Status of Tuberculosis

in Indigenous Peoples of

Latin America and the Caribbean
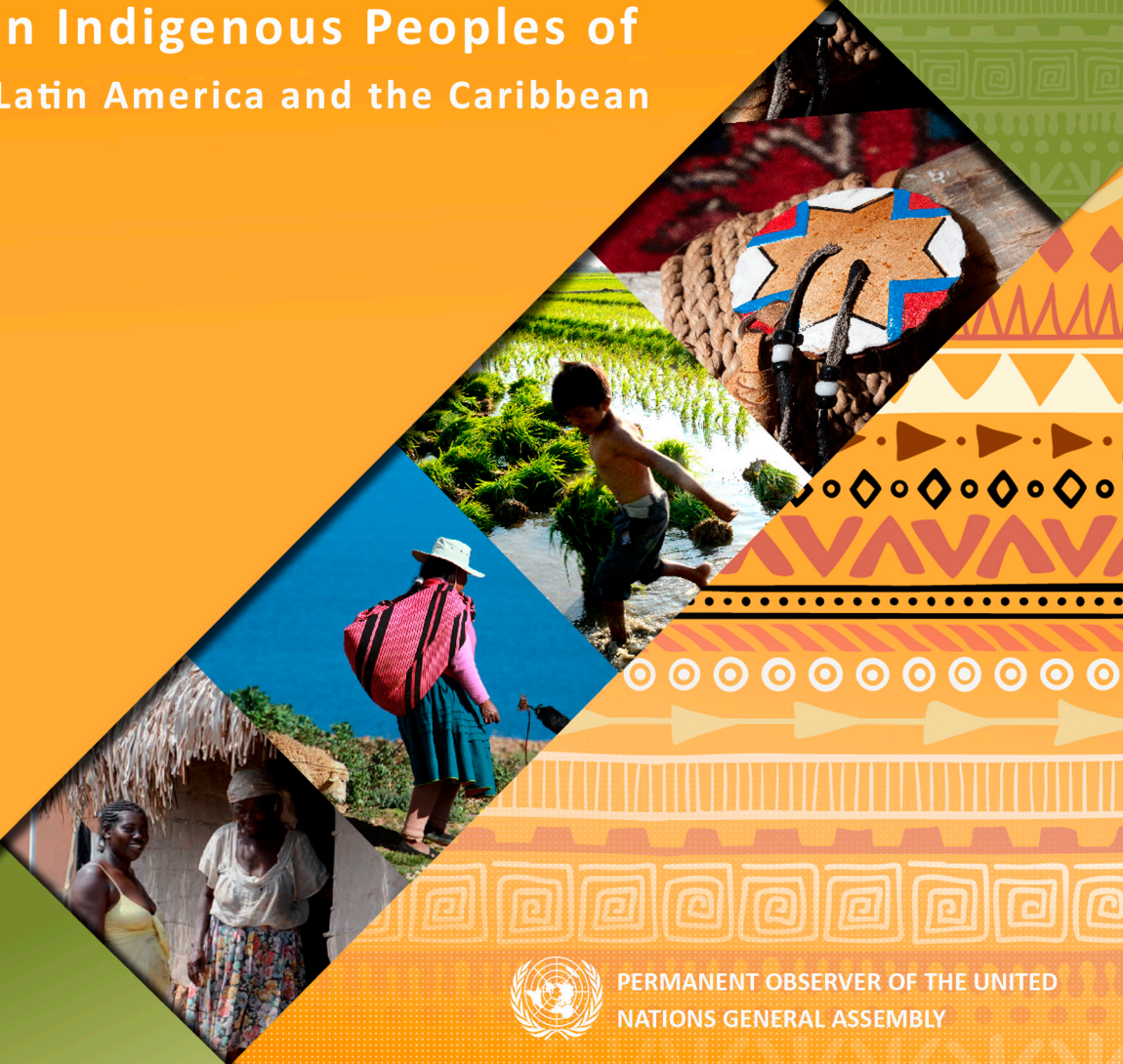
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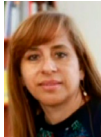
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Executive Summary

Tuberculosis is one of the diseases that causes the greatest number of deaths in the world, especially among people infected with HIV. Although an epidemiological transition has been observed in Latin America, expressed by the substitution of communicable diseases for noncommunicable diseases, the change in morbidity and mortality from more young people to older ones, and the predominance of morbidity over mortality; tuberculosis has remained a health problem that particularly affects indigenous peoples, exacerbating historical inequalities. In Latin America and the Caribbean (LAC), every year at least 60,000 patients with tuberculosis (TB) are diagnosed and treated, of whom a large proportion are children and women; 17 to 20,000 TB patients infected with HIV are neither identified nor diagnosed and/or 3,400 to 5,000 patients with MR-TB (multi-resistant tuberculosis) are identified and/or diagnosed, and at least 20 to 26,000 patients die with TB.[1] The analysis of TB in the region identify indigenous peoples as one of the groups at risk.

TB trend among indigenous peoples in LAC

It has been confirmed that TB was present among indigenous peoples before the European arrival, and that with their arrival epidemics exacerbated. This contributed to the decimation of indigenous populations via the creation of cross-cultural patterns due to the interaction between cultures and the probable presence of other micro-bacteria. One of the limitations reported when analyzing the epidemiological profiles of indigenous peoples in the region is the lack of statistical information disaggregated by ethnic origin within the statistical systems in healthcare.

Therefore, the available data are mostly local, dispersed, and linked to specific projects, without continuity once they are completed. However, all the data reveal that, in the case of tuberculosis, the gaps between indigenous peoples and the rest of the population have remained or have even increased over the last decades.

The data for 1990 to 2011 showed that the prevalence of cases of tuberculosis in the LAC region decreased by 62%, and the prevalence of deaths decreased by 61%. 60% of all new cases of tuberculosis in the continent corresponded to Brazil, Peru, Mexico and Haiti.[2]

However, the incidence of tuberculosis in indigenous populations is higher than in the general population (incidence of 300 to 400 per 100,000 inhabitants). The highest rates were found in the indigenous populations of Brazil, with tuberculosis incidence rates of 1,855.3 per 100,000 inhabitants and 1,156.8 per 100,000 inhabitants, in the years 1993 and 2000 respectively[3].

In Brazil, Chile, Mexico, Paraguay, Peru and Venezuela (the Bolivarian Republic of Venezuela), among other countries, higher rates of tuberculosis have been observed in the indigenous population compared to the rest of the population. In the case of the Guaraní people of the Plurinational State of Bolivia, the prevalence was 5 to 8 times higher than the national average[4]

A similar situation is observed with the indigenous peoples of Peru and the State of Zulia in Venezuela, where the Yukpas, Baries, Paraujanos and the Guajiros indigenous peoples showed higher morbidity and mortality due to tuberculosis.[5]

The same trend was found in Colombia. From 2001 to 2005, an increasing trend in the number of cases of tuberculosis among indigenous peoples of the departments of the Amazon, Cesar and Nariño was recorded. In 2005, 88.3% of the cases corresponded to pulmonary tuberculosis and 11.7% to extra-pulmonary tuberculosis, and the affected age groups were those under 15 years of age, those aged 55 to 64 years, and those older than 65 years of age. Of the total number of cases registered in 2005, 61.7% corresponded to indigenous people and 38.3 % to the non-indigenous population. In some departments, such as Cesar and Nariño, there was variability in both the incidence rate and the mortality rate in the period studied, the most affected being people from indigenous populations. The most affected age groups were people from age 35 to 44 (24% of cases) and people from age 45 to 54 (21% of cases). [6] In 2009, 11,122 cases of TB were reported in Colombia, of which 6% affected indigenous peoples. The incidence in that country was 26 per 100.000 inhabitants, while in indigenous peoples it reached more than 80 per 100,000. [7]

3 Basta PC, Coimbra CE, Escobar AL, Santos RS. Epidemiological aspects of tuberculosis among the Suruí Indigenous People, Amazon Region, Brazil. Rev Soc Bras Med Trop. 2004; 37 (4): 338-42; mentioned by Dante R. Culqui, Omar V. Trujillo, Neptali Cave, Rula Aylas, Oswaldo Salaverry, César Bonilla; Tuberculosis among the indigenous peoples of Peru 2008

4 Neves Bóia et al., 2009.Mentioned by ECLAC, 2014.

5 Dante R. Culqui, Omar V. Trujillo, Neptali Cave, Rula Aylas, Oswaldo Salaverry, César Bonilla; Tuberculosis among the indigenous peoples of Peru, 2008

6 PAHO, 2007, mentioned by ECLAC, 2014

7 PAHO-WHO. "III Reunión regional Éxitos y desafíos en el control de la TB en pueblos indígenas

Table
Chile, Paraguay and Peru: Incidence rate of tuberculosis according to ethnic condition.
Various years.
Per every 100,000 inhabitants

	Health services	Indigenous population	Non-indigenous population
Chile 2004- 2006	Arica	121.9	18.0
	Antofagasta	57.3	7.9
	Arauco	28.0	12.0
	Bio	23.0	11.9
	North Araucanía	16.2	10.5
	South Araucanía	21.6	10.0
	Valdivia	21.5	10.4
	Osorno	52.7	17.5
Paraguay 2005 and 2010	Entire country	Indigenous population	Total population
	2005	393.0	38.1
	2010	351.0	32.8
Peru 2005	Department	Aymara population	Non-Aymara Population
	Puno	33.0	19.6
	Moquegua	68.0	52.9

Source: PAHO/WHO (Pan American Health Organization/World Health Organization), Tuberculosis in the Americas.Regional report 2011. Epidemiology, control and financing , Washington, DC, 2012 [online http://www.paho.org/hq/index.php?option=com_docman&task=doc_view&gid=22425&Itemid; Ana María Oyarce and Malva-Marina Pedrero, "Perfil epidemiológico básico de la población mapuche (Basic epidemiological profile of the Mapuche population)". Communes of the Lafkenche area of the South Araucanía Health Service, Santiago de Chile, MINSAL, 2009; "Perfil epidemiológico básico: Pueblos Kawésqar, Yámana y Mapuche-williche (Basic epidemiological profile: Kawésqar, Yámana and Mapuche-williche peoples)".Magallanes Region, Santiago, Chile, MINSAL, 2009; "Perfil epidemiológico básico de la población mapuche residente en la Región de Los Ríos (Basic epidemiological profile of the Mapuche population in the Los Ríos Region)", Santiago de Chile, MINSAL, 2009; "Perfil epidemiológico básico de

(III Regional Meeting Successes and challenges in the control of TB among indigenous peoples)". Panama City, Panama, March 2 and 3, 2010

la población mapuche residente en la Provincia de Arauco (Basic epidemiological profile of the Mapuche population resident in the Province of Arauco)", Santiago de Chile, MINSAL, 2009; "Perfil epidemiológico básico de la población aymara en el área de cobertura del Servicio de Salud Arica (Basic epidemiological profile of the Aymara population in the coverage area of the Arica Health Service)", series "Análisis de la Situación de Salud de los Pueblos Indígenas de Chile (Analysis of the Health Situation of the Indigenous Peoples of Chile)", No. 1, Santiago, Chile, MINSAL, 2006. Taken from ECLAC, 2014.

Furthermore, diseases associated with TB and indigenous people have been malnutrition 23%, diabetes 20%, HIV 11%, alcoholism 6% and others not identified 8%. [8]

For example, in the region of Veracruz, Mexico, diabetes has been found to alter the response to antituberculosis treatment due to a decrease in the levels of the antibiotic in the blood. Thus, in the case of the antibiotic rifampicin, a 53% reduction in its usual concentration has been observed in patients suffering from the combination of pulmonary tuberculosis and diabetes mellitus. This seems to be related to the interaction of said antibiotic with drugs administered for the control of diabetes, such as sulfonylureas and biguanides, which reduces their efficacy and, consequently, increases the predisposition to develop resistance to the antibiotic. Therefore, high rates of undiagnosed or poorly controlled cases in indigenous people who have infectious diseases such as tuberculosis diabetes have been recorded, which affects the infectious condition when treatment is not accompanied by measures to control diabetes. Therefore, diabetes should be considered a factor for the preventive treatment of tuberculosis in endemic areas.

