

Ezio Távora dos Santos Filho

Zaira Machado dos Santos
Gomes

Strategies for tuberculosis control in Brazil: networking and civil society participation

ABSTRACT

Although no significant changes in the tuberculosis indicators have been registered in Brazil in recent years, there is a clear shift in the political scenario regarding the manner this disease has been tackled, with the appearance of civil society standing out. Considerations about the conditions that contributed to its emergence are made, such as the origin, composition, actions, partners and perspectives on social mobilization. Due to initiatives for tuberculosis control on an international level and attempts to encourage social mobilization on state and municipal levels, the Brazilian federal government began to engage in a more consistent and coherent policy, also including civil society in its actions. In spite of being an actor acknowledged by the public power and considered strategic for the success of tuberculosis control actions, community participation requires incentives and constant support from other sectors.

KEY WORDS: Tuberculosis, prevention & control. Consumer participation. Participative planning. Health public policy. Brazil.

INTRODUCTION

In the last few years, the scenario of tuberculosis (TB) in Brazil has been changing radically. Statistic data do not show improvement in the indicators of TB, represented by the expressive progress in the rate of cure and in the expected decrease in the rate of mortality. Even so, the positive shift in the perspective on the fight against this disease is unquestionable. The most remarkable aspect is the recent and still limited civil society mobilization. This mobilization stands out for its vigor; its capacity to articulate on many levels; the awareness raising for the problem of TB it promotes; its interest in deepening and expanding its knowledge; and its slow yet growing actions towards TB control.

In this article, "civil society" is particularly defined as community organizations with a humanitarian character (groups of people affected by pathologies or disabilities), associations of residents in low income areas, minority representative groups, and charities, among others. Despite the relevance of education and research associations, student associations, professional associations and entities such as foundations in this scenario, they are not confounded with the community organizations in this study.

The proposal of the present analysis is to evaluate five aspects of this "new-old" actor, civil society, aiming at outlining a clear profile and taking into consideration the conditions that contributed to its reappearance: origin, constitution, actions, partners and perspectives on the social mobilization in Brazil.

The following considerations are based on the author's experience with activities in social mobilization to fight TB since 2002. Moreover, some of the results

Mecanismo Coordenador de País (Brasil) para o Fundo Global contra a Aids, Tuberculose e Malária. Rio de Janeiro, RJ, Brasil

Correspondence:

Ezio Távora dos Santos Filho
R. Correa Dutra, 149 sala 102
22210-050 Rio de Janeiro, RJ
E-mail: tbhiv@eziocon.net

Received: 4/14/2007

Approved: 6/21/2007

of a survey on the context and control policies against TB, which was completed between the years of 2005 and 2006 in Brazil, are presented.*

ORIGIN

The establishment of initiatives constituted by community organizations regarding tuberculosis is quite recent. Until a short time ago, the complete absence of participation of those organizations in the fight against TB was evident.

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 TB*⁷ (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.

Since 2002, the *Programa de Controle da Tuberculose do Estado do Rio de Janeiro* (Tuberculosis Control Program of the State of Rio de Janeiro) and the *Divisão de Tuberculose da Secretaria de Estado de Saúde de São Paulo* (Tuberculosis Division of the Health Department of the State of São Paulo) have adopted a specific strategy for civil society mobilization to include this community component in the fight against TB.⁶ Furthermore, at the end of this same year, community agents and other local actors were included in the project of strategy expansion of DOTS (Directly Observed Treatment Strategy) in the community of Rocinha, in the city of Rio de Janeiro. It was promoted by the *Programa de Tuberculose da Divisão de Transmissíveis da Secretaria Municipal de Saúde do Rio de Janeiro* (Tuberculosis Program of the Transmissible Diseases Division from the Municipal Health Department of Rio de Janeiro).***

Three aspects contributed to the decision, on different government levels, to promote civil society’s inclusion in the efforts to control TB, particularly on a community basis. The first aspect is the legitimacy and legal support of this participation. The participation of “users” is a requirement in the composition of health councils

on all three levels of government, which contributes to the definition of the recommendations that will guide the definition of health policies that orient the *Sistema Único de Saúde* (National Healthcare System – SUS).****

