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**Community contribution to TB care:  
a Latin American perspective**



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Author: Ernesto Jaramillo  
formerly Research Associate, Corporacion CIDEIM, Cali, Colombia  
currently Medical Officer, Stop TB Department, WHO Geneva, Switzerland

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## **Table of Contents**

Executive Summary	1
1. Background	3
2. Methods	4
3. Settings	4
4. Findings	5
5. Discussion	12
6. Conclusion	14
7. References	14
Appendix I. Guide for semi-structured interviews	15
Appendix II. Key informants interviewed	16



## **Executive Summary**

Implementation of the DOTS strategy for tuberculosis (TB) control depends on a wide range of health service providers, including the community. Documented literature on community-based DOTS in Latin America is scanty. Lessons from a Latin American perspective on community-based TB care can help to understand and identify the role that the community plays in TB control in the region, with potential relevance to other regions. This report describes the results of a literature search on community-based TB care in Latin America, and of field visits to selected community-based TB care projects in Bolivia and Colombia, made in order to understand the origin, performance, acceptability, effectiveness, and sustainability of some of the existing projects.

Three sites in Colombia and two in Bolivia, where the DOTS strategy is already implemented, were visited. The findings in these sites suggest a relatively uniform pattern of community participation in TB care in the region. Overall, the community participates in TB control by identifying TB suspects, supporting TB patients by directly observing treatment (DOT), tracing contacts of index cases, providing social support to patients in need and, in some sites, lobbying the local government for placing TB control high in the public health agenda. The members of the community were trained in all the cases by the parent community organization or staff of the local national TB programme (NTP) before providing TB care. The care they provide is consistently delivered according to NTP guidelines and supervised by staff of the local NTP, and socially accepted by the community and the TB patients.

In two out of the five sites visited there are projects with a community-based (“bottom-up”) origin, while in the other three sites they were promoted by non-governmental-organizations (NGOs) or charismatic leaders in the area. Although the NTP is generally receptive to these community-based initiatives, it has played a rather reactive role in three out of the five sites visited. This reactive role is weakening the performance and consolidation of some of these community-based projects since the volunteers are not always clear about how they can help the NTP and the TB patients.

Evaluation of the effectiveness of the projects visited is problematic, as the managers do not keep adequate records of the activities performed. This hampers any *ex post facto* evaluation. Indeed, there are no reliable data available to measure the community contribution to the total of suspect cases found, contacts traced, and cases found and held in the sites. However, this contribution is rather small, according to the persons responsible for the project and to the NTP officers. Indeed, they estimate that less than five percent of the total of TB suspects examined by the NTP were referred by a community member; and even less than five % of the total of TB patients receiving treatment under DOT are being cared for by a community member.

The sustainability of the projects is linked to the sustainability of the parent NGO or the grassroots movement that gave birth to the project. These parent organizations are well consolidated in political and managerial terms, but in the Latin American context they are quite vulnerable to the lost of financial support from local and international funding bodies.

Although many patients are benefiting directly from the care provided by the community members, it is unlikely that they are making a substantial difference on the performance of the NTP in terms of case finding and cure rate. However, these volunteers are demonstrating great interest in, and capacity to care for, TB patients. They facilitate the adherence to treatment, in particular, those patients more likely to interrupt or abandon treatment. NTPs could benefit from community-based TB care projects much more than they do now in those projects described in this report, if they play a more proactive role in educating the community about the technical and political challenges that the NTP faces, and motivating the community to support the NTP.

## **1. Background**

The community can contribute to NTP implementation of the DOTS strategy for TB control in a number of ways (Maher et al, 1999). Documented literature on community-based DOTS in Latin America is scanty. Lessons from a Latin American perspective on community-based TB care can be helpful to understand and identify the role that the community is playing in TB control in the region, with relevance also for other regions.