After Africa, the Americas report the highest number of individuals diagnosed with TB/HIV. Of the total number of people affected by TB who were tested for HIV, 18% were positive. In the case of Panama, at the country level, an 83.73 co-infection was found among the new cases and 16.27% among retreated cases; however, among indigenous people in 2007, there was 6.7% of co-infection and only 4.4% in 2008.[9]

Another factor that is affecting the epidemiological profile of indigenous peoples related to TB is voluntary or forced migration, and the displacement of indigenous communities from their ancestral lands. Therefore, it has been recommended that indigenous people who migrate to the cities are prioritized because there they become a higher risk

8 *Dr. Dolores Arana Saldaña. Successes and challenges in TB control programs in indigenous villages in Mexico. PAHO-WHO. "III Reunión regional Éxitos y desafíos en el control de la TB en pueblos indígenas (III Regional Meeting Successes and challenges in the control of TB among indigenous peoples)". Panama City, Panama, March 2 and 3, 2010*

9 *Cecilia Arango. TB control among indigenous peoples in Panama.*

population

Some challenges for the creation of TB control services in indigenous peoples

One of the main challenges for the establishing of culturally relevant health services for indigenous peoples in LAC is that their concept of "health" derives from a holistic vision that articulates people, families, community, villages and territories to reach together harmony and balance. Indigenous health articulates biological, psychological, social, economic, political, environmental, energy-related and spiritual dimensions.

The loss of the harmony or balance of the individual or the community arises due to the alteration of the body's own conditions, but it can also have its source in the family, the community or in nature itself. All the actions of the individual or the community, within the community, family and nature, have repercussions on one's health or in the creation of diseases and, in this context, human beings are an integral and interacting part of the cosmos.

An important component of this vision of indigenous health is spirituality, in which the presence of the spirits of the dead, the ancestors, or protective spirits of nature and even uncontrolled evil spirits, generate imbalances that affect health. In this context, each indigenous people has their own perception of health and disease.

Based on the above-mentioned, when establishing TB care services, it is important to know what the perception of the origin of the disease for each group is. For some, the disease is related to god, or it is one of the spirit, or it is the result of witchcraft, spells or sorcery, among others. In this regard, in Peru, an exhaustive study was carried out on risk factors and perceptions, elements that must be considered when designing and implementing programs for the eradication of diseases. According to said study, some causes that explain the disease were: i) excessive moisture that is absorbed by the body because of the individual's lack of self-care; ii) poor diet or lack of food; iii) evil or witchcraft; and iv) magical causality.[10]

The type of therapy applied depends on the origin of the disease. For example, shamanic healing procedures are based on the recitation of therapeutic mantras on an object, liquid

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10 Dante R. Culqui, Omar V. Trujillo, Neptali Cave, Rula Aylas, Oswaldo Salaverry, César Bonilla; *Tuberculosis among the indigenous peoples of Peru, 2008.Public. Printed version ISSN 1726-4634 "Revista Peruana de Medicina Experimental y Salud Pública (Peruvian Publication on Experimental Medicine and Public Health)" v.27 no.1, Lima, Mar. 2010*

or plant that links it to the patient. From the indigenous vision, it is assumed that this treatment will have an almost immediate effect on the disease. Therefore, the delay in the improvement (more than two days) is an indication of a diagnostic error and consequently of the treatment undertaken. It is easy to imagine that this vision, when applied to the treatment of tuberculosis –which asks for the administration of the same antibiotics for a minimum period of 6 months– may have a negative impact on the adherence to treatment.[11]

To these diverse perceptions on TB we need to add those related to diabetes and HIV when they coexist, making the approach to care more complex. It is also important to consider conceptions related to sexuality when dealing with HIV, as sexuality is defined by norms of social control created by the community and shared within the families.

