

Meanings of ‘Tuberculosis’ in Rural Indigenous Communities from a Municipality in the Colombian Amazon

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Objective. The purpose herein was to describe the meanings on tuberculosis (TB) in rural indigenous communities from a municipality in the Colombian Amazon. **Methods.** This was an ethnographic study with theoretical reference of dialectical hermeneutics, which created focus groups, one for each rural community of Puerto Nariño, for a total of 15 focus groups. The participants were community leaders and health referents. **Results.** Seventy-nine subjects participated, mostly midwives, kurakas, traditional physicians, and shamans. The analysis yielded four categories: knowledge of TB, attitudes regarding TB, community practices of TB, and the intervention proposal on TB by the participants. It was found that community leaders recognize TB as a disease that can cause death, but which can be cured if timely care is secured. The study also identified the need to conjugate western medicine with traditional medicine. **Conclusion.** It is recognized that meanings may impact upon knowledge, attitudes, and practices that affect early detection and treatment

of the disease. In addition, this work corroborates the need to strengthen and develop educational programs on tuberculosis supported by the real needs of the communities to enhance their knowledge, attitudes, and practices on the disease

Descriptors: health knowledge, attitudes, practice; tuberculosis; focus groups; qualitative research; indigenous population.

Significados de ‘tuberculosis’ en comunidades rurales indígenas de un municipio de la amazonia colombiana

Objetivo. Describir los significados sobre la tuberculosis (TB) en comunidades rurales indígenas de un municipio de la Amazonía colombiana. **Métodos.** Estudio etnográfico con referencial teórico de la hermenéutica dialéctica, en el cual se realizaron grupos focales, uno por cada comunidad rural de Puerto Nariño, para un total de 15 grupos. Los participantes fueron líderes comunitarios y referentes en salud. **Resultados.** Participaron 79 personas, en su mayoría parteras,

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curacas, médicos tradicionales y chamanes. El análisis arrojó 4 categorías: conocimientos sobre TB, actitudes frente a la TB, prácticas comunitarias de la TB y la propuesta de intervención sobre la TB desde los participantes. Se encontró que los líderes comunitarios reconocen la TB como una enfermedad que puede causar la muerte, pero que tiene cura si se brinda atención oportuna; e identifican la necesidad de conjugar la medicina occidental con la medicina tradicional. **Conclusión.** Se reconoce que los significados pueden incidir en conocimientos, actitudes y prácticas que afectan la detección precoz y el tratamiento de la enfermedad. Además, se corrobora la necesidad de fortalecer y desarrollar programas educativos sobre tuberculosis sustentados en las reales necesidades de las comunidades, para el fortalecimiento de sus conocimientos, actitudes y prácticas sobre la enfermedad.

Descriptor: conocimientos, actitudes y prácticas en salud; tuberculosis; grupos focales; investigación cualitativa; población indígena.

Significados de 'tuberculose' em comunidades rurais indígenas de um município da Amazônia colombiana

Objetivo. Descrever os significados sobre a tuberculose (TB) em comunidades rurais indígenas de um

Introduction

Tuberculosis (TB) is an infectious disease of global distribution, which is predominantly of airborne transmission. The easy transmission of TB and the precarious living and working conditions have placed the disease as a public health problem. The most recent global report on TB, issued by the World Health Organization, revealed that 10.4-million people contracted TB, globally, in 2015,⁽¹⁾ and that the most-affected populations are: persons deprived of their freedom, the indigenous, and health care workers.⁽²⁾ Indigenous peoples have great ancestral heritage that enriches the culture of humanity; nevertheless, they are considered one of the populations with highest vulnerability to acquire TB due to their geographic location, limited access to health services and education, and to the precarious living conditions (overcrowding and poverty),

município da Amazônia colombiana. **Métodos.** Estudo etnográfico com referencial teórico da hermenêutica dialética, na qual se realizaram grupos focais, um por cada comunidade rural de Puerto Nariño, para um total de 15 grupos focais. Os participantes foram líderes comunitários e referentes em saúde. **Resultados.** Participaram 79 pessoas, na sua maioria parteiras, curacas, médicos tradicionais e pajés. A análise mostrou 4 categorias: conhecimentos sobre TB, atitudes frente à TB, práticas comunitárias da TB e a proposta de intervenção sobre a TB desde os participantes. Se encontrou que os líderes comunitários reconhecem a TB como uma doença que pode causar a morte, mas que tem cura com a atenção oportuna, e identificam a necessidade de conjugar a medicina ocidental com a medicina tradicional. **Conclusão.** Se reconhece que os significados podem incidir em conhecimentos, atitudes e práticas que afetam a detecção precoce e o tratamento da doença. Ademais, se verifica a necessidade de fortalecer e desenvolver programas educativos sobre tuberculose sustentados nas reais necessidades das comunidades, para o fortalecimento dos seus conhecimentos, atitudes e práticas sobre a doença.