The second aspect that influenced this decision was the agreement made by many countries, including Brazil, in the Declaration of Amsterdam to Fight Tuberculosis in 2000. In this agreement, governments made the commitment to “monitor and evaluate their national TB programs according to standards set by the World Health Organization (WHO) and to support partnerships with non-governmental institutions (NGOs) and with the community.”⁸ This Declaration was later endorsed by the Washington Commitment in October of 2001.⁹ Nonetheless, since the Global Conference on Health Promotion in 1991,³ TB has been considered a global emergency and the WHO (1993) recommended DOTS,⁴ as well as transparency, monitoring and evaluation of TB control policies and implementation of partnerships, either with the community sector or with other relevant sectors. This “legal framework” for the inclusion of representatives from the community in the discussion and deliberation of TB public policies, its monitoring and evaluation has allowed or, at least, helped international cooperation agencies to finance actions along these lines. As an example, there is the support given by the United States Agency for International Development (USAID) to state programs in Rio de Janeiro and São Paulo since 2002, and, previously, to some actions of the *Programa Nacional de Controle da Tuberculose* (National Tuberculosis Program in Brazil – PNCT).

The third and most relevant aspect for this initiative was the perception by state administrators that, in practice, the absence of monitoring of public policies in TB by civil society promoted slowness, lack of transparency and inefficiency of governmental actions and policies in their plenitude. In other words, the absence of demands from society motivated the government’s lack of commitment to its own decisions, as it was the case with the Brazilian Government. Moreover, this caused the “lack of urgency” for the release of resources and the implementation of policies for TB control.⁶

With this realization, some state and municipal administrations started to organize their own strategies for

* Data extracted from the report *Política de Tuberculose no Brasil: uma perspectiva da sociedade civil. Tempos de Mudanças no Controle da Tuberculose no Brasil* (Tuberculosis Policy in Brazil: a civil society perspective. Changing Times in the Control of Tuberculosis in Brazil), presented in July of 2006, in São Paulo.

** Personal communication obtained from interview with Dr. Eleny Guimarães Teixeira, *Universidade Gama Filho* (Gama Filho University) and *Liga Científica Contra a Tuberculose* (Scientific League against Tuberculosis), Rio de Janeiro, by phone, on 9/20/2006.

*** Personal communication obtained from interview with Dr. Solange Cavalcante, from the *Programa de TB da Divisão de Transmissíveis da Secretaria Municipal de Saúde do Rio de Janeiro* (Tuberculosis Program of the Transmissible Diseases Division from the Municipal Health Department of Rio de Janeiro), by phone, on 9/20/2006.

**** Personal communication obtained from interview with Mr. Mario Scheffer, journalist for CREMESP e member of *Grupo Pela VIDDA-SP* (Pela VIDDA-SP Group), by phone, on 9/20/2006.

civil society mobilization. The PNCT finally committed itself to recovering and reaffirming its own policies¹ in 2004,* to execute and speed up DOTS implementation in Brazil.¹⁰

As a result, it can be observed that the social mobilization to fight TB in Brazil in the last few years did not happen spontaneously, unlike what was witnessed at the turn of the 20th century, with the creation of the *Liga contra a Tuberculose* (League against Tuberculosis).² The reaction to the appearance of the HIV epidemic and AIDS in the 1980s was also spontaneous. In both cases, the participation of those victimized by the disease was a crucial aspect for a natural and consistent response by society. In the beginning of the 20th century, tuberculosis affected the population indistinctly; even wealthy citizens were not immune to the disease. In the 1980s, the HIV and Aids epidemic struck the gay community notably: middle class people with good educational level and skilled at articulating with several sectors of society, due to their experience fighting for human and civil rights in Brazil, and also the experience of the gay movement itself since the previous decade.**

Due to the characteristics of the people affected by TB annually – mostly of low income, facing stigma because of the disease,⁶ and having restricted access to health –,*** spontaneous and well articulated political reactions – as observed in the beginning of the AIDS epidemic – should not be expected.