Strategies used in the establishment of TB programs

The main strategies used to establish TB control programs have been:

a) **Community engagement: leaders, community agents and traditional therapists.** Training and inclusion of leaders and community agents into the activities of the Public Health System to address TB-related issues has been carried out in several countries.

b) **Inclusion of TB programs into the Primary Health Care (PHC) strategy**. Some countries have incorporated TB control into PHC programs, emphasizing the simplified management of community agents, medical assistants and community health workers.

c) **Inclusion of TB programs in municipal and micro-regional plans.** In other cases, there are efforts related to the engagement of municipal authorities, or as part of micro-regional development strategies. Efforts in which social security entities assume the responsibility of guaranteeing the delivery of medicines for TB were also reported. In the efforts of engagement of the municipal governments, these were accompanied by a public health surveillance network composed of community promoters. These are also combined with training, local diagnosis, an information and notification systems, permanent provision of medication to health units, and the work with local social and political actors.

d) **Decentralization of diagnosis and treatment.** One of the greatest challenges encountered in TB care efforts for indigenous peoples is precisely the diagnosis due

11 Rojas, 2004

to the dispersion of the communities, the distance and difficulties of access to centers in which medical services are concentrated, and the discrimination that indigenous peoples suffer secondary to their linguistic, cultural and socio-economic conditions, among others. Therefore, the decentralization of the diagnosis and treatment has been one of the strategies promoted in the efforts analyzed.

The decentralization of diagnosis and treatment allowed, for example, for Ecuador to reach a level of up to 91.7% of cured patients and a very low percentage of abandonment of treatment (1.58%).[12] Similar results can be observed in other efforts, as in the case of Paraguay, where the Primary Health Care (PHC) strategy with community agents increased the actions in new TB cases of all types, as well as the success rate and the cure of pulmonary tuberculosis with bacterio-excretion (TBP BK+), with a decrease in mortality from 26.5/100,000 in 2008, to 21.1/100,000 in 2009.

e) **Creation of shelters for patients and relatives.** Some countries, such as Panama, Colombia and Peru, have opened different types of shelters during the treatment phase based on to the characteristics of coverage of the services, geographical distribution of the population, and the requirements related to the patient's condition. In the case of Peru, the shelter included family members for a period of up to 4 months. The greatest difficulty of this strategy is that it is difficult to support, and the risk of limiting adherence to treatment due to prolonged removal and decontextualization of the patient.

f) **Intercultural health strategies.** The analysis of the efforts that have been promoted in the LAC region to confront TB, allows us to identify that measures have been applied in several of them to break down barriers to access healthcare suffered by indigenous peoples, by adopting intercultural approaches. These measures are aimed at improving the quality of health services by recognizing individual and collective human rights of indigenous peoples, establishing mechanisms of articulation between the Western and the Indigenous health systems, while ensuring the full and effective participation of the communities.

Results achieved with the strategies used

The efforts analyzed allowed for the attainment of satisfactory results regarding the diagnosis, the permanence in the program due to the decrease of the abandonment

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12 PAHO-WHO, 2007

levels, the increase in healing, and the reduction of the incidence. Another important result was the improvement in the levels of coordination and management from the local to national levels. Better results were observed when there was community coordination and commitment by local political structures.

Also important have been continuous training, information, education and communication, especially when these activities were carried out by members of the communities and in their own languages. It is important to propose joint work with the community authorities from the beginning, and for that process itself to contribute to community empowerment.

It has been observed that better results are achieved when they participate in the identification of the health determinants that affect the diagnosis and treatment of tuberculosis. The engagement of volunteer personnel, leaders and health promoters responsible for carrying out direct observed therapy strategies is essential in remote areas that face difficulty in accessing government's health services. The success of the strategy also depends on the availability of adequate training and monitoring systems.

Among the lessons learned from the analysis of the different initiatives, the following are worth mentioning:

   a) Community engagement, with broad involvement of indigenous authorities, is indispensable

   b) Articulation between public health and traditional indigenous systems is fundamental

   c) Joint monitoring and use of information relevant to the community contributes to ownership and sustainability.

   d) Political will from central governments, accompanied by decentralization and appropriation of the program by local health personnel allows for the improvement of indicators of healing.

   e) Multisectoral engagement and partnership building is important.

   f) Family and community reciprocity are fundamental

   g) The application of a comprehensive TB strategy allows addressing social determinants of health status.