The Latin American region is composed of 21 countries. Most of the population of the region share the same religion (Roman Catholic) and language (Spanish), with exceptions such as Brazil (where Portuguese is spoken), and small indigenous communities (where local languages are spoken). The ethnic backgrounds of the vast majority of the population is the result of the mixing between native indigenous, Africans, and Europeans. The economy is still very much dependent on agriculture and exports of natural resources, with some countries having a greater degree of industrialization, such as Mexico, Brazil, Venezuela, Peru, Chile, Argentina and Colombia. Income inequalities are huge in the region, particularly in countries such as Brazil, Guatemala and Colombia. Parliamentary democracy has been the prevalent political regime in the region since the last decade. The health care infrastructure shows great disparities. Whilst some countries have relatively good systems of health, good public health care infrastructure and state-of-the-art health care technology, some others have a relatively precarious system of health and relatively poor public health infrastructure.

The Americas Region contributes 9% of the worldwide total of sputum smear-positive pulmonary TB case notifications (WHO, 2001). The TB situation is particularly serious in countries such as Haiti, Peru and Bolivia, which have smear-positive pulmonary TB case notification rates of up to 110 per 100,000 population (WHO, 2001). The DOTS strategy is being expanded progressively in the region, with Peru as a well known successful examples (WHO, 2001). Unlike in Africa, where the intersecting epidemics of TB and HIV impose a huge burden on health care systems, the burden of HIV-related TB in Latin America is comparatively low and has not seriously affected the performance of NTPs.

There is evidence of effective community participation in health in several countries of the region, particularly in the control of diseases transmitted by vectors (Leontsini et al, 1993; Rojas, 2001). In some of these countries the community participation is mainly the result of a weak state, as in Colombia. Yet in others it is the result of high prevalence of poverty that feeds the arrival of foreign NGOs promoting community participation in health care, as in Bolivia. To understand the origin, performance, acceptability, effectiveness, and sustainability of projects of community-based TB care in Latin America a search and review of the existing literature, field visits to selected community-based TB care projects in Bolivia and Colombia were made. Community-based TB care is defined, for the purposes of this work, as any community-based TB activity that facilitates the implementation of the DOTS strategy.

## **2. Methods**

A search using MEDLINE and LILACS-BIREME (a database specializing in health literature produced in the Americas) was performed using “community” and “tuberculosis” as key words. Sites for evaluation were selected in consultation with officials of the Pan American Health Organization (PAHO). Criteria included implementation of the DOTS strategy, a community-based TB care project directly known by the chief officer of the NTP, and approval by the chief officer of the NTP.

Methods employed to collect data in the sites visited included observation of community-based TB care activities, interviews of key informants using a semi-structured guide (see Appendix 1), and review of NTP records. The key informants interviewed were leaders of the community project, and health officers in charge of TB control activities. Jotted notes of the interviews were taken. Analysis of the qualitative data was made following standardized procedures such as creation of categories, sorting out of repetitive and new ideas within the text, until a description as thick as possible was obtained.

## **3. Settings**

### **Bolivia**

The two sites visited in Bolivia were Montero and Oruro. Montero, in the Department of Santa Cruz, is a town with a population of 61,000. This region has a booming economy and consequently over recent years has attracted many immigrants from the poorest regions of the country. Around 60% of the population is urban and belongs to low income-groups. Oruro, the capital of the Department of Oruro, has a population of around 390,000. Mining is the main economic activity. Around 55% of the population is urban, and the rural population is widely spread over a vast area that makes access to health care services difficult.

### **Colombia**

The three sites visited were Barranquilla, Popayan, and Toribio. Barranquilla is a city with a population of one million and is the capital of the department of Atlantico. Around 30% of the Colombian imports and exports go through this port situated in the Colombian Caribbean. Around 90% of the population is urban, and one third of it belongs to low income groups. Popayan is a town with a population of 221,000 and is the capital of the department of Cauca, having an economy based on agriculture and services. 90% of the population is urban. Toribio is a town with a population of 28,000 in the department of Cauca; four hours drive from Popayan. 90% of the population is native indigenous living in very poor conditions. Life expectancy is around 50 years, and 80% of the population has basic needs unmet.