It is possible to affirm there is still no awareness on the dimension of the TB-HIV co-infection problem in relation to affected populations or even organizations that fight for the AIDS movement. Hence, even if people living with AIDS are personally victimized by the growing co-infection problem, the AIDS movement cannot properly commit to the TB cause unless awareness raising and capacity building are promoted. Organizations that work with AIDS are overloaded with the growing, complex demands of their target populations – who grow poorer and needier each day – and also face a sharp decrease in financial and human resources. Furthermore, their loss of political meaning in the last few years, particularly due to the policy of visibility adopted by the *Programa Nacional de Doenças Sexualmente Transmissíveis e Aids* (Brazilian National Program on Sexually Transmitted Diseases and AIDS – PN-DST/Aids), contributes to limit the

consistent incorporation of the issue of TB in their agenda. The fact that community organizations also have to confront the popular belief that TB is a disease that has been eradicated or is under control – a “problem in the past” –, not worthy of greater attention, adds up to the challenge.

Thus, governments and cooperation agencies should be the ones to encourage and support those community initiatives to assure the sustainability of the participative process of social mobilization.

COMPOSITION

The most relevant initiatives involving the mobilization of civil society were the creation of the *Fórum de ONG Lutando Contra a Tuberculose no Estado do Rio de Janeiro* (Forum of NGO Fighting Tuberculosis in the State of Rio de Janeiro) and the incorporation of the issue of TB by the *Fórum de ONG-Aids do Estado de São Paulo* (Forum of AIDS NGO of the São Paulo State), both in 2003. More recently, in 2005, the *Rede para o Controle Social da TB no Estado de São Paulo* (Tuberculosis Social Control Network of the São Paulo State) was founded. All these entities have a heterogeneous composition of several partners, the great majority being genuinely communitary, including people who are affected by these diseases. They are composed by organizations that fight against certain diseases and/or disabilities, plus children protection organizations, harm reduction organizations,, feminist groups, ethnic and sexual minorities groups, faith-based organizations, sex workers’ organizations, as well as groups dealing with homeless’ or prison populations.. Despite the diversity of composition, which counts on members with different capabilities, organizational structures and institutional development levels, all these community entities have limitations in common. These limitations involve defining their guidelines, addressing their demands, planning activities to fight TB or the TB-HIV co-infection. Such limitations tend to be overcome with time.

ACTIONS

The actions by the community entities in the fight against tuberculosis have been particularly concentrated on the networking among diverse social and govern-

* Ministério da Saúde. Secretaria de Vigilância em Saúde. Programa Nacional de Controle da Tuberculose. “Plano de Ações PNCT 2004-2007” Brasília; 2004 (Word document).

** Santos Filho ET. *Saindo da sombra: o movimento social brasileiro no financiamento do Banco Mundial ao Programa Nacional de Aids* (Leaving the shadow: the Brazilian social movement during the World Bank financing to the National Aids Program [Master’s dissertation]. Rio de Janeiro: Instituto de Relações Internacionais da PUC-RJ (International Relations Institute at PUC-RJ), 2002. Available at http://www.maxwell.lambda.ele.puc-rio.br/cgi-bin/db2www/PRG_0490.D2W/INPUT?CdLinPrg=pt (Accessed on 7/18/2007).

*** Country Coordinating Mechanism, Mecanismo Coordenador de País, MCP (Brasil). “Strengthening of the DOTS strategy in large Urban Centers with High Tuberculosis Burden in Brazil”, Proposta do CCM-MCP (Brasil) junto ao Fundo Global contra a Aids, Tuberculose e Malária, para a 5ª Ronda, submetido em junho e aprovada em setembro de 2005 em Genebra. [Accessed on 7/18/2007] Disponível em http://www.theglobalfund.org/search/docs/5BRAT_964_0_full.pdf

mental actors; plus, on making the problem noticeable to their target populations or the general population, aiming their sensitization.

Thus, since its creation in August of 2003, the *Fórum de ONG Lutando Contra a Tuberculose no Estado do Rio de Janeiro* (FTB-RJ – Forum on NGOs Fighting Tuberculosis in the State of Rio de Janeiro) has been standing out as regards the promotion of information on TB issues in the local, national and international spheres, always broadening and diversifying its direct mail. Furthermore, the FTB-RJ has been promoting activities to empower its member organizations; promote partnerships among community, academic and governmental sectors, cooperation agencies, and also with other social movements, especially the AIDS one. The FTB-RJ has also been participating in several active fronts such as the Brazilian Partnership against TB. In addition, it has been dedicating itself to the representation of the Stop-TB Partnership in Brazil, the membership at the *Rede-TB* (TB Network) and the work with the Country Coordinating Mechanism (CCM) for the Global Fund.