Descritores: conhecimentos, atitudes e prática em saúde; tuberculosis; grupos focais; pesquisa qualitativa; população indígena.

which potentiate social inequalities.⁽³⁾ In Latin America, the indigenous population is affected by TB with a propagation frequency 2.5 times higher than that of the rest of the population⁽⁴⁾ and with a mortality rate five times higher.⁽⁵⁾

In Colombia, for the 36th epidemiological week of 2016, the department of Amazonas reported a rate of TB incidence of 134.9 cases per 100 000 inhabitants, a high figure in comparison to places in the country occupying the second and third places of case reports: Chocó and Buenaventura, with an incidence rate of 31.9 and 31.7 cases of TB per 100 000 inhabitants, respectively.⁽⁶⁾ Mortality due to TB in the department of Amazonas is at 10.73 per 100 000 inhabitants, ten times higher than that of Bogotá, which reported rates at 1.1.⁽⁷⁾ The permanence of TB is related to flaws in the control programs and to the population's precarious living conditions, in

addition to the erroneous knowledge and meanings of the disease. It must be mentioned that these are related to social, geographic, and cultural processes appertaining to their organization. Diverse studies have identified the importance of learning the meanings and knowledge in relation to TB, so that these, well guided, can contribute to controlling the disease.⁽⁸⁾ In addition, the scientific evidence on TB in the indigenous population extolls the need to design public health policies, as well as educational interventions to control the disease;^(9,10) consequently, the need was noted to describe the meanings of TB in rural indigenous communities of Puerto Nariño (Amazonas) in favor of guiding the decisions made in health and performing culturally adapted interventions, aimed at these communities, so that they impact positively upon their health-disease processes for prevention and control of TB.

Methods

The ethnographic study used as principal technique for the collection of data from the focus groups, whose conformation highlighted the importance in these regions of the community leaders because these people can influence on the meanings the indigenous communities have on TB. Data was collected from March to July 2016. This document presents the information emanating from the focus groups, due to the length of the material gathered, given that other information collection techniques were used. The focus groups are a strategy that permits inquiring on knowledge and values of certain groups from their context and delving into ideas and perceptions of the subjects; likewise, these groups permit obtaining reflections and options to solve problems provided by the very study subjects. This technique permitted identifying the meanings on TB through participative and constructivist discussion of educational actions with the indigenous population.⁽¹¹⁾

A focus group was created in each of the 15 rural communities from Puerto Nariño: Ticoya, San Juan de Atacuari, Boyahuasu, Naranjales-

Barrio Tinajita, Naranjales, Puerto Esperanza, Puerto Rico, Santa Teresita, San José de Villa Andrea, Nuevo Paraíso, San Francisco, Tarapoto, Palmeras, and San Martín de Amacayacu. Each focus group had the participation of four to nine people, and each lasted approximately one hour. To establish a dialogue of knowledge on the theme, guiding questions on TB were designed, supported on scientific literature. The participants had as inclusion criteria that of being community leaders, hence, the study involved individuals with the following roles: midwives, shamans (differentiated by the community as individuals who use spiritual means for healing), traditional physicians (differentiated by the community as people who use plants as means of healing) and kurakas or vice-kurakas, who represent the traditional social and political authority of the indigenous communities. The focus groups were directed by two nursing professionals and these were accompanied by two indigenous liaisons who helped understand the native languages. The focus groups created complied with the criteria of quality and saturation of the information collected.⁽¹²⁾

The information collected was organized in the Atlas Ti program, by assigning codes to each of the focus groups and to each of the participants from each group; for example, code "GF15P1" represents focus group number 15 (GF15) and participant number one (P1). The analysis was performed through dialectical hermeneutics, through the continuous construction and deconstruction of the concepts and meanings provided by the participants.⁽¹³⁾ The research received ethical support and informed signed consent was obtained from each participant.

Results

The study had the participation of 79 individuals (44 men and 35 women). With respect to the role played, 26 were midwives, 9 kurakas or vicekurakas, 8 traditional physicians, 7 health promoters, 7 shamans, 6 health aides, and 16 other community leaders. From the analysis of the focus groups, four categories emerged: knowledge

of TB, attitudes regarding TB in the indigenous community of Puerto Nariño, community practices to manage TB, and intervention proposal from the indigenous perspective on TB, which are described in the following.

Knowledge of TB

The category on knowledge of TB revolved around three subcategories: concept and causes of TB, diagnosis of TB, and treatment of TB.

Concept and causes of TB

The participants recognized TB as a contagious disease that causes death; while also identifying that it is a curable disease: GF2P5: with tuberculosis, I have seen that people die, I know that because a neighbor died from coughing and vomiting blood; GF10P3: well, I think that disease attacks humanity a lot because it can be transmitted to people, but it can be cured when it is detected soon or when it is just starting. With respect to the causes of TB, some participants spoke of the existence of a bacteria: GF10P4: tuberculosis is a bacillus that attacks the human being's immunity and which has affected some communities a lot; on the contrary, others believe the cause of TB is external: GF15P3: before, our grandparents told us that it was a disease from the 'cutipe' (fuzz) of the tiger or blows to the back due to a bad fall.

Regarding the risk factors for acquiring TB, the participants mentioned: GF9P2: the disease is eating away at the person because they don't eat anything during the work day and do drink alcohol and smoke; GF12P1: sometimes people have the house closed shut without good ventilation, so here is where people get tuberculosis because there are too many people and the germ (bacteria) stays there and has no way out. Respiratory transmission was understood as contagion through the air when coughing, speaking, or through saliva: GF8P1: tuberculosis is transmitted through the air when coughing or when stepping on the catarrh (term:

sputum) of the person with tuberculosis, another example is: GF4P3: if a person has tuberculosis and invites you to their house to drink masato (a typical corn-based beverage of the indigenous), here the tradition is that the same totumo (vessel) is used for everyone to drink from, so you get infected. With the aerial form of transmission, the participants recognized the lungs as the principal organ affected, although it may affect other parts of the body: GF14P1: tuberculosis is a disease produced by a bacteria that attacks the lungs, but can also affect the red blood cells; GF7P1: it is a microorganism that penetrates the lungs and opens holes and wounds.

Diagnosis of TB

As means to diagnose TB, bacteriological and radiological tests were mentioned: GF3P1: they take samples of the catarrh (sputum), I think it is three small cups that are filled (bacilloscopy) and that is taken to the hospital. Shamans and traditional physicians identify individuals with TB through signs and symptoms: GF15P1: you have over 15 days of coughing with yellow catarrh, and the body starts to weaken until the person gets skinny or dries up (term used to refer to weight loss).

Treatment of TB

Participants identified the treatment with anti-tuberculosis drugs as the hospital treatment: GF9P3: the pill (medication) he was taking was because a physician always came and gave it to him; he took one in the morning and another one in the afternoon, that was for four or six months. However, they state that it is difficult for people to adhere to the anti-tuberculosis treatment due to their requiring economic resources for transportation, the long duration of the treatment, and the fear of the people because of the adverse effects of the anti-tuberculosis drugs, GF6P3: those medications from the hospital are strong because there are people who when they take the pills, it is like the body does not receive it well, they say they get shaky or dizzy; GF12P3: the hospital thing does not happen much here

because, for example, for me to get my treatment I have to go to the hospital of Puerto Nariño and sometimes there is no money to buy the gasoline for the 'peque-peque' (boats with small motors), and I would have to travel for two hours up river and then another two hours down river to come back; but, what about work?

Additionally, from the participants' meanings, the traditional treatment is important and affordable for the population, but, for example: we here have tried to cure with traditional medications, but it is not enough because the bacteria is very strong for the traditional medicine. In this sense, focus groups permitted establishing the discussion on the different plant remedies from the different rural indigenous communities to treat TB, among which there are tree barks: GF12P3: the bark from that tree is cut and cooked and when it is very thick it gets bitter; you give that to the patient without cooling it down, that has to be drunk for a month without stopping. Another widely used remedy is the blowing of breath or prayers by shamans to eliminate the tuberculous spirit: GF5P2: I work or heal with prayers for the spirits to help me get the disease out of the body; GF15P3: the knowing, who knew much about spirituality, cured with tobacco, until they extracted the ailment the person had.

Attitudes regarding TB in the indigenous community of Puerto Nariño

Support to people with TB

The participants described different attitudes regarding people with TB; one of these is that of support: GF15P2: you need not be afraid of the disease because if you are afraid, then it gets you much faster, that is like summoning the ailment to the body. GF6P4: you do have to talk to him (the person with tuberculosis) because sometimes people who are not sick will reject those who are sick, and that gets their mood down and drops their defenses and that is why they die.