## **4. Findings**

### *Literature Review*

A literature search using LILACS and MEDLINE databases, databases of national science and technology offices, and NTP officers as key informants only produced two reports of community-based TB care projects. Both were implemented in Chiapas (Mexico). Results of the projects suggest that the community can be very effective for delivering care to TB patients. The project implemented in “Los Altos”, Chiapas, consisted of training of peasants in strategies for case finding, and diagnosis by microscopy (Olvera et al, 2000). The evaluation of the training course showed that the peasants were able to carry out case- finding and diagnostic procedures effectively. In the project implemented in Chicomuselo (Chiapas) peasants were trained in case-finding, diagnosis by microscopy, supervision of treatment, contact tracing, and tracing of children who had not received BCG vaccination (Solorzano et al, 1991). The evaluation of the performance of the peasants showed that 82% (24/29) of patients enrolled, finished the treatment, and that a cure rate of 100% was achieved.

### **Bolivia**

#### *Montero (Santa Cruz)*

The notification rate of sputum smear-positive pulmonary TB in Montero is 178/100,000. TB control in Montero is based on the DOTS strategy and is fully integrated into the 11 health care areas of the province. Treatment has been given under direct observation (DOT) since 1995. In fact, this is a “demonstration area” of the DOTS strategy in Bolivia. Health teams from other regions of the country come to Montero to be trained in the DOTS strategy. The cure rate was 90% in several cohorts of 1999 and 2000, and beyond the target of 80% in all of them.

There are two community-based TB care projects in Montero, one led by the local public health care authorities and other NGO-led. The NGO is the “Consejo de Salud Rural Andino” (Andean Rural Health Council), which provides primary health care services in Villacochabamba, a slum of 13,000 inhabitants. In both projects the components of care which are community-based include the active finding of TB suspects, supervision of treatment at the patient household, tracing of defaulters, participation in the monthly meeting of the club of TB patients, and visiting the household of TB patients during the first days of treatment to check on adherence to treatment. All these activities are coordinated and supervised by a health care worker in charge of the TB control programme. Patients on treatment selected for direct supervision by community providers are those living far from the nearest health post. There are no data about the percentage of the community contribution to TB care in both projects. The managers of the NGO and the local NTP estimate that the community providers are supervising less than 6% of the total of patients receiving treatment.

In the case of the NGO project, the community member providing TB care can also play the role of guarantor of treatment adherence, that is, the provider behaves as a godfather or godmother, who checks that the patient adheres to treatment. Once a patient is diagnosed with TB, a community leader and/or a community TB care

provider is informed of the situation and invited to play the role of guarantor exerting social pressure on the patient to maintain adherence.

One commonly used strategy is to ask patients to leave a personal belonging in hands of the NGO's health care worker as a sort of guarantee that they will maintain adherence. The community leader witnesses the agreement between the nurse or physician in charge of the NTP, and checks the patient's adherence to treatment. The personal belonging is given back to the patient once the treatment is finished.

The community-based TB care providers are selected by the community itself, and trained in an overt way, which enables the community members to see that the providers have gained new knowledge. This has facilitated, according to the managers of both projects, wide social acceptability of the role played by the TB care providers. Overall, the community and patients fully accept the rules proposed by the NGO for giving treatment. The high cure rates achieved by the programme is resulting in around ten patients per year coming from distant regions to Montero to receive treatment. Some of these patients argue that the reason for coming to Montero is the reputation of the health care centre for treating and curing TB.

The community TB care providers of both projects do not receive any salary. However, they do receive incentives such as free medical consultations when needed, discount on prescribed drugs and, in the case of those working with the NGO for several years, incentives such as building materials to improve their house.

The main justification for community-based TB care in Montero was the poor adherence of TB patients to treatment. The public health leaders and the staff of the NGO attribute the decrease of non-adherence, from 50% in the early 1990s to the current 5%, to community-based TB strategies employed during the last years. However, there are no data to demonstrate the effectiveness of the community-based TB care, and its impact on case finding and cure rate.

The prospects for sustainability of these two projects in the mid-term are high. On one hand, the project led by the public health care system has been implemented during the last ten years by a team of health care workers who are proud of having Montero as a demonstrative area for DOTS. The sustainability of the project does not depend on the availability of economic resources but on the labour stability of the health care workers in charge of the NTP, who are the leaders of the project. This stability is unpredictable in Bolivia. On the other hand, the NGO has a fully committed team that has been working in the region for more than ten years, and that has community participation as a fundamental column of the health care they provide. The NGO follows the guidelines of a natural leader in the public health sector of the region who is well experienced in getting funds from abroad to keep the local health projects running.

#### *Oruro (Department of Oruro)*

The notification rate of sputum smear-positive pulmonary TB in Oruro is 27/100,000. TB control in Oruro is based on the DOTS strategy, which is fully integrated in six out of the seven health care areas of the department. A successful TB programme in this

department dates back to the 1980s when Belgian NGOs funded several health care projects with TB control as a priority. According to the informants interviewed, during the late 1980s community volunteers provided 30% of TB care.

Unfortunately there are no records to establish the exact dimension of the community contribution to case holding at that time. Currently, the cure rate in all the health care areas is above 80%.

The community-based TB care project in Oruro is lead by the "Asociacion de Promotores de Salud del Area Rural de Oruro" (APROSAR) (Association of Health Promoters of the Rural Area of Oruro). The origin of APROSAR is linked to 'Project Concern'. This was an NGO based in the USA working in primary health care in Oruro since the early 1980s, with community volunteers as health care providers. In the late 1980s, this NGO decided to leave the area and the rural health care providers created APROSAR with the help of 'Concern International'. The aim of APROSAR is to increase the coverage of primary health care services relying on health care 'volunteers', selected by the community they belong to. The volunteers are trained in primary health care, and do not receive any incentive during the period of work. For the volunteers it is just a privilege to work for the community. They have good relationships with the community, who accept the social function they play.

As in Montero, the components of TB care which are community-based include the active finding of suspect cases, tracing of defaulters, and supervision of treatment in the patients' households. Patients on treatment selected for direct supervision by community providers are those living in the rural areas, who usually live far away from the nearest health post. Health professionals employed by APROSAR closely supervise the care given by the volunteers.

The exact contribution of community-based TB care in Oruro is unknown, as APROSAR has not kept records of the TB care given by the volunteers. However, they estimate that community providers have supervised less than 5% of the total of TB patients on treatment. This is understandable taking into account the fact that TB cases in Oruro are concentrated in the urban area.

TB control has been a priority of this NGO since its foundation in the late 1980s, despite the relatively low notification rate in the communities they are working with. For example, the NGO has successfully piloted a project in 2001 aimed at expanding DOTS in an area where TB control was poorly implemented. The sustainability of the community-based TB activities in Oruro is dependent on the sustainability of the NGO. From a political point of view there are no visible threats to the operation of the NGO coming from either the community or from the government. In fact, the NGO is a powerful ally of the public health care system as it delivers services in the areas where the state cannot. However, the NGO does not receive any funding from the government, and depends on the economic support of international aid agencies that have been financing its operation.

## **Colombia**

### *Barranquilla (Department of Atlantico)*

The notification rate of sputum smear-positive pulmonary TB in Barranquilla is 20/100,000. TB control is based on the DOTS strategy and treatment has been delivered under DOT for more than a decade. TB control activities were centralized in a hospital specializing in lung diseases until 1995, when the national health sector reform started. Due to the health sector reform, the TB control activities, including treatment, were integrated into the newly created public and private health care units. The cure rate is up to 77% in the cohorts of 2000.

There are two community based-TB care projects in Barranquilla, both led by associations of female volunteers, namely the Liga Antituberculosa Colombiana, Seccional Atlantico (LAC) (Colombian League Against Tuberculosis and Lung Diseases, Chapter of Atlantic), and the volunteers association "María Rafols". The LAC is a local chapter of a national NGO created 60 years ago in Bogotá, the capital of the country, aimed at providing social support to TB patients on treatment. The Barranquilla chapter was created 50 years ago. The members of this NGO are ladies from well-to-do families, with strong links with the social and economic *élite* of the city. During the past 50 years, the NGO has accumulated physical capital derived from donations given by members of the local community. These include the hospital where TB treatment was given until 1995 and a primary school where relatives of TB patients received formal education, at the time when all TB patients were hospitalized while receiving treatment. The volunteers do not maintain a direct relationship with the patient but with the health care workers in charge of case finding and holding.