In the last three years, FTB-RJ has been promoting activities of social awareness related to the issue of TB, such as interventions at squares and train stations, among other places, on the World TB Day – March 24th. Nonetheless, FTB-RJ has yet a restricted capacity to reach the population in general. This is due to financial resources' limitation and still restricted capacity to plan and execute original actions. These restrictions are certainly related to the recent formation of the entity and also the lack of specific financing for organizational and institutional development. However, its evident dynamism shows proofs of its capacity to gather several community actors, promote visibility and bring great potential for this movement.

Other entities have opened diverse important fronts, especially in the state of São Paulo. The same representative appointed by the *Fórum ONG-Aids do Estado* (Forum of AIDS NGO of the State) to deal with the issue of TB-HIV was also invited for representation at the *Fórum de Patologias e Deficiências* (Forum on Pathologies and Disabilities) and later to the *Conselho Nacional de Saúde* (National Health Council). This double function has allowed the issue of co-infection to be discussed among counselors, improving its growing networking. Likewise, the *Rede Paulista de Controle Social* (São Paulo's Social Control Network) is already celebrating its first anniversary and expands the social partners' front in the fight against TB in the most populated state in Brazil.

To measure the impact of these recent community initiatives is a complex task. Nevertheless, its importance is absolutely unquestionable: today there is

more information on TB on the press, even though it is not completely satisfactory. Many community organizations already discuss the issue in the two largest urban centers in Brazil; tuberculosis policies definitely seem to be moving forward vigorously. Undoubtedly, this renewed spirit is due to the new components in the scenario of the fight against TB and consequently to the increase in its visibility. Thus, new demands from the organized civil society should be expected and therefore the possibility of a greater control of the disease in Brazil. However, if the short period of time - in which new partnerships and activities have been implemented - were considered as a measure of impact, the positive balance of these new actors would be evident. Finally we hope that established indicators will soon be helping evaluating the impact of social participation on the control of TB.

PARTNERSHIPS

In the previous years, governmental and academic sectors have been receptive and willing to establish a growing dialogue and partnership with the community sector. International donors are also perceptive to the demands for social mobilization and monitoring of TB policies, particularly when it comes to issue such as representation and legitimacy. A convergence of interests is evident therein, something that will be beneficial to all.

In spite of the fact that different levels of government have been increasingly striving to incorporate the practice of relations with community organizations, it is undeniable that governmental institutions still show some resistance when dealing with this notoriously critical actor. NGO are acknowledged by governmental institutions for their ability to involve society, great capacity to meet demands and interests from public healthcare services' users. Nonetheless, some situations still represent discomfort to the governmental system, due to the lack of practice in the participative process of decision-making.

From the community side, the perception of unbalance in strength and capabilities certainly provokes discouragement to greater involvement in the participative process. Nevertheless, social movements' organizations should work better in order to make good use of qualification opportunities, although some advances can be already noticed.

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.

The recent experience of creation of the CCM for the Global Fund has been a landmark in this partnership scenario. By demand from the Global Fund itself, which does not designate resources to governments directly, the mentioned mechanism is formed in each proponent country. The CCM is composed of a broad universe of actors: different government sectors, academia, diverse representations from civil society and from the affected people. This innovative structure encourages partnership, once it compels them to negotiate towards common aims. The resources designated to Brazil refer to DOTS expansion. Thus, CCM emphasizes TB control and a more consistent development of social mobilization in different regions in Brazil, aiming the monitoring of the implementation activities of the Brazilian project towards the Fund.

The creation of the *Parceria Brasileira contra a Tuberculose* (Brazilian Partnership against Tuberculosis – PBT) in 2004 was another recent initiative by the *Ministério da Saúde* (Ministry of Health), widely promoted in the press. The PBT is part of an international global initiative proposed by the Stop-TB Partnership in Geneva.

Ideally proposed by the Stop-TB Partnership itself, at its headquarters at the WHO, to perform the function of local representatives or similar initiatives, national partnerships were created in numerous countries, aiming at the promotion of dialogue and the interconnection of sectors, for the development of TB policies in each country. The specific goal for the creation of “national partnerships”, as PBT was conceived in Brazil, is to generate accountability in the TB public policies, something that is quite remarkable. Therefore, increased capacity to add up resources, strengthen efforts and invigorate actions would be stimulated.

Nevertheless, the Brazilian PBT, a pioneer in this process, has not presented self-sustainability until now, depending on the Brazilian government to finance its activities. This is certainly a limiting element in the process.

PERSPECTIVES

The current situation of Brazil regarding the fight against TB is promising. The set of new proposals, the different partners being gathered in several fronts, and the first consistent results in DOTS expansion⁵, contribute to optimize and strengthen the interest about the problem and the struggle against it.

It can be affirmed that, in the current scenario of the battle against TB in Brazil, the actions of the community sector are vital and unquestionable. In addition, the participation of those who work directly and/or represent the populations affected by the problem cannot be disregarded.

More important than meeting demands or international orientations is to be engaged in policies and actions that are consistent and sustainable, regarding the major interests of the country and, in other words, on behalf of the population.

CONCLUSIONS

Current administrators of TB programs in Brazil should find the means to continue promoting social mobilization, reinforcing and deepening its capacity for action. There is a favorable momentum.

It should not be expected that community response in the control of TB be spontaneously generated. Such possibility is quite remote due to lack of financial resources of most of those who are affected by the problem, their low level of education and little ability to advocate within the community organizations.

Administrators should finally understand that, by promoting social mobilization, the administration will be strengthened through co-responsibility, established by the participative process involving all segments, thus achieving more legitimacy and transparency.

The uncertainty still observed among partners in different sectors (community, governmental, private and academic) dealing with the problem is still an obstacle for a greater advance in fighting the disease. Only the practice of participation, networking, advocacy and multi-sector cooperation will provide the necessary conditions for an effective control of tuberculosis in Brazil.

REFERENCES

1. Ministério da Saúde. Secretaria de Políticas de Saúde. Plano Nacional de Controle da Tuberculose. Brasília; 1999.
2. Nascimento DR. Fundação Ataulpho de Paiva – Liga Brasileira Contra a Tuberculose: um século de luta. Rio de Janeiro: Quadratim; 2002. p.30.
3. Organización Mundial de la Salud. Cuadragésima cuarta Asamblea Mundial de la Salud. Actas resumidas de las Comisiones. In: 44ª Asamblea Mundial de la Salud; 1991 mayo 6-16. Ginebra; 1991.
4. Organización Mundial de la Salud. El marco para el control de la tuberculosis eficaz. 1994. OMS/TB/94.179.
5. Ruffino-Netto A, Villa TCS, organizadores. Tuberculose: implantação do DOTS em algumas regiões do Brasil: histórico e peculiaridades regionais. Ribeirão Preto: Instituto do Milênio Rede TB; 2006.
6. Santos Filho ET. Política de TB no Brasil: Uma perspectiva da sociedade civil: Tempos de mudanças no controle da tuberculose no Brasil. Rio de Janeiro: Open Society Institute; 2006.
7. Silva CL, organizador. Instituto do Milênio Rede TB – Rede Brasileira de Pesquisas em Tuberculose – Relatório das atividades de Pesquisa 2002-2004. São Paulo: Instituto do Milênio Rede TB; 2005. p.16.
8. Stop-TB Partnership. The Amsterdam Declaration to Stop TB”. Amsterdã: STP-OMS/WHO, 2000. [Acesso em 17/7/2007] Disponível em: http://www.stoptb.org/stop_tb_initiative/assets/documents/decla.pdf
9. Stop-TB Partnership. The Washington Commitment to Stop TB. Washington: STP-OMS/WHO, 2001. [Acesso em 17/7/2007] Disponível em http://www.stoptb.org/events/partners_forum/2001/Documents/WashCommitm_Eng12Dec.pdf
10. World Health Organization. The five elements of DOTS. DOTS remains at the heart of the Stop TB Strategy. Geneva; 2001. [Acesso em 17/7/2007] Disponível em: www.who.int/tb/dots/whatisdots/en/index.html

ZMS Gomes is assistant consultant.

Conflict of interests: It should be made clear that ET Santos Filho has been a humanitarian activist for a long time and also a victim of tuberculosis.