delivery services, family planning, immunization; for under 5, treatment and curative services; environmental hygiene, like latrines (we teach how to construct and how to use it), have separate rooms for cattle… is not easy due to the cost; waste disposal, preparing the pi (burry the waste); and how to drink water, how to protect it from the animals, boiling. (CHW, Ethiopia)

In Brazil, the general activities described by the CHWs prioritize the linkage of community and health care units, home visits, counseling for diseases such as diabetes, hypertension, TB, and user follow-up. Only one CHW emphasizes promotion and prevention actions.

Regarding TB actions, the CHWs in Rio de Janeiro state there is training, although some have not yet done so. Training sets are useful, valid, and relevant: *There is always some new information. As much as we know, there is always something new* (CHW, Brazil). The most important activity related to TB actions would be the active search for respiratory symptoms in the community, referral to the health unit, treatment follow-up, control of absentees, and educational actions. In Agaro, CHWs say that there is no specific training for TB. They perform the following

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activities: identification of TB suspects, monitoring of medication use, collection of medications at the HC, counseling in health education, mainly in environmental hygiene, including ventilation, cohabitation with animals, eating habits such as boiling milk.

Regarding the supervision of TB activities, only 3 of the 11 CHWs interviewed in Rio de Janeiro reported having supervision: *Yes, by the nurse. She asks how patients are, and whether they are coming for treatment* (CHW, Brazil). Supervision is not enough for the CHWs in Agaro: *They come and ask us in general, but it is not formal supervision with feedback. It is superficial supervision. They only ask if we accomplished the activities* (CHW, Ethiopia).

Most CHWs (8) in Rio said they do not use the TB handbook, working mainly with what they learned in the training courses and the information shared with the team. Agaro's CHWs also did not use the TB handbook, explaining that the referral form and the treatment monitoring card are enough for their daily tasks (Figure 1).

Toolbox: know-how, techniques and action models

In the Brazilian case, one of the CHWs points out that their function is multitasking, like a Swiss knife (*home visit, patient guidance, group activity)*, displaying the multiple possibilities of action, in responding to the demands of both the users and the HC.

While the directly observed treatment is good, the CHWs have points to consider. The typical difficulties reported in both sites concern the identification of suspected cases, abandonment of treatment, and overloading of activities, and others vary. Half of Agaro's CHWs complain about having to go to the HC, which is distant, to pick up the medications without any kind of financial support (*The greatest difficulty is having to pick up the medication at the health center, as we have to pay for transportation ourselves*), or even the long distances traveled to reach the patients. This means having to use different resources, such as the support of community volunteers to help reach more distant areas or obtain information: *I need to involve volunteer community health members to help me reach certain areas of the region. They give me information about the community.*

Several CHWs in Rio reported the following difficulties: lack of resources and partnership in the territory, lack of help from health professionals, fear of catching TB, and the poor living conditions. The CHWs did not mention the local violence as an interference in the performance of the activities, although this subject appeared in informal conversations, mainly with health professionals. The research team also had to take care when they went to the HC. They were instructed by the nurse to call in advance to ask if they had access to the site due to conflicts in the territory (conflicts between the police and drug dealers and tensions between different drug criminal factions). It was also necessary to replace the car that the research team used to access the community due to its color, identified with the color representation of the group contrary to the command dominating the place. Some of the HCs' TB patients were engaged in drug trafficking, and different strategies were used by health professionals and CHW to carry out the treatment, such as the intermediation by a relative who went to the HC to receive TB medicines and guidance. The CHWs also reported meeting the patient in a neutral location, which did not put them nor the user at risk.

When asked about what they did when a patient started being absent or thinking of abandoning the treatment, the CHWs at both sites seemed to have an active behavior, but with different strategies. In Rio, the CHWs reported going to the households, trying to know what was happening, encouraging or sharing with the supervisors, in order to try to find ways to assist the patient (*I encourage them to continue the treatment. If it is the case, I go along with them, ask for the family help, that's it)*. In Agaro, they reported that abandonment rarely occurred, but it mostly shows the risks of TB becoming a chronic disease, including the possibility of dying, developing resistance to drugs, and becoming a risk to the family. Two of them emphasize the importance of reinforcing home visits.

Regarding suggestions for improving TB actions, CHWs, in general, suggest community mobilization for the dissemination of TB information. Most CHWs of the unit evaluated in Rio emphasized the importance of greater disclosure about the disease with lectures, campaigns, distribution of flyers, street actions to alert the community, including the use of tools such as *photos, movies, being more visual than verbal so as not to be tiring.*

The CHWs in Agaro mentioned the importance of raising awareness about prevention actions, primarily through the involvement of healed individuals and community members

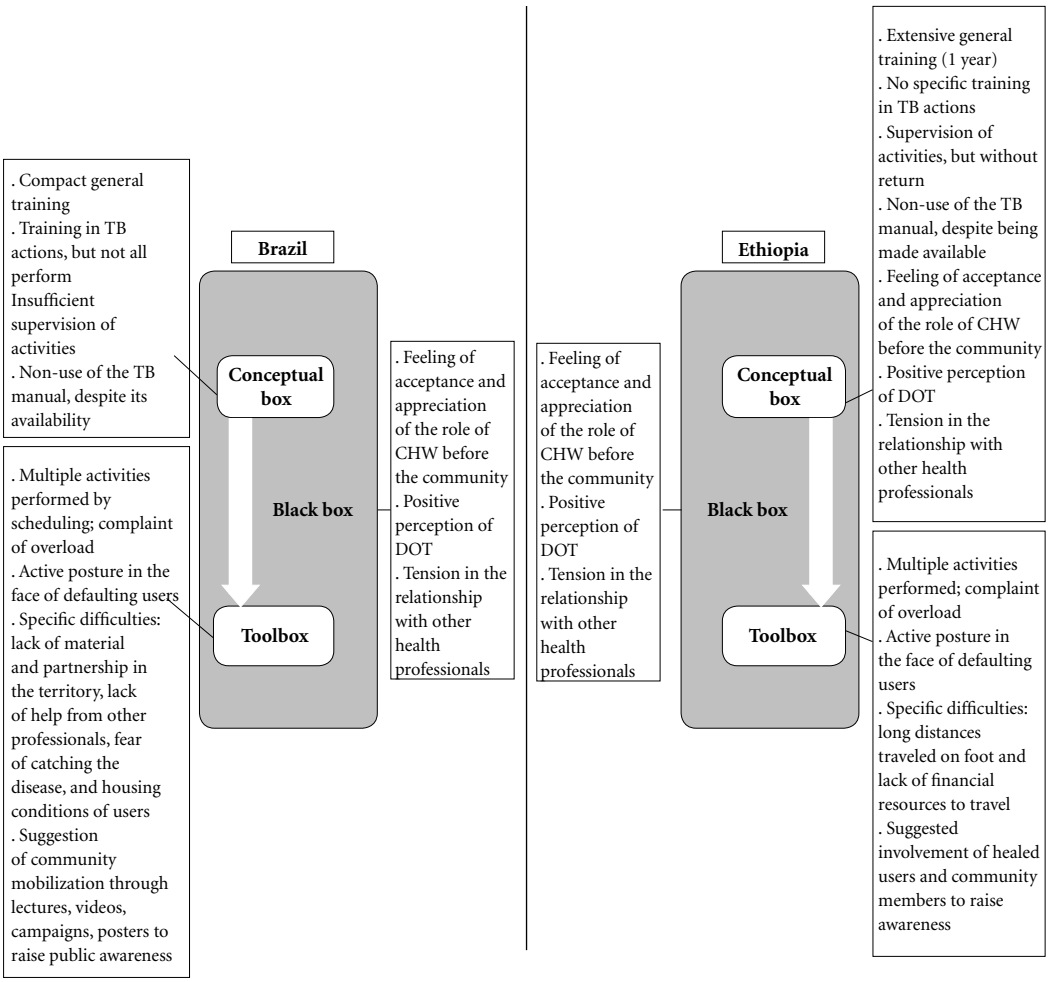

Figure 1. Results Brasil and Ethiopia by sites of belonging.

Source: Elaborated by authors.

who can help raise awareness. They also suggest appropriate training and supervision.