Rejection and stigmatization of people with TB

On the contrary, other attitudes are fear and stigmatization, as evidenced in the following: GF3P1 generally, people are always afraid of him (the person struck with TB), and the man I had last year came here every day and my children would be scared.

Community practices to manage TB

Route of TB

According to the difficulties of geographic access of the municipality of Puerto Nariño (can only be reached via riverine transport), the departmental control program and community leaders were in charge of generating a strategy to train the communities with knowledge about TB; said strategy is "the route of tuberculosis". This was done to enhance early detection actions of respiratory symptoms and strengthen adherence to anti-tuberculosis treatment by articulating traditional and western medicine. In this sense, it was identified that some communities were aware of the route and it functioned there, and others were not aware of its existence or manifested flaws in it. GF3P1: within the route, we search for respiratory symptoms and conduct promotion and prevention activities; also, the patient is diagnosed and is intervened with both medicines to cure the patient; GF8P1: in the route we are weak, here it almost does not work, or they don't even know what it is.

Care of patients with TB

Health care of patients with TB is related to knowledge of the risk factors of the disease, to the ancestral beliefs, to caring for the body and the hygienic and isolation actions: GF3P3: my wife would try to eat three times a day and sometimes egg, chocolate, and beans for the body to cure itself; GF15P3: during the time of treatment they cannot drink alcohol or masato; they cannot

eat 'contras' (ancestral diet) as well as greasy food, which is why they can only eat 'bocachico' (*Prochilodus magdalenae*) and sardine. Another important care is using masks, covering the mouth when coughing or sneezing, and completing the treatment: GF8P3: I could not cough like that in front of my children, or in bed or anything, that is why I had my piece of cloth because I did not want my children to get infected with that.

Preventive measures against TB

As prevention measures to avoid being infected with TB, the community states: GF8P3: rooms must be clean because where it is dark is where the germs are, that is what the promoter teaches us, and to keep Windows open; as prevention measures, there are also those that contribute to isolation: GF11P1: what we do here is to stay away from him (the person who is sick with tuberculosis); GF7P1: I would tell my community that when we do 'Minga' (community work of social utility), we should bring our own water and our own utensils and to avoid inviting the person who is sick. Lastly, it is necessary to carry out spiritual protection for the whole family, through prayers; GF2P4: the protections are for them (those sick with tuberculosis) to keep from infecting when they are sick at home; look, I have cured people in my house, and my children have not been infected because I pray for them and protect them.

Intervention proposal from the indigenous perspective of TB

Finally, an intervention proposal emerges from the perspective of the participants, that is, that it stems from the meanings and knowledge the region's indigenous communities have on TB to carry out educational actions culturally adapted to them.

Importance of intervening

The different indigenous communities had as a common point the need conduct educational

interventions as formative process on TB; for the purpose of adjusting some beliefs and myths on the disease, which can affect the good development of the control program: GF11P3: that was about 20 years ago that treatments were with injections and that is why people would get bored because they had to be injected every day, but thank God nowadays it is with pills (oral medications) and that makes the patient feel safer, but people don't know that because they are not aware of their health. Another important aspect for the intervention is to establish an interaction with the indigenous population, which promotes the exchange of traditional and ancestral knowledge with western knowledge: GF2P2: Clearly, that is sharing western knowledge with traditional knowledge, for all the species and cultures to be talking.

Intervention adapted to the indigenous community

The indigenous communities have a learning level linked to ludic and dynamic activities: GF14P1: having workshops, offering them or teaching each person about it, showing films, booklets, brochures or something different, GF4P2: they should come, give their talk, but not only in a classroom, they should do recreation, sports and all that for the children and the elderly and tell us then how tuberculosis occurs, and in between a snack, lunch, or a 'sancocho' (soup stew) spend the whole day with you to share ideas and all that.

Poor support in health and social programmatic actions

The participants recognize that TB is a reality within their context and referred to neglect and poor support from the health institutions: GF11P1: the hospital is not helping us and does not provide support to bring the patient to town (municipal seat of Puerto Nariño) because here we do not have a motor (boat for river transport), we only have a small shallow (boat) that is broken, we have no fuel, these are things that during an emergency we don't have and sometimes you take four hours by river. In addition, participants state that the hospitals have not carried out training,

workshops, or educational courses on TB: GF14P1: it is an institution that has never been present in the community, on some occasions people have come, but from the Governor's office.