The association "María Rafols" was created ten years ago by middle class neighbours of the hospital belonging to the LAC where patients were hospitalized for receiving treatment, and by nuns of a Roman Catholic religious group working in the same hospital. The resources for the association to carry out its work, come from donations given by the members and local commercial companies.

The community-based TB care given by the LAC consists basically of material support such as drugs, monthly package of food to patients in need, and money for patients to pay the cost of transport to attend the health post everyday for receiving treatment under DOT. The LAC employs a social worker who assesses the patient's candidate for receiving social support presented by the health care workers of the NTP. The community-based TB care given by "María Rafols" consists of tracing defaulters, provision of material support such as drugs, food and transport to patients in need, and visiting patients' households to check their adherence to treatment. Unlike LAC, the care given by María Rafols is delivered directly by the volunteers of the association. None of these organizations participate in delivering of treatment or case finding. The NTP officers have not requested help from these community organizations for case finding and delivery of treatment.

In both organizations the volunteers enroll themselves in the group or are invited to participate by other volunteers after an open evaluation of the candidate. Volunteers

usually have a poor training in TB control strategies. The relationship of the volunteers with the staff of the NTP is mainly limited to receiving information on the patient needs to be met for maintaining adherence to treatment and, in the case of the volunteers of 'Maria Rafols', receiving information about defaulters. In the case of defaulters the 'Maria Rafols' volunteers visit the patients, explore reasons for defaulting, and try to resolve the problem and encourage them to maintain adherence. In fact, the awareness of the existing social, emotional and economic barriers for patients to adhere to treatment is the main motivator for both organizations to provide care.

The volunteers do not receive any incentive, apart from the acknowledgement given by the patients receiving the social support. The patients socially accept the care given by both groups of volunteers. However, it is clear that the LAC concentrates efforts on patients still receiving treatment in its hospital, while "Maria Rafols" has a much closer relationship with the health care workers of the decentralized health care units.

The extent of the contribution to TB care given by these organizations is unknown. Indeed, the percentage of the community contribution to TB care and its effectiveness have not been established since none of the organizations keep records of the care they provide. The local NTP has no data to establish the effectiveness of the contribution that these organizations make to case holding.

The prospects of sustainability of projects in the near and mid term are high. Both projects are "bottom-up" community-based initiatives that do not depend on external funding. In fact they have been active for at least ten years in the case of 'Maria Rafols' and 50 in the case of the LAC. However, the members of both organizations still do not grasp the nature and implications of the health sector reform for the care they are used to providing. The decentralization of the health care system and the low priority of TB control in the local public health agenda have resulted in the loss of, or strain on, the communication they usually have had with the TB control officers. If this situation is not resolved adequately these community initiatives could stagnate.

#### *Popayan (Department of Cauca)*

The notification rate of sputum smear-positive pulmonary TB in Popayan is 31/100,000. TB control in Popayan is based on the DOTS strategy and is fully integrated into the 19 public health care units, with a cure rate of 78% in the year 2000 cohorts.

In 1997 several professors from the Faculty of Health Sciences (School of Medicine) of the Universidad del Cauca created the 'Grupo de Estudio de Tuberculosis' ('TB study group'). This Group is aimed at facilitating the DOTS expansion in Popayan and in the department of Cauca through the fostering of academic and community-based TB control activities.

The components of care which are community-based in Popayan include the active finding of TB suspects, tracing of defaulters, supervision of treatment at the patient household, lobbying of the local government for political support for TB control, and

the creation and maintenance of vegetable gardens for providing material support to patients. These activities are coordinated and directly supervised by the leader of the Group, a medical doctor specializing in internal medicine, who reports to the chief officer of the local NTP.

