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Social Networking in Tuberculosis: Experience in Colombia

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1. Introduction

Tuberculosis (TB) is an infectious disease caused by different species of *Mycobacteria*. Human disease is usually caused by *Mycobacterium tuberculosis*, also known as the Koch's bacilli, which can affect any organ or tissue in the body. Although this, pulmonary disease, with their particular hallmarks such as occurrence of cough with expectoration lasting more than 15 days, is the main corporal area affected by this mainly tropical pathogen (Rodríguez-Morales et al. 2008). In such cases, previous to a microbiological diagnosis, individuals in such state are so-called respiratory symptomatic.

Besides those symptoms/signs, disease can be manifested with hemoptysis, fever, night sweating, general malaise, thoracic pain, anorexia and weight lost. This disease is still a significant public health problem due to its highly transmissibility, but is highly potentially preventable and treatable condition (Curto et al. 2010, Dim et al. 2011, Orcau et al. 2011, Marais & Schaaf 2010, Glaziou et al. 2009). Even more, in the context of HIV and newer immunosuppressive conditions mycobacterial diseases emerge as public health threat in the World (Vargas et al. 2005).

According to the World Health Organization (WHO), in 2010, there were 8.8 million (range, 8.5–9.2 million) incident cases of TB, 1.1 million (range, 0.9–1.2 million) deaths from TB among HIV-negative people and an additional 0.35 million (range, 0.32–0.39 million) deaths from HIV-associated TB. Important new findings at the global level are: a) the absolute number of TB cases has been falling since 2006 (rather than rising slowly as indicated in previous global reports); b) TB incidence rates have been falling since 2002 (two years earlier than previously suggested); c) Estimates of the number of deaths from TB each year have been revised downwards; d) In 2009 there were almost 10 million children who were orphans as a result of parental deaths caused by TB (World Health Organization 2011).

Beyond its epidemiology, particularly mostly due to pulmonary disease, other important forms of disease represent also a significant burden in the World. When the infection affects organ other than the lung is called extrapulmonary TB. The most common form of this disease is at the pleura, followed by the lymphatic nodes. Extrapulmonary TB includes

various manifestations according to the affected organ. Prognosis and time to develop disease also can vary according to the affected organ.

Disease can range a spectrum that can begin from a latent infection or reactivation slowly evolving into a focal or whole spread and involvement of multiple organs, which makes it difficult to diagnosis by clinicians and health care workers, who many times could not identify it timely (Castañeda-Hernández et al. 2012a). One of the most severe forms of extrapulmonary TB is the meningitis (TB meningitis), which occurs as a result of hematogenous spread of bacilli into the subarachnoid space. This is known as a complication of primary TB and may occur years later as an endogenous reactivation of a latent tuberculosis or as a result of exogenous reinfection (Glaziou et al. 2009, Hoek et al. 2011, Galimi 2011, Garcia-Rodriguez et al. 2011).

Tuberculosis is a complex disease in terms of the multiple factors that are involved in its occurrence and persistence in the human societies. In first place there are factors associated with the bacillus (viability, transmissibility and virulence), with the host as a biological individual (immune status, genetic susceptibility, duration and intensity of exposure) as well, at the bacillus-host interaction (place of affection, severity of illness).

At a second, clinical level, the occurrence of pulmonary tuberculosis undiagnosed or untreated, overcrowding, malnutrition, immunosuppression from any cause (HIV infection, use of immunosuppressive drugs, diabetes, cancer, chronic renal failure, silicosis, alcoholism and drug addiction), are also important factors.

At community public health interventional level, protective factors include the BCG (Bacille Calmette Guérin) vaccine, applied in developing countries, which provides protection before exposure and prevent severe infection forms, especially in infants and young children, reaching up to 80% of protection against the development of forms of the disease such as meningeal and miliary TB (Garcia-Rodriguez et al. 2011, Garg 2010, Black et al. 2003, Francis et al. 2002, Arbelaez et al. 2000, Ginsberg 2000).

Additional to those clinical implications, changes in the susceptibility of the etiological agent to the therapy used drugs has imposed more challenges in the management of TB. The magnitude of problem with TB now lies in the fact that one third of the world population is infected by *Mycobacterium tuberculosis*. Even in the 21st century, TB kills more people than any other infective agent. This, then, occurs in part as a result of a progressive decrease in its susceptibility to anti-TB drugs or resistance emergence. Cases of resistant TB, defined by the recommendations of the World Health Organization (WHO) as primary, initial, acquired multidrug resistant (MDR-TB) or extensively drug resistant TB (XDR-TB) are emerging in different areas of the World.