Discussion

The results permitted learning that the indigenous population expresses in its meanings their vulnerability regarding the tuberculosis infection due to their precarious living conditions and their geographic location. These findings have been corroborated by other studies conducted in the department of Amazonas, which mention social determinants, like deficient living conditions, rapid increase of population density,⁽⁹⁾ food insecurity, lack of knowledge of the disease, malnutrition, unemployment, low income sources, and the characteristics of the homes (small, poorly ventilated and illuminated, and with numerous dwellers), which intensify the vulnerability for TB;⁽¹⁴⁾ also, the geographic location of the indigenous communities hinders their access to health services, given that it demands economic resources to acquire fuel to bring patients to the local hospital in Puerto Nariño (located in the municipal seat).⁽³⁾ With respect to the aforementioned, it is important to highlight that there are routes from a community to the municipal seat that can take three hours or more, according to the type of boat or motor used and the navigation conditions through the Loretoyacu and Amazonas Rivers.

Regarding knowledge about TB, it was demonstrated that some individuals have mistaken knowledge, which affect their meanings and beliefs around this disease. In this regard, a study identified that, in spite of having programs to control TB, inadequate knowledge and practices still persist against this disease as a consequence of culture.^(15,16) In the indigenous communities, autochthonous processes of self-care prevail, traditional prevention and healing, due to their easy access, low economic cost, and minor discomfort. This influences upon the low attendance to the hospital,⁽¹⁷⁾ which – in

turn – represents a higher risk of acquiring the tuberculosis infection and delays in diagnosis and timely treatment of the disease.⁽¹⁵⁾ With this in mind, the literature refers to the importance of surveillance and control of patient's contacts with TB and fortifying the communication between the health staff and the indigenous populations.⁽¹⁸⁾

According to the aforementioned, interculturality is a fundamental aspect, insofar as the indigenous communities recognized the importance of the cultural meeting between ancestral knowledge and modern knowledge to establish an exchange of knowledge and a cultural negotiation that permits comprehending both cultures in health-disease processes and construct spaces for the practice of modern medicine and traditional medicine, as proposed by other authors, when stating that it is important to address the health-disease concepts of the indigenous populations through educational processes that know and understand their culture and context.^(19,20) Similarly, community leaders and health referents accepted that there were themes they ignored about TB, as consequence of the scarce support from health institutions in conducting educational workshops that permit replicating information in the community. In this respect, an author states that formation processes did not fit the language or culture of the indigenous populations.⁽²¹⁾ Also found is the lack of an assigned budget for the different levels articulated to the good performance of the program and the health institutions, which is why it is imperative to strengthen the programmatic actions supported with financial, logistic, and human resources, which combine practices of traditional medicine and western medicine with community agents trained in health and with continuous support to adequately carry out activities for early detection of TB.⁽²²⁾ In agreement with the previously stated, this study unveiled the need to conduct educational interventions with innovative strategies on TB, as indicated by a study that identified the need to develop programs with social support in the indigenous populations to improve their living and health conditions.⁽²³⁾

It is important to highlight that, to achieve a greater impact of controlling TB in the indigenous population, it is necessary to enhance the

research and the interventions of entities related to the program⁽²⁴⁾ to sensitize, diagnose, and treat TB.⁽²⁵⁾ Further, it is a priority for the State to assign economic resources for this region of such high cultural and social wealth of the Colombian geography, to strengthen programmatic and social actions to control TB. Finally, the importance of qualitative studies is denoted, given that they reveal meanings of health-disease processes as complex as tuberculosis and become potential in directing health programs and services.

To conclude, given the approach used, it is recognized that this study applies for the participating population, that is, the rural indigenous communities from a municipality in the Colombian Amazon. From the description of the results found, the study identified some meanings of TB that can affect the disease's early detection; among them, erroneous knowledge, attitudes, and practices that require guidance from education interventions. However, this study showed that community leaders from the indigenous populations identify key aspects of TB, such as that it is a disease that can cause death, but which can be cured. Likewise, the participants propose measures to develop educational interventions that are adequate for their culture; hence, the need was identified to strengthen educational programs and programmatic actions in health to TB, through strategies appropriate to their culture and context, which sensitize and contribute in the prevention and control of TB. Intercultural dialogues should be enhanced, so that participation by the indigenous communities is indispensable to create educational proposals adapted to their culture and tradition, as well as having support from competent state entities.

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conducted to strengthen individual, social, and programmatic actions to control TB.

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