Public policies for tuberculosis control in two marginal urban indigenous communities of Lima

Políticas públicas de control de la tuberculosis en dos comunidades indígenas de la ciudad de Lima

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Abstract

The study focused on public policies for TB control in urban marginalized Quechua and Shipibo communities, elucidating aspects related to the implementation effectiveness of social development programs and strategies. Urban ethnography was used as part of the qualitative study. The Quechua community was more organized and self-managed its progress, counting on the support of the municipality, while the Shipibo-Conibo community remained stagnant, fragmented and unstable in its organization. The inclusion of health policies as part of local government policies is still a challenge, so coordinate these with other sustainable development strategies is a crucial endeavour, taking care not to distort cultural identity or disrupt aspects related to the implementation of other national health strategies in the absence of which municipal intervention would be unjustified.

Keywords: Tuberculosis, public health policy, cultural competency, indigenous peoples, local government.

Resumen

El estudio se centró en las políticas públicas para el control de la tuberculosis en comunidades urbanas marginales quechuas y shipibos, dilucidando aspectos relacionados con la eficacia de la implementación de programas y estrategias de desarrollo social. Se utilizó la etnografía urbana como parte del estudio cualitativo. La comunidad quechua estaba más organizada y autogestionaba su progreso, contando con el apoyo del municipio, mientras que la comunidad shipibo-conibo permanecía estancada, fragmentada e inestable en su organización. La inclusión de las políticas de salud como parte de las políticas de los gobiernos locales sigue siendo un reto, por lo que coordinarlas con otras estrategias de desarrollo sostenible es un esfuerzo crucial, cuidando de no distorsionar la identidad cultural o perturbar aspectos relacionados con la implementación de otras estrategias nacionales de salud, en ausencia de las cuales la intervención municipal sería injustificada.

Palabras clave: Tuberculosis, política de salud pública, competencia cultural, pueblos indígenas, gobierno local.

Introduction

Tuberculosis (TB) is a reemerging disease with a high prevalence in developing countries[1], especially in suburban populations of large cities. The incidence of active TB and the prevalence of latent TB are higher in indigenous groups in urban areas than in rural ethnic groups[2], which is why health interventions have been reinforced in these populations, applying policies with social strategies that take into account economic inequity and stigmatization[3]. However, in these cities the epidemiological dynamics are different compared to rural areas[4], since many ethnic groups are heterogeneous when it comes to the social behavior of the disease, as cultural, social and racial issues persist in the face of biomedical treatment[5].

In the world, the incidence of high costs in indigenous people affected by sensitive TB was 36% and for MDR-TB it reached 83%[6]. Despite the introduction of health security in these com-

munities, many afflicted households bear high economic costs, which further impoverish them[7]. Several countries have already identified priority areas and some projects funded by international capital have been successful, but these have not been adapted to local realities and are unsustainable to date[8]. In contrast, China, India, Russia and South Africa have strengthened their health systems and public policies, implementing actions between public-private partnerships for TB control (abandonment cases, treatment and work), complemented with strategies and initiatives carried out with the United Nations by means of the Global Fund. These results could point the way towards an adequate improvement strategy for the sustainable development of these urban ethnic groups[9], where social inequality and inequity in health services are still present in many indigenous populations[10,11], as well as affecting migrants and prison inmates, which evidences an underreporting of cases that has consequences for program planning and patient care[12].

In Peru, the indigenous peoples of the Amazon have been identified as a group vulnerable to TB[13], with underlying factors such as delayed detection, diagnosis and treatment, which are mostly related to the deficiencies of the health system that only provides scattered assistance to rural indigenous communities, while it segments territorial scenarios according to different levels of TB. Consequently, health needs and access to medical care become a challenge, especially in isolated communities[14], Consequently, health requirements and access to medical care pose a considerable challenge, especially in isolated communities[14], where people with TB are slow to access health services due to stigma and sociocultural discrimination[15,16]. For this reason, a comprehensive view of the problem is a national health priority[17], especially for those living in marginal urban areas[18], where the cycle of social inequity is perpetuated.

Sixty percent of the population is concentrated in the urban areas of the Peruvian coast, compared to the highlands (with 30%) and the Amazon jungle (10%)[19]. Consequently, population density in recent years has led to the development of emerging patterns in urban illegality[20], which has produced a new social configuration, characterized by spatial segregation, increased inequality and misery, and a lack of urban planning.

In other words, it has become a socio-cultural health phenomenon that crosses the social, political, economic and affective spheres of the small Quechua and Amazonian populations settled in the country's large cities[21,22]. Thus, Lima concentrates indigenous communities in marginal urban areas[23] who experience loss of land, poverty, unemployment, deterioration in the quality of life and an aggressive cultural fusion with the new domains of globalization. The application of national policies, translated into the effectiveness of strategies or programs for TB control, have not shown results in the fulfillment of their objective; therefore, social deterioration that is not addressed by national economic policies continues to be a concern, especially in indigenous groups[24]. Consequently, these populations have tried to configure a new conception for themselves in accordance with globalization, while maintaining the origins of the territory, language and social interaction of their own identity throughout the social fabric. For this reason, this study focuses on public policies for TB control in two indigenous communities located in marginal urban areas of Lima, seeking to elucidate the factors involved in the effectiveness of implementing these control and prevention programs and strategies.