The development of resistance TB may result from the administration of mono-therapy or inadequate combinations of anti-TB drugs. A possible role of health care workers in the development of multi drug-resistant TB is very important. Actually, multi drug-resistant TB is a direct consequence of mistakes in prescribing chemotherapy, provision of anti-tuberculosis drugs, surveillance of the patient and decision-making regarding further treatment as well as in a wrong way of administration of anti-TB drugs. The problem of XDR-TB in the world has become very alarming. Only adequate treatment according to directly supervised short regimen for correctly categorized cases of TB can stop the escalation of MDR-TB or XDR-TB, which is actually, in large magnitude, a global threat in the 21st century (Torres et al. 2011, Solari et al. 2011, Chadha et al. 2011, Arenas-Suarez et al. 2010, Ferro et al. 2011, Martins 2011).

Another important issue in TB is the social component, related to a complex background and multiple interacting factors that internally and externally affect individuals affected by

the disease, which still represents a significant stigma in many communities in the World. Given this setting, TB approach is complex and requires not only medical but also psychological and especially sociological approaches in order to improve its management from a collective medicine perspective as well better acceptability by non-affected people surrounding infected individuals at their communities or neighborhoods. In this way, programs approaching taking all these considerations in count will benefit with better strategies that allow good interactions between social actors involve in the complex social matrix in which sometimes TB can be present at societies. Taking advantage from this, regular activities, such as proper diagnosis and treatment would be achieve in a more efficient way (Murray et al. 2011, Santin & Navas 2011, Juniarti & Evans 2011). This chapter will cover how using social networks in the context of tuberculosis control program would achieve a better management of cases at individual and at a collective level in a western area of Colombia, where TB is a highly prevalent condition and where available resources for disease management and program are still limited in multiple aspects.

2. Social networking

Human societies can be regarded as large numbers of locally interacting agents, connected by a broad range of social and economic relationships. These relational ties are highly diverse in nature and can represent, e.g., the feeling a person has for another (friendship, enmity, love), communication, exchange of goods (trade), or behavioral interactions (cooperation or punishment). Each type of relation spans a social network of its own. A systemic understanding of a whole society can only be achieved by understanding these individual networks and how they influence and co-construct each other. The shape of one network influences the topologies of the others, as networks of one type may act as a constraint, an inhibitor, or a catalyst on networks of another type of relation.

For instance, the network of communications poses constraints on the network of friendships, trading networks are usually constrained to positively connoted interactions such as trust, and networks representing hostile actions may serve as a catalyst for the network of punishments. A society is therefore characterized by the superposition of its constitutive socioeconomic networks, all defined on the same set of nodes. This superposition is usually called multiplex, multirelational, multimodal, or multivariate network (Szell et al. 2010). Summarizing, a social network is a social structure made up of individuals (or organizations) called "nodes", which are tied (connected) by one or more specific types of interdependency, such as friendship, kinship, common interest, financial exchange, dislike, sexual relationships, or relationships of beliefs, knowledge or prestige (Palinkas et al. 2011, Szell et al. 2010).

Understanding and modeling network structures have been a focus of attention in a number of diverse fields, including physics, biology, computer science, statistics, and social sciences. Applications of network analysis include friendship and social networks, marketing and recommender systems, the World Wide Web, disease models, and food webs, among others (Zhao et al. 2011). Social network analysis (SNA) is the study of structure. It involves relational datasets. That is, structure is derived from the regularities in the patterning of relationships among social entities, which might be people, groups, or organizations. Social network analysis is quantitative, but qualitative interpretation also its necessary. It has a long history in sociology and mathematics and it is creeping into health research as its analytical methods become more accessible with user friendly software (Hawe et al. 2004). SNA views social relationships in terms of network theory consisting of nodes and ties (also called edges, links, or connections).

Nodes are the individual actors within the networks, and ties are the relationships between the actors. The resulting graph-based structures are often very complex. There can be many kinds of ties between the nodes. Research in a number of academic fields has shown that social networks operate on many levels, from families up to the level of nations, and play a critical role in determining the way problems are solved, organizations are run, and the degree to which individuals succeed in achieving their goals (McGrath 1988, Palinkas et al. 2011, Szell et al. 2010, Zhao et al. 2011, Hawe et al. 2004).

In its simplest form, a social network is a map of specified ties, such as friendship, between the nodes being studied. The nodes to which an individual is thus connected are the social contacts of that individual. The network can also be used to measure social capital – the value that an individual gets from the social network. These concepts are often displayed in a social network diagram, where nodes are the points and ties are the lines.

Its use in health (Bhardwaj et al. 2010, Lawrence & Fudge 2009), and more on in infectious diseases (Klov Dahl et al. 2002), has been recently highlighted, including sexually transmitted infections (Perisse & Costa Nery 2007), as well in TB (Boffa et al. 2011, Waisbord 2007, Curto et al. 2010, Burlandy & Labra 2007, Santos Filho & Santos Gomes 2007, Freudenberg 1995, Murray et al. 2011).

3. Tuberculosis as a social issue

Multiple studies have evidenced links between social, economic and biologic determinants to TB, recently using modeling approaches that have been used to understand their contribution to the epidemic dynamics of TB (Murray et al. 2011). Specifically, different authors have evidence for associations between smoking, indoor air pollution, diabetes mellitus, alcohol, nutritional status, crowding, migration, aging and economic trends, and the occurrence of TB infection and/or disease. We outline some methodological problems inherent to the study of these associations; these include study design issues, reverse causality and misclassification of both exposure and outcomes. From a social perspective, multiple analyses can be useful and approaches to modeling the impact of determinants and the effect of interventions as the follow will help: the population attributable fraction model, which estimates the proportion of the TB burden that would be averted if exposure to a risk factor were eliminated from the population, and deterministic epidemic models that capture transmission dynamics and the indirect effects of interventions. Can be stated that by defining research priorities in both the study of specific determinants and the development of appropriate models to assess the impact of addressing these determinants (Murray et al. 2011, Santin & Navas 2011, Juniarti & Evans 2011).

Although not considered neglected, TB disproportionately affect resource-constrained areas of the World, including Latin America. In tropical and subtropical areas of this region, the vicious cycle of poverty, disease and underdevelopment is widespread, including TB as one of the significant pathologies involved. The burden of disease associated to TB in this region is highly significant in some countries (eg. Bolivia, Haiti, Brazil, among others). TB has burdened Latin America throughout centuries and has directly influenced their ability to develop and become competitive societies in the current climate of globalization.

Therefore, the need for a new paradigm that integrates various public health policies, programs, and a strategy with the collaboration of all responsible sectors is long overdue. In this regard, innovative approaches are required to ensure the availability of low-cost, simple, sustainable, and locally acceptable strategies to improve the health of neglected

populations to prevent, control, and potentially eliminate poverty diseases, such as TB. Improving the health of these forgotten populations will place them in an environment more conducive to development and will likely contribute significantly to the achievement of the Millennium Development Goals in this area of the globe (Franco-Paredes et al. 2007). For example in Colombia, TB is still a significant public health problem. Figure 1 shows the WHO profile for TB in Colombia for 2010.

4. Social networks in tuberculosis

Multiple studies have evidenced links between social, economic and biologic determinants to TB, recently using modeling approaches (Guzzetta et al. 2011, Drewe et al. 2011, Wilson et al. 2011, Bohm et al. 2008, Cook et al. 2007, Cohen et al. 2007, Ayala & Kroeger 2002). Tuberculosis is the archetypal disease of poverty, and social inequalities undermine TB control (Rocha et al. 2011, Lonnroth et al. 2010). Poverty predisposes individuals to TB through multiple mechanisms, such as malnutrition (Rocha et al. 2011, Lonnroth et al. 2010, Cegielski & McMurray 2004), and TB worsens poverty as it increases expenses and reduces income (Rocha et al. 2011, Pantoja et al. 2009, Pantoja et al. 2009, Kemp et al. 2007, Lonnroth et al. 2007, Rajeswari et al. 1999).