The “TB Study Group” trained three different groups of community members in TB control strategies (case finding and delivery of treatment under DOT): a group of 40 volunteers belonging to BRAMPO (Brigada de Apoyo al Municipio de Popayan) (Support Team for Popayan), a community based organization; around 15 presidents of the “Juntas de Accion Comunal” (legally established associations of neighbours); and 19 “inspectores de policia” (the governmental judiciary authority in the rural areas of the municipality). Both “presidents” and “inspectores” were chosen by the Group for delivering community-based TB care due to the political influence they have in the local community.

There are no data to establish the percentage of community contribution to TB care and the effectiveness of the care they provide. However, according to the leader of the group, community providers are supervising less than 5% of the total of patients enrolled on treatment, the rest of patients receive treatment under DOT in the health care units of the local public health system. The leader of the TB Study group estimates that from 5 to 10% of the TB suspects examined by the NTP in 2000, were found by the volunteers.

Those patients living in the rural areas far from the nearest health post are selected by the leader of the “TB Study Group” for having treatment supervised by community providers. The patients and community accept this way for delivering TB care, despite the stigma attached to TB still prevalent in the area, as it facilitates adherence to treatment.

The “TB Study Group” has raised awareness amongst community groups and local NGOs (BRAMPO, the local chapter of Rotary International and Lion’s International, the Colombian League Against Tuberculosis-Chapter of Cauca) about the TB situation in the city and the main obstacles faced by the NTP to achieve its targets. Under the leadership of the “TB Study Group”, these groups have successfully lobbied the local government for raising TB control in the political agenda. The main result of this lobbying is the Act passed by the Major of the City in 2000 declaring TB control as a priority in the local public policy. The effect of this Act has not been reflected in allocation of additional resources for TB control, but at least the government is not blocking the efforts of the “TB Study Group”.

Apart from the activities mentioned above, which facilitate the achievement of the NTP objectives, the “TB Study Group” has promoted other community-based activities aimed at strengthening the household economy of TB patients and groups at high risk of developing TB. The “TB Study Group” has established thirteen communitarian vegetable gardens in the urban and rural areas of Popayan within the last two years. The Group thinks that DOTS is the strategy to prevent TB patients of dying, and that

production and consuming of groceries from the vegetable gardens is a strategy that contributes to prevent infected people from developing the disease. Members of the community and some TB patients operate these gardens, and the products are delivered to TB patients in need of nutritional support and, mainly, to refugees affected by the ongoing social conflict in the country. There are no data about the output of these gardens and their impact on the household economy of both patients and refugees.

The main justification for community-based TB care in Popayan is the difficulty facing the NTP in delivering DOT in the rural areas of the municipality, and the lack of political will during the last years to have TB control as a public health priority. The sustainability of these community-based activities depends on the support received by the “TB Study Group”, the real leader of the community participation process, from the local Public Health Office and the Director of the Universidad del Cauca. The chances for the Group to survive are high since both the Public Health Office and the University derives important benefits from the role played by the Group. The Public Health Office now has a revitalized TB control program, thanks to the actions of the Group; and the University can demonstrate its capacity to influence the local public health arena and to lead community-based activities in health.

#### *Toribio (Department of Cauca)*

The notification rate of sputum smear-positive pulmonary TB in Toribio is 43/100,000. TB control in Toribio is based on the DOTS strategy and is fully integrated into the two health care units of the municipality. Treatment has been given under direct observation (DOT) since 1997, and cure rate is at least 78% in several of the year 2000 cohorts.

The community-based TB care in Toribio was initiated in 1997 by the then new director of the local hospital “Alvaro Ulcue” in response to the poor adherence and cure rates achieved by the NTP there. At that time TB was still considered by the community as an incurable disease due to the low cure rates achieved by the local TB control program. This poor effectiveness of the local NTP added to the existing mistrust of the community in the formal health care system and in the health care workers. This mistrust partly originated in the rejection by the health care workers of any community member who followed the advice of traditional healers. The hospital staff, under the leadership of the new director, integrated some of the traditional health care practices into routine activities of the formal health system, mainly those related with obstetrics and general internal medicine.

The main care provided by community members are finding of TB suspects, tracing of contacts of index cases, administering TB drugs under DOT, participation in the monthly meetings of TB patients, and lobbying of the local government to have TB high on the public health agenda. Community members providing care to TB patients are usually selected by the community based on complex criteria that include the capacity or potential for leadership of the candidate but not their willingness to work. In short, the community members providing TB care, and other services to the community, are not volunteers but individuals appointed by the community for that job. Those selected have no other option than to accept as they can suffer some sort of social

discrimination for not being willing to collaborate in community affairs. They usually do not receive material incentives, though some working exclusively on health care issues receive a reward of around US\$80 paid by the hospital. Overall, the main reward they do receive is an upward move in the social status within the community. As in the other community-based experiences described in this report, the hospital does not keep records that allow us to measure the community contribution to TB care and the effectiveness of the care the “volunteers” provide.

Over the past 20 years, social and political mobilization in the indigenous communities of the region contributed to an overthrow 8 years ago of the traditional partisan non-indigenous groups who held the political control of the municipality. The municipal authorities are directly elected by the indigenous community, and are now held fully accountable to the electors. Under the technical influence of the director of the hospital, the community has successfully lobbied the Mayor of the city during the last three periods to make TB control a public health priority.

In addition to the TB care activities mentioned above; the community has also a vegetable garden in the backyard of the hospital. The indigenous communities of Toribio have a cosmic vision where the physical world and the social life are not fragmented but fully integrated into a single unity. Therefore, nutrition, economics and health are not independent but deeply related. Based on these beliefs and on the health education in TB given by the director of the hospital, the TB patients are the main actors in the vegetable garden. Every month they gather to work in the garden, and to distribute the production amongst the patients participating in the meeting. It is at this moment that the patients and the health care workers in charge of NTP activities discuss TB issues.

It is quite likely that this project will be sustainable in the mid-term as it is part of a large social community mobilization process that is not reliant on a specific leader or on the availability of certain economic resources. This community-based TB care experience is mainly the result of the cultural values prevalent in this community, which have been catalysed by the technical advice of a culturally-sensitive medical doctor (the hospital director) aware of TB as a public health issue.

## **5. Discussion**

The review of these five projects can only give the reader a flavor of the strengths and weaknesses of community-based TB care in Latin America, given the selected nature of the review and the dearth of research in the topic. A more systematic study that includes experiences in other countries of the region can help to improve the insight that this report can give on the role and potential of community-based TB care in Latin America.

Bolivia and Colombia are two countries with important differences in their health care systems, in the incidence of pulmonary TB, and in the proportion of people living in poverty. Colombia has a much better public health infrastructure, a very active ongoing process of health sector reform, fewer people living in poverty and one fifth of the TB incidence of Bolivia. However, the community-based TB care is similar in both

countries in some respects: the projects are nested in a parent organization (NGO or a legally established organization); community members help the NTP in case finding or case holding or in both; and the projects are socially accepted by the community and the health care workers. The projects report a significant contribution to facilitating adherence to treatment in those patients that have received the community-based care. Unfortunately, however, the lack of good quality records prevents the NGOs and the NTP from carrying out a formal evaluation of the effectiveness of the care delivered.

One important difference is the emphasis of the Colombian projects, unlike the Bolivians, on the provision of social support to the patients instead of direct delivery of health care services such as case finding and provision of DOT. This could be explained by the strength of the public health infrastructure of the Colombian health care system, which is less dependent on the community for delivering of health care, and by the culturally-determined foundations of the projects located in Barranquilla and Toribio. In Barranquilla, the care is being promoted and given by women reacting to the suffering they observe in TB patients. Whilst in Toribio, the community solidarity (one of the principles essential to the social fabric of the indigenous community), and the holistic view of life seem to inspire the integration of the economic production with TB control and the sharing of this production with those most in need.

The origin of the projects is quite diverse. There are “bottom-up” projects, such as those based in Barranquilla, Toribio and Oruro, in which members of the community lead the initiative in caring for the TB patients. There are also “top-down” projects such as those nested in a local NGO (as in Montero), or linked to an academic initiative (as in Popayan). Arguably, the “bottom-up” projects seem more likely to be sustainable in the mid-term than the “top-down”. The sustainability of the former, unlike the latter, is not dependent on the availability of economic resources because the main motivator of the volunteers participating in the project is, sympathy to, and concern regarding, the situation of the people with TB. Meanwhile, the “top-down” projects are contingent on the political decisions taken by the parent organization of the "community-based project", that might be or might not be interested in keeping TB control as a priority on its agenda.

Within the five projects visited, only the project of Toribio shows evidence of a mutual accountability between community and local government (responsible for the NTP activities). Indeed, the main contribution of the community, in this case, is the exerting of political influence on the local government to keep TB control high on the local public health agenda. It is necessary to take into account that this project was set up in the context of community-based political mobilization, in which health care and TB control was only one of the many frontlines. The absence of this relationship in the other projects visited may reflect the ‘health care providing’ nature of the NGOs promoting the community-based TB care, and the absence of political interests in the social groups involved.

The local NTPs have been ready to accept the community participation promoted either by the community itself or by NGOs, but have limited the role of the community to

“rowing” instead of “rowing” and “steering”. This is not surprising given that the training that the NTPs give to the volunteers is focused on the delivery of health care services, instead of including the education on the managerial and political aspects of TB control.

## **6. Conclusion**

Community-based TB care does not appear to make a substantial difference to the performance of the NTP, in terms of case finding and cure rate, in the sites visited. More rigorous record keeping would enable a better evaluation of the effectiveness of the current efforts. These community-based initiatives show great potential capacity to deliver TB care as part of NTP activities. NTPs could benefit more from these initiatives if they play a more proactive role by educating the community about the challenges facing TB control, both in technical and political terms.

## **7. References**

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## **Appendix I. Guide for semistructured interviews**

- What is the policy and strategy of the NTP?
- How is the DOTS strategy being implemented?
- On what grounds is the community-based TB care project justified?
- What is exactly the community doing in TB control? Costs? Quality?
- Who supervises the activities performed ? To whom do they report?
- Whose interests were taken into account in launching the project?
- Who is financing the project?
- How were the community-based TB care providers selected and trained?
- Do they receive any incentive? How much? For how long? Under what circumstances?
- What is the opinion of the community of the role played by the community-based TB care providers? Do they trust them? Under what circumstances does the patient reject providers?
- What is the nature of the relationship between the community and the local NTP, or the health care workers in charge of TB control activities?
- Is there any evaluation of the performance of the community-based TB care providers?
- Is there any measure of the contribution of the community-based TB care providers to the achievement of TB control targets (effectiveness in terms of usual TB programme indicators, i.e. case finding and treatment outcomes, and costs)?
- What factors favour and do not favour the sustainability of the community-based TB care components within the NTP?

## **Appendix II. Key informants interviewed**

### **Bolivia**

Mirtha del Granado, MD  
Chief officer, NTP Bolivia

#### *Montero*

Pilar Villarroel, Nurse  
Public Health Office  
Dardo Montaña, MD  
Director of Consejo de Salud Rural Andino

#### *Oruro*

Ricardo Torrico, MD  
Chief officer of TB control programme of Oruro  
Anastacio Choque Mamani, health volunteer, President of APROSAR

### **Colombia**

Jorge Victoria, MD  
TB officer, Ministry of Health.  
Celsa Sampson, MD  
PAHO official

#### *Barranquilla*

Magda Lucy Perez, MD  
Medical Officer, Public Health Office  
Doris Dominguez  
Volunteer, President of association “Maria Rafols”  
Elcira Kidd de Vera  
Volunteer, President of LAC - Atlantico

#### *Popayan*

Alfonso Tenorio, MD  
Professor, Department of Internal Medicine, School of Medicine, Universidad del Cauca  
Helena Quintero NS  
Public Health Office, Department of Cauca.

#### *Toribio*

Juan A. Orozco, MD  
Director Hospital “Alvaro Ulcué”  
Gabriel Paví  
Mayor of Toribío