Black box: The CHW myths, beliefs, values and experiences

The statements of all CHWs, both in Brazil and in Ethiopia, show an acceptance and appreciation of their roles by the communities where they work. Three of the CHWs in Rio are identified as an essential part: *I just think we came to add.*

The relationship with the patients and the community in both locations is described positively: *It is the same for all patients. I see them if they are taking medicine, if the appointments are on schedule* (CHW, Brazil)*; There is a strong, close relationship. We are considered to be family. I was born, raised, and got married here. Many consider me as a daughter* (CHW, Agaro).

All CHWs interviewed in RJ described the perception of DOT as useful, since it allows the treatment to be carried out to the end with follow-up, hindering abandonment. It also breaks

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the stereotypes: *I think it's very good because it's a way for someone to complete the treatment, being followed. I believe it's great that it breaks all stereotypes, shame.* However, there are some resistances: *It's nice, but there is resistance. Some patients do not accept that you go there every day.*

The CHWs in Agaro agree that it is a significant intervention: *I think it's the best strategy. The previous treatment, in which the patient was not followed, led to a great abandonment.* However, most also criticize: *It's a fascinating intervention, but if we have the proper supervision, training, and the medication here (health care units), not having to go to the health center to pick it up, it would be perfect.*

Some CHWs identified both sites regarding the relationship with health professionals. One of the CHWs in Ethiopia reports: *I try to discuss the cases at the health center, but they do not consider me... I think it's because I'm a CHW.* In Brazil, a CHW says that one of the difficulties experienced is *lack of partnership in the territory and help of professionals.*

The view of the health professionals

The health professionals in Rio emphasize the importance of CHWs. However, they indicate that their level of commitment varies a lot. Some describe as having a close relationship and much interaction. Others refer having a more distant and formal relationship. Most point out some difficulties in the work of the CHWs, signaling the lack or insufficiency of training for TB, which would generate a lack of understanding of the problem and incomplete actions. There are also reports that some CHWs are not familiar with the routine or the patients' flow to the HC. Another difficulty identified is that the CHWs are rooted in "community culture": *We have to work to change this idea that the CHW is not a resident but a health worker.*

Concerning health professionals in Agaro, the difficulties associated with CHW are lack of knowledge about the side effects of drugs and their interactions, lack of financial support to go to the health center to pick up the medications (*Sometimes the CHW refers the patient to the health center to get the medications*), gaps of knowledge in the follow-up of treatment, especially in tracking the absentees. According to the professionals, the CHWs should have formal training in TB actions: *Only a few CHWs can perform many recommended activities. They need more training and empowerment.*

Practitioners from both locations make suggestions to improve the relationship between them and CHWs. In Rio, they reiterate that the HC direction could help *giving lectures on the operation of the routines, the programs, facilitating integration*. They also emphasize the need to share the workflow with the CHWs, the dispensing of medication, and a better deployment of actions (to facilitate the search for contacts and administration of medications), including social activities such as meetings and parties. Further training in TB actions for CHWs is also suggested. They believe that training would value the CHWs since they are not seen as a profession. One of the respondents said some health professionals still resist CHWs.

Regarding Agaro's CHWs, most professionals point out the importance of strengthening the link between professionals and CHWs and recognize that there is a gap in their supervision. They recommend the provision of specific training, regular supervision, and collaborative activities in TB prevention and treatment: *The program is good in terms of drug supply and activities, but the link between practitioners and CHWs must be strengthened through collaborative activities in TB prevention and control actions.* One of them points out that one of the difficulties is because the professionals do not assign the CHWs the same status as them.

Discussion

This study explored the practices and perceptions of CHWs and health professionals in Brazil and Ethiopia, from the perspective of the sites of belonging. We identified how CHWs are aware of the importance of their role as a link between the community and the health unit. As pointed out in several studies[24-27], they believe in the importance of their role and activities in TB control. The sense of commitment[28] emerges as an essential value in the theory of sites, identified in both contexts, Rio and Agaro. The activities of the CHWs are, therefore, not restricted to the value of their function, but encompass their role of caring, looking at, sharing, and interacting with the people in the community[29]. Rationality is not limited to purely technical adequacy but takes into account the values, rules, and perception of the local world[1]. Although they complain about the lack of specific training in TB (Ethiopia) and supervision (Brazil and Ethiopia), lack of logistical support, or financial resources to go to the

health units (Ethiopia), the actions are carried out, but require adjustments and adaptations. For example, in Ethiopia, they use their financial resources to go to the health units to pick up the medicines at the HC and need to mobilize community members to help identify TB suspected cases. In Rio, they need to make adaptations in the administration of the DOT.