Materials and Method

The ethnographic design included the interpretation of the subjects' ways of life and thinking, as well as dialogic sequence analysis[25]. The study included two settings: the Shipibo-Conibo community of Cantagallo, a shantytown on the banks of the Rimac river since 1933, geopolitically attached to the jurisdiction of the district of El Rimac[26]; and the Quechua community of Amauta hill, district of El Agustino, founded in 1965, also originated by the constant high Andean population invasions[27]. Both native communities are affected by TB and are considered a source of infection in Lima[18].

Results

Public policies for TB control

Over the last twenty years, three technical sanitary norms (2006, 2013 and 2018) have been in place, each with epidemiological intervention plans for biomedical treatment, carried out, moreover, in a health system segmented into three categories: direct contributory regime, subsidized regime and private regime. Therefore, today the practical application of these norms is inadequate, and the lack of proper management coordination between public/private/civilian institutions is notorious, which adversely affects disease control in indigenous communities. However, the isolated efforts of a municipality, in alliance with a health department, made a difference in integrated health management.

Thus, the Quechua enjoy municipal ordinances, since the community collaborated in the implementation of public health policies such as the creation of the District Health Government[1] -GODISA[28] for TB control in an entire district, providing them with an exclusive facility for its administration, with a comprehensive health plan and the creation of the integrated and itinerant health network program (PRIISA[2]) for 'extramural' interventions. It also included healthcare for people with cancer (diagnosis of breast, cervical and prostate cancer) and intervention to reduce anemia and chronic malnutrition.

On the other hand, in the Shipibo-Conibo community, very little progress was made with respect to these policies, despite the fact that the national health strategy carried out the Lima Breathes Life, Together Against TB plan in 2011. The reason that the analysis identified is closely linked to the lack of synergy with local municipal goals, which gave priority to urban civil construction with significant reduction of housing opportunities, and no accompanying benefits in terms of improvement of basic utilities. The city council assistance only made an appearance when this community suffered the biggest fire in its history in 2016, but, just as sudden as it came, it disappeared, further exacerbating the distrust in the government and resentment against the country's political system.

1 Gobierno Distrital de Salud – GODISA.
2 Programa de Redes Integradas e Itinerantes de Salud - PRIISA

Execution of Public Policies

From 2013 to 2015, municipal ordinances and directives were implemented to control TB, pointing out the evolution of the strategic proposal within public policies. With the additional contribution of the TB Zero Plan experience, implemented in a capital district between 2009 and 2015, a new formulation was reached: "The sociopolitical approach, based on territorial needs" (Ministry of Health Official -MINSA, 2020), which articulated an inter-institutional work between MINSA and the Municipality of El Agustino. As an example was the creation of GODISA, which, in addition to institutionalized participation spaces, developed health agenda agreements prioritized by the population.

Health accessibility was strengthened with PRIISA brigades in high-risk areas, which provided complementary care to health facilities. GODISA's main funder was the Integral Health System and the Municipality of El Agustino; therefore, health promotion and prevention actions were designed in the institutionalized areas of the municipality, while care and recovery actions were developed in MINSA's health facilities, in addition to others in the public sector. This strategic alliance benefited the Quechua community living under the jurisdiction of this district.

In contrast, the Shipibo-Conibo community did not experience the same scenario, as it was solely regulated by the central and metropolitan governments. This choice was ascribed to the fact that, as an indigenous community, they enjoy direct protection from the State, through ministries and other entities. In the health sector, the directly observed therapy strategy (DOTS) was implemented in accordance with MINSA's national plans. Thus, patients in the Shipibo-Conibo community received treatment under the supervision of health professionals in that jurisdiction. However, the management dynamics in the Shibipo-Conibo community depend on the community leaders, which is a significant limitation due to their passive attitude and distrust of project management and opportunities for community improvement.

Many health policies have been developed as of today, one of them being the Directly Observed Therapy (DOTS and DOTSplus) for drug-sensitive TB, multi-drug resistant TB (MDR), and extensively drug-resistant TB (XDR-TB). From a public health perspective, some progress has been observed in capital districts, and other interior regions of the country with high incidences. The WHO/PAHO had warned about the magnitude of the problem in marginal urban areas, and in 2000, MINSA, together with local governments, began to give the necessary importance to TB control. Currently, MINSA has prioritized the program in all health facilities, especially in primary health care, by allocating professionals dedicated exclusively to its implementation and training community health workers (CHWs). However, management flaws and deficiencies were detected regarding budgetary expenditure, which revealed a disastrous reality in terms of reaching goals: "sometimes, money allocated for TB was spent on other budgetary programs, on staff payments, or on other administrative expenses" (nurse, 2020).