Furthermore, poor TB-affected households often experience stigmatization; adding barriers to TB control (Rocha et al. 2011, Atre et al. 2011, Dhingra & Khan 2010, Pungrassami et al. 2010, Jittimanee et al. 2009). Poor people at the greatest risk of TB are therefore, in many settings, also the least able to access TB care (Rocha et al. 2011). Then, socio-economic interventions adapted to the needs of TB-affected households living in impoverished peri-urban shantytowns and other demographical settings.

The socio-economic interventions can successfully engaged most TB-affected households in an active civil society that was associated with marked improvements in uptake of TB prevention, diagnosis and treatment, resulting in strengthened TB control (Rocha et al. 2011). The development of social networks and SNA, however, has been mostly approached only for investigation of TB outbreaks (Fitzpatrick et al. 2001, Sterling et al. 2000) and fewly in the support with the strategies of the WHO for TB Control (World Health Organization 2011).

The WHO Stop TB Strategy, recently revised (World Health Organization 2011), stated a vision for a TB-free world, with a goal of to dramatically reduce the global burden of TB by 2015 in line with the Stop TB Partnership targets and the Millennium Development Goals (MDGs) which pursue the significant reduction in endemic diseases, such as TB and others, even regional diseases (e.g. Chagas disease), that can represent an impediment in achieving the MDGs (Franco-Paredes et al. 2007). In their components, it is included Empower people with TB, and communities through partnership through: a. Pursue advocacy, communication and social mobilization; b. Foster community participation in TB care, prevention and health promotion; and c. Promote use of the Patients' Charter for Tuberculosis Care (World Health Organization 2011).

In Brazil, one of the countries in Latin America where TB is a major public health problem, recent experiences suggest the importance of networking and civil society participation for TB control (Santos Filho & Santos Gomes 2007). In that country, until 2003, the presence of civil society in the fight against TB took place by means of several initiatives from researchers, healthcare professionals and medicine students, especially from the Sociedade Brasileira de Pneumologia e Tisiologia (Brazilian Thoracic and Tuberculosis Society), Rede

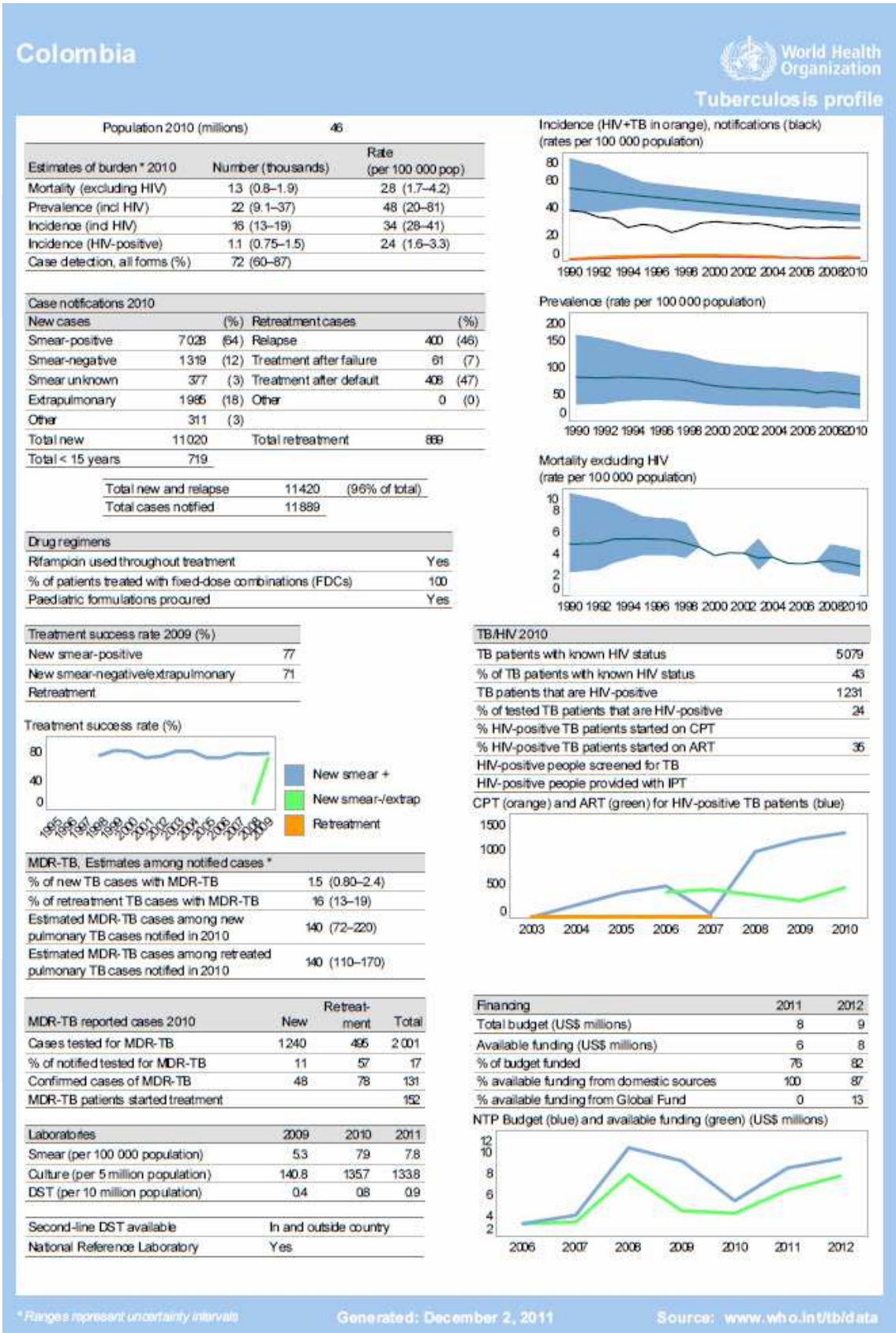


Fig. 1. Tuberculosis epidemiological profile for Colombia according to the World Health Organization, 2010.

TB (TB Network) and Liga Científica contra a Tuberculose (Scientific League against Tuberculosis). Since their creation, these entities have been constituted by people who are committed to TB control, though lacking the “community” component represented by people who are affected by and live with the disease (Santos Filho & Santos Gomes 2007). After that in recent years more organizations were involved in the fight against TB in the country.

The actions by the community entities in the fight against tuberculosis have been particularly concentrated on the networking among diverse social and govern mental actors; plus, on making the problem noticeable to their target populations or the general population, aiming their sensitization (Santos Filho & Santos Gomes 2007). For some relevant social actors, such as the Rede TB (TB Network) and the Liga Científica (Scientific League), the participation of the community sector in their activities aims at contributing to greater efficacy of their actions and responses to certain problems that are presented. Without the user’s voice and perspective, there is the risk of repeating mistakes of not evaluating correctly the efficacy of actions such as applied methods and methodologies in health services (Santos Filho & Santos Gomes 2007). Then, multiple strategies are important in this context of development of new alternatives in the control of TB. The practice of participation, networking, advocacy and multi-sector cooperation will provide the necessary conditions for an effective control of tuberculosis in Brazil, as well in other countries where they would be applied (Santos Filho & Santos Gomes 2007).

5. Social networks in tuberculosis in Pereira, Colombia

Taking in account general epidemiology of TB in Colombia and particularly at a municipality where this strategy of social networking was developed, social conditions were analyzed (Collazos et al. 2010, Jalil-Paier & Donado 2010, Ascuntar et al. 2010, Mateus-Solarte & Carvajal-Barona 2008, Jaramillo 1999). Also, in the scenarios were considered the recent impacts of the health sector reform (Carvajal et al. 2004, Ayala & Kroeger 2002), that also have influenced the TB control programs from a national to a local perspective. Pereira is the capital municipality of the Department of Risaralda (Figure 2). It stands in the center of the western region of the country, located in a small valley that descends from a part of the western Andes mountain chain. Its strategic location in the coffee producing area makes the city an urban center in Colombia, as does its proximity to Bogotá, Cali and Medellín.

For 2011, Pereira municipality has an estimated population of 459,690. Official reported records for TB in Risaralda registered a disease incidence for 2011 of 66 cases per 100,000 pop (as 15 December) (which is above the national average rate of 24 cases per 100,000 pop). Pereira is divided into 19 urban submunicipalities: Ferrocarril, Olímpica, San Joaquín, Cuba, Del Café, El oso, Perla del Otún, Consota, El Rocío, El poblado, El jardín, San Nicolás, Centro, Río Otún, Boston, Universidad, Villavicencio, Oriente y Villasantana. Additionally also has rural townships which include Altagracia, Arabia, Caimalito, Cerritos, La Florida, Puerto Caldas, Combia Alta, Combia Baja, La Bella, Estrella- La Palmilla, Morelia, Tribunas. The municipality of Pereira has a diversified economy: the primary sector accounts for 5.7% of domestic product, the secondary sector shows a relative weight of 26.2%, while the tertiary sector is the most representative with a 68.1%. The GDP of Pereira grew by 3.7% in 2004. For 2010, Pereira reported 301 cases of TB (incidence rate of 65.85 cases per 100,000pop). In Pereira, previously reported interventions have been developed and working intersectorially with the academia in order to increase the impact of activities in TB control (Castañeda-Hernández et al. 2012b).

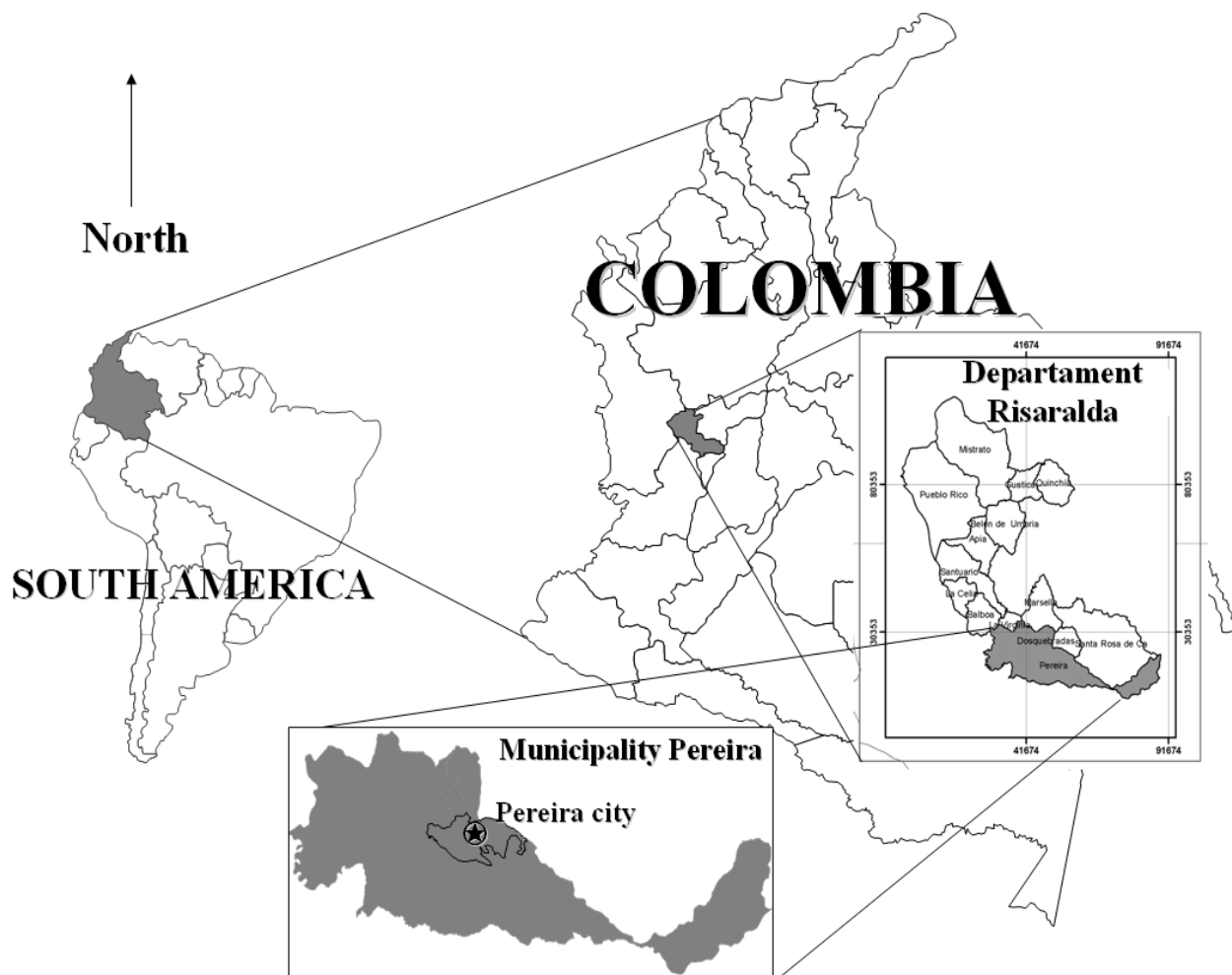


Fig. 2. Relative location of Pereira, Risaralda, Colombia, South America.

In the country, the strategic plan “*Colombia Libre de Tuberculosis para la Expansión y Fortalecimiento de la Estrategia Alto a la TB, 2010-2015*” (Colombia Free of TB for the Expansion and Enhancement of the Strategy Stop TB, 2010-2015), define as goal the achievement of notifications of new positive baciloscopies cases in more than 70% and a curation rate of at least 85%. In this context the routine surveillance allow to follow management and measurement of the impact of the realized actions by the control programs at municipal, departmental and national level, in order to generate interventions that contribute to achievement of the established goals to stop the advance of TB in the country.

Those considered strategies in the referred plan include the previously mentioned pursue advocacy, communication and social mobilization (ACMS), from the WHO Global Plan to STOP TB (World Health Organization 2011). In the context of wide-ranging partnerships for TB control, advocacy, communication and social mobilization (ACSM) embrace: advocacy to influence policy changes and sustain political and financial commitment; two-way communication between the care providers and people with TB as well as communities to improve knowledge of TB control policies, programmes and services; and social mobilization to engage society, especially the poor, and all allies and partners in the campaign to Stop TB. Each of these activities can help build greater commitment to fighting TB.

Advocacy is intended to secure the support of key constituencies in relevant local, national and international policy discussions and is expected to prompt greater accountability from governmental and international actors. Communication is concerned with informing, and enhancing knowledge among, the general public and people with TB and empowering them to express their needs and take action. Equally, encouraging providers to be more receptive to the expressed wants and views of people with TB and community members will make TB services more responsive to community needs. Social mobilization is the process of bringing together all feasible and practical intersectoral allies to raise people's knowledge of and demand for good-quality TB care and health care in general, assist in the delivery of resources and services and strengthen community participation for sustainability. Thus, ACSM is essential for achieving a world free of TB and is relevant to all aspects of the Stop TB Strategy. ACSM efforts in TB control should be linked with overarching efforts to promote public health and social development (World Health Organization 2011).

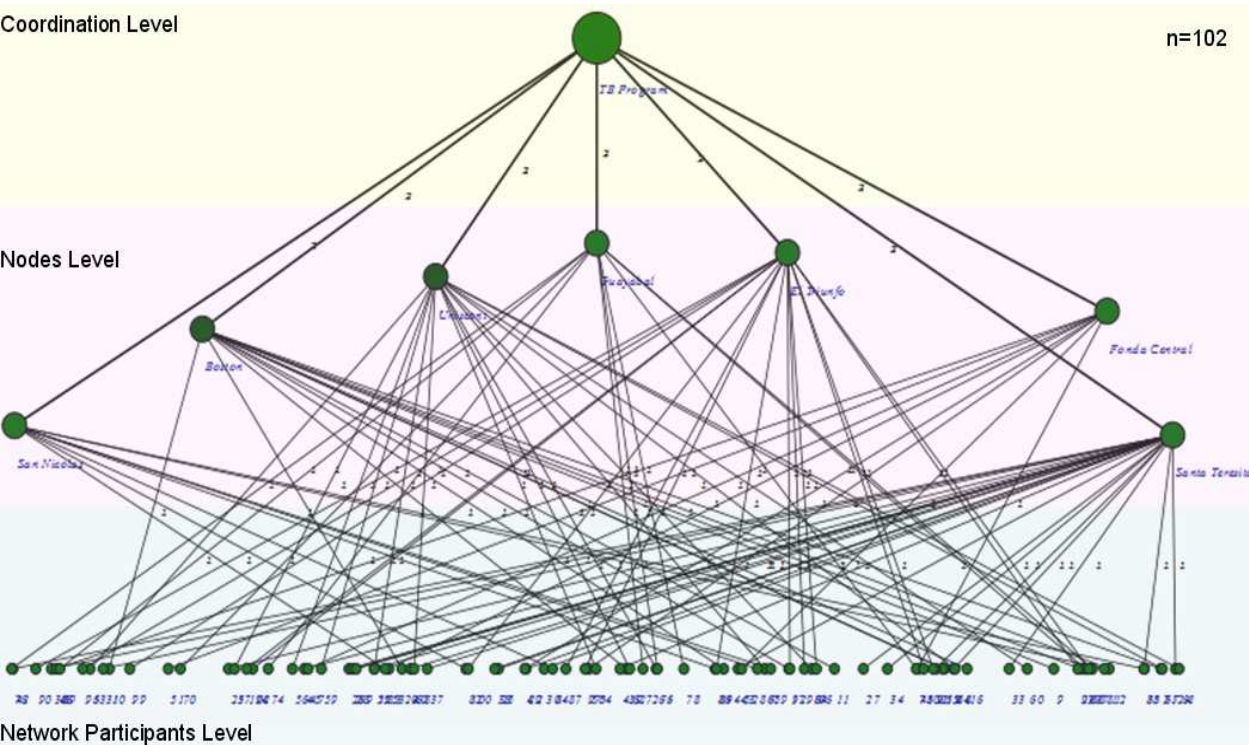


Fig. 3. SNA for Tuberculosis Network in Pereira, Colombia (developed with the Software SocNETV 0.81).

With these considerations in mind, in Pereira a social network for TB was developed. This network include the participation of ex-patients with TB, also healthy general population participated. All of them through the creation of nodes of the network, which were considered for this purposes as communitarian organizations constituted for a common objective and which are present regularly at neighborhoods in the municipality. Nodes were located at the 7 most highly prevalent areas of the municipality, previous to epidemiological analyses of those areas. Then, these locations were oriented to focalize the actions through the impact that, once established, this network would have on the control activities for TB in the areas of the municipality where most cases are concentrated.

In Pereira, with coordination of the TB control program on the top of the organization, a social network was developed with 7 strategically located and voluntary participation nodes

(Figure 3). This social network included more than 100 people supporting the program of TB in the municipality, then strengthening the control and surveillance activities necessary to reduce and to impact more the actions against the disease.

The nodes were constituted as communitarian organization, recognized by the communities and by the different related institutions, seen as long-lasting entities, with clear objectives and work plans for continued activity at the community. In all cases the participation was completely voluntary and non-profit.

As one of the key aspects of this network, multiple programmed activities were developed, including regularly meetings for discussions and for education on TB, giving multiple and different type of incentives in order to increase the interest on participation, holding workshops and different age-oriented designed activities that include games and handy-craft works, but in every case taking in consideration an structured and varied programation to include activities for TB education.

With this social TB network the municipal TB control program pursue to improve case detection and treatment adherence, combat stigma and discrimination, empower people affected by TB and mobilize political commitment and resources for TB.

Further implications of this social network, however, should be analyzed in the long term in order to measure its impact of epidemiological indicators of TB in the municipality.

6. Conclusions

Tuberculosis control in the XXI century requires new approaches and interventions, particularly those based in education and prevention with a community-based orientation. Programs such as the social network developed in Pereira TB control program, should performed in other highly endemic places. As the WHO recommends to pursue the ACMS (advocacy, communication and social mobilization), strategies as the social network allow to enhance particularly the communication and social mobilization components. Unfortunately at many national plans of TB control, how translate the ACMS in specific actions is not well defined in most occasions.

As has been previously stated, in the establishment of a social network for TB, previous diagnosis, including geo-referenced characterization, it is necessary to select the areas where the nodes will be established, taking also in consideration the suitability as the willingness of the potential participants of the network in each area and node. Finally, with the mining of the activities described, but also beginning with the idea of raise the awareness about the disease, taking in consideration a high level of diversity on the activities, as has been stated in order to warrant the continuous interest and participation of the network members on it.

In the future, in order to enhance the function and structure of the whole social network, further meetings between the nodes are expected. As now, only nodes interact internally, but the idea for the future activities in this setting is increase the links internally, but also between the main nodes in order to potentially increase the participation in the whole network.

Activities such as the development of social network of TB in Pereira will enhance the prevention, education and surveillance in the community, allowing a better integrated approach to the TB control in these scenarios and increasing the health profile in the community decreasing the lost opportunities for diagnosis and treatment of TB cases, finally leading to an improvement of the TB prevention and control.

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