In a previous study carried out in Rio on the same site, the professionals stated that they performed what they called "improvised DOT" [30]. In these cases, a relative would intermediate the treatment at home, and by going to the health unit weekly to get the medication, receive nurse guidance, and administer the treatment at home. Thus, the sites and their actors have a certain degree of plasticity, often incomprehensible to whom is outside.

However, the fact that the CHWs in Rio did not talk to the evaluation team about local violence caught our attention. Some studies[31,32] report the silence of the CHWs when the subject related to traffic is approached, which is interpreted as a form of defending their territory[32]. This is not so evident regarding nurses and doctors. They signalize to researchers that it is vital to be observant of local rules (not going to the health unit wearing a specific color). CHWs do not seem to have this protection, and so, probably, do not feel comfortable talking about local violence. We see, therefore, different discourses that are not equitable. The CHWs will thus correspond to their position as part of the community, although they are working within a health unit with other types of rules and codes.

Cunha and Frigotto[33] signaled that the CHWs occupy a differentiated position bordering diverse realities, circulating through several internal and external spaces in the community. Thus, we wondered whether this topic not mentioned by the CHWs in Rio would not constitute a parallel "black box", since they must incorporate in their experience other codes and values. Furthermore, this implies new organizational arrangements and practice, reflecting on the Toolbox. Health professionals, in part, would also be subject to this rule (not using a specific color) so that they can work within the territory without intimidation.

In Ethiopia, violence is not the point. The most significant difficulty reported by CHWs is the geographic distance, not the distance imposed by external barriers. Therefore, there is no change in codes or values. The black box triggered is that of the community of a country of millennial culture, expressed even in the profile of the CHWs: young Muslim women.

Another peculiarity of the local contexts refers to the prevention activities for CHWs in Ethiopia related to their working rural environment (milk boiling or living with animals in the house). Thus, the conceptual boxes and toolboxes used vary with rural and urban contexts. This would also occur when addressing the issue of community TB mobilization alternatives. It is interesting how the CHWs in Rio suggest mobilization alternatives involving visual and audiovisual resources, appropriate for urban contexts. In contrast, the CHWs in Ethiopia seek arrangements with community members so they can be partners in prevention and control actions.

We observed in both Rio and Agaro a certain tension in the relationship between CHWs and health professionals. It is clear from the statements that professionals formally value the work of the CHWs, despite some criticisms, mainly due to the lack of specific TB training (predominantly in Ethiopia), lack of supervision and collaborative activities among professionals and CHWs in both locations. In Brazil, some professionals indicate that the level of commitment of CHWs varies widely[34]. Health professionals believe that CHWs are not part of the health team because they are understood as part of the community, despite their strategic role. The CHWs, in turn, do not seem sufficiently recognized and valued by health professionals, feeling somewhat discriminated against. Seabra et al.[35] allude to the fact that as the CHWs belong to the community, they can become a reason for conflict with the health team. As we have seen, this can lead CHWs to conflicts of interpretation and management of the conceptual boxes (cognitive content) and toolboxes. Crispim et al.[36] refer to the importance of the synergy in the group activities and the cooperative accomplishment within the health teams concerning the TB actions. Lopes[31] indicates that the health team's lack of recognition of the work developed by the CHWs leads them to demotivation, frustration, and psychic suffering.

Employing the sites of belonging theory enabled us to perceive that the *homo situs* has an ethic, an identity, and rationality built in its site of belonging, and can adapt to multiple spatial and organizational entities[1,21]. The conceptual boxes and toolboxes are thus adapted according to the beliefs, experiences, and values that give sense and direction to the different actors (black box). This implies a continuous effort to overcome the main challenges seen in both contexts

(geographic distance in the Ethiopian case and drug traffic violence in the Brazilian context). A unique work is assumed and accomplished by the CHWs, and managers should pay special attention to these actors, which play a strategic role in TB prevention and control actions.

Collaborations

GCP Cardoso and E Moreira dos Santos designed the study, wrote the article and carried out the final review of the manuscript. BM Ereso participated in the data collection and analysis. Y Kiflie, K Woldemichael and W Lemma contributed to the analysis.

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