Regarding the Quechua community, the local government clearly understood that one of the keys to reducing TB was the establishment of basic utilities and other works that would speed up transportation and dignify the homes of its population. Extramural home visits worked best for TB patients, as it was found that people with the disease did not go to the referral health center for fear of stigmatization and/or the constraints of poverty.

In the Shipibo-Conibo community, an executing agency to enforce public health policies could not be identified. Each community sector was organized according to its own interests and had its own leader. There were also discrepancies within the community when it came to implementing any of the health strategies, a factor that hindered healthcare personnel's efforts. However, and in contrast to the Quechua community, an interesting factor that became evident was the fluid social interaction regarding the disease, characterized by the absence of stigmatization towards TB patients. It is a reality that overlaps into other contexts such as the work, cultural, economic and political environments of the same community, therefore, participation within it is active, and emotional, affective and spiritual support is given to affected families. However, it is necessary to organize these communities more effectively and prove, with concrete evidence, that well-implemented policies are indeed successful in controlling this disease.

Public policies for TB control have been implemented by the State - Ministry of Health, through the Law for Comprehensive TB Prevention and Control Care (Law 30287); in addition to technical standards and community intervention plans, which have been reflected in epidemiological accounting for years[5]. Although health systems and public policies have been strengthened at a worldwide level[29], work has just begun at the national level, as observed in the work carried out in some regions of the country[30] based on the observations and recommendations of public-private partnerships in control and treatment care[14], although strategies and initiatives developed by the WHO[31] have not been fully considered.

The common factors in TB control in the communities under evaluation were a segmented health system[32] and a governmental structure that does not guarantee the closing of gaps or prioritize social determinants[33], which leads to the need to change these strategies to others that would yield better results, in a scenario of global interconnectivity that would facilitate the dissemination of prevention and health promotion processes. Other important aspects are the inconsistencies in the budgets allocated to health solvency, considering that vulnerable populations still do not have access to adequate health services[8] Therefore, the search for TB cases in ethnic groups would be a highly successful strategy towards improving outcomes in TB treatment and the sustainable development of these populations.

In both communities, there is evidence of a cultural fusion between indigenous and western cultures. However, the Quechua community is more organized, with ancestral medicinal practices and rituals of energetic spiritual cleansing, whereas the Shipibo-Conibo community showed a greater tendency to associate illnesses with the cursing of spirits as punishment for negative behavior. A common aspect observed in both communities was the expressed sentiment: "born poor, live poor, die poor", an erroneous perception of inherited poverty. Furthermore, in so-

cial confluence spaces that are not related to their own culture, they adopt subaltern positions, while, within their own environments, they play a dominant role among their own, a situation that is well accounted for by subaltern theory[34].

Although social roles do not exempt communities from social inequity, stigmatization[35] and social discrimination, the ineffectiveness of the State in this aspect has a very poor perception of equity among the community members evaluated. It may be necessary to deepen the socio-anthropological aspects towards new visions of interculturality in health epidemiology, as well as in understanding the social dynamics caused by TB in marginal urban environments as a result of migration to large cities[24]. Therefore, the interculturality of TB is a new concept of social interaction between western society and native cultures whose cultural themes are seen as determining factors in the process of recovery from TB. However, there remains a need to understand the social interaction for the diachronic intervention of the sanitary approach offered as a solution, on the grounds of socialization between health professionals and the inhabitants of both communities. Finally, the loss of cultural identity could be the ultimate goal of a western culturalization process; since the different times of evolution of cultural and epidemiological processes make it imperative to focus public policies on the educational level, not as an option, but as an obligation, to create health awareness and culture in future citizens. This is a compelling reason to strengthen and develop educational programs on TB tailored to the real needs of the communities.

Finally, public policies exist for TB control: laws, technical norms and intervention plans as strategies, but the lack of implementation still persists. There are municipal ordinances that have made some health strategies effective for the benefit of the Quechua community, but the lack of governmental sustainability has meant that not all of them have been successfully implemented, and they have not been carried out. Moreover, the Shipibo-Conibo community lacks governance, as it is in the hands of internal leaders who are unable to reach consensus on community welfare decisions, thus exacerbating its vulnerability to TB. The passiveness of their organization and excessive internal social fragmentation has hindered the effective implementation of TB control policies.

Despite some successful experiences, it is still a challenge to include health policies as part of local government, —while at the same time linking them to other development policies in terms of educational conditions—, without distorting the cultural identity of each of the communities, or disrupting aspects related to the implementation of other national health strategies without which municipal intervention would not be justified. It is imperative a change of mentality that should not only bring political effervescence, but also sustainability of democracy, interculturality and good governance, grounding them through education.

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