Recommendations

At the community level

a) When considering the initial steps for an intervention to control TB in indigenous communities, to develop and implement a strategy to sensitize the indigenous authorities, governments and community organizations, so that they include in the plan a prioritization of TB control activities.

b) Generate information to be used in advocacy activities through the realization of a participatory situational diagnosis, for the joint identification of health problems, to identify the importance of TB in the community, as well as the factors that affect it.

c) In the creation of the program, to establish mechanisms of coordination and articulation between Western medicine and traditional indigenous medicine, defining the roles of traditional therapists and the use of indigenous therapies, among others.

d) In case the communities have a community development plan (or a life plan), to promote the inclusion of activities linked to TB programs, to ensure the sustainability of the actions of prevention and control of tuberculosis.

e) Establish and maintain an information system in the community that allows them to know their health condition and, in terms of TB, to use indicators that are generated by the community itself.

f) To connect patients and former patients, family members, promoters and leaders, as part of the Directly Observed Treatment (DOTS) strategy, in the supervision of treatment of the communities, especially in remote communities, jointly addressing the political, environmental, social and cultural factors that affect the adherence to, or lack thereof, the treatment by the patients in indigenous communities.

At the national level

a) Improve the diagnosis and treatment of TB cases among indigenous peoples, it is recommended to prioritize people who live at risk, such as:

    i) indigenous people living in slums of cities, those deprived of their freedom, migrants and displaced persons;

ii) Indigenous people with risk factors: people with HIV and diabetes mellitus (DM), those undernourished, alcoholics, and drug users.

b) Include in policies and programs of TB care for indigenous peoples, the cases of peoples displaced to large cities.

c) In order to reduce TB mortality, to adopt measures to decentralize early diagnosis, strengthening laboratory networks, incorporating new diagnostic techniques and using traditional community and territorial articulation, governance and health networks.

d) Facilitate community engagement in the following activities: Directly observed treatment (DOT), continuous training of health personnel, well-established referral and counter-referral systems, and in the strengthening of information systems.

e) Pay special attention to integrated TB and HIV programs to: improve access to TB diagnosis among those infected with HIV, initiating Antiretroviral Therapy (ART) to all TB/HIV patients as soon as possible during TB treatment, provide preventive treatment, timely diagnosis of TB in HIV (syndromic approach), preventive treatment in people with HIV, and infection control in health services.

f) Expand studies to identify and characterize the problem of TB/HIV origination, and promote the access of TB patients to counseling, voluntary HIV testing and prevention and treatment of HIV infection.

g) Guarantee the financial and administrative sustainability of TB prevention and control actions.

h) Promote the systematization and exchange of efforts among countries and regions, addressing various aspects, including those that allow the evaluation and strengthening of community work in the administration and adherence to supervised treatment.

i) Encourage health programs in indigenous peoples to address TB determinants, such as nutritional status, alcoholism and housing, among others.

j) Support programs to increase the technical and professional capacities of community personnel, including the allocation of fees for the training of doctors at universities.

k) Promote the multisectoral approach among government institutions, articulating

between programs and other public policies, paying special attention to social protection programs so that they incorporate the universal health right approach throughout.

At the international level

a) Use the momentum generated as a result of the 40 years of the Declaration of Alma Ata and the SDGs to mobilize the engagement of the international community in the promotion of the fight against tuberculosis among indigenous peoples.

b) Increase global awareness and supervision of tuberculosis applying an intercultural approach, and integrating indigenous cultural values, traditions and ways of life in the activities of defense of the right to health.

c) Promote funding generation at the international level for the control of tuberculosis among indigenous peoples.

d) Raise awareness, leverage and develop the capacities among indigenous peoples on health-related issues, to guide actions towards the control of tuberculosis.

and) Promote greater engagement of indigenous peoples in tuberculosis research, generating information disaggregated by ethnic origin at the national and sub-national levels, by risk group and geographical areas, promoting communication by means of information, including scientific journals.

f) Promote that, in the South-South cooperation programs, the efforts of the countries to strengthen the administration and adherence to TB treatment in distant communities be considered.