The role of the community in the control of tuberculosis

Dermot Maher*

Stop TB Department, World Health Organization, CH 1211 Geneva 27, Switzerland

Summary Setting: High tuberculosis (TB) prevalence countries, where National TB programmes (NTPs) need to ensure widespread access to effective treatment. Objective: To review possible ways in which communities can contribute to TB control and to describe the project “Community TB Care in Africa”. Design: A review of the literature on community contribution to TB control and a progress report on the project “Community TB care in Africa”. Results: Eight district-based projects in six countries (Botswana, Kenya, Malawi, South Africa, Uganda, Zambia) participated in the overall “Community TB care in Africa” project. District TB programmes offering patients the choice of community or health facility treatment supervision generally performed effectively, with satisfactory rates of treatment success. Average health system and patient and family costs were lower in comparison with controls. Conclusion: Investigators formulated policy recommendations. NTPs should: (1) extend TB care to the community to improve access; (2) identify suitable community TB treatment supporters in consultation with the community; (3) ensure that effective systems extend into the community for recording and reporting, and for supply of anti-TB drugs; (4) monitor community contribution to TB care using standard indicators; (5) develop costed plans for expansion of the community approach. Ministries of Health should: (1) ensure adequate financing; (2) coordinate the efforts of NTPs, donors and NGOs to ensure sustainability; (3) consider opportunities for collaboration between NTPs and HIV/AIDS programmes.

Introduction

Although National Tuberculosis Programmes (NTPs) in most countries have often concentrated on promoting access to effective TB care through government health facilities, many NTPs are now increasingly promoting access to effective TB care through other health service providers, including the community. The need to promote community contribution to TB care as part of NTP activities is particularly urgent in sub-Saharan Africa, where human immunodeficiency virus (HIV) is fuelling the TB epidemic, and increasing TB cases are out-stripping the ability of government health service providers to cope. With reliance often on government health service providers, very few NTPs in high HIV prevalence countries are achieving adequate TB case-detection and treatment outcomes.¹

On account of the sparse published experience of community contribution to TB care in countries badly affected by TB/HIV, in 1996 WHO initiated the coordination of the “Community TB Care in Africa” project. Investigators from this project met in Zimbabwe in 2000 to share results and to recommend policy guidelines. The main focus of WHO’s efforts in evaluating and promoting community contribution to TB care has been in sub-Saharan Africa, the region most badly affected by HIV. However, the project results and policy
recommendations are likely also to be relevant to TB care in other regions.

This paper reviews the published experience of the ways in which communities can potentially contribute to TB care and of the results of schemes of community contribution to TB care, and provides a progress report on the "Community TB Care in Africa" project coordinated by WHO.

Review of ways in which communities can potentially contribute to TB care

The public health approach to TB control rests on detection of the infectious cases and their cure. The ways in which communities can potentially contribute to TB control as part of NTP activities are therefore activities which help to improve case detection and successful treatment outcomes. The following section reviews the main ways in which communities can potentially contribute to TB care:

- Direct observation of treatment, support and motivation of patients, general support, case detection, increasing community awareness, access to drugs.

The initial emphasis is on improving treatment outcomes rather than intensifying case-finding. It is important to expand case-finding only in settings achieving a high cure rate, otherwise expanded case-finding with a low cure rate results in increased numbers of inadequately treated TB patients (contributing to an increased pool of infectious cases) and increased drug-resistance. In settings achieving high rates of treatment success, it will be valuable to explore how community contribution to TB care can also extend to help identify TB suspects in order to intensify case-finding.

Direct observation of treatment (DOT)

One element of the WHO-recommended TB control strategy DOTS is the provision of short-course chemotherapy under proper case management conditions. These include direct observation of treatment for all smear-positive pulmonary TB patients. Direct observation of treatment is one of a range of measures recommended by WHO to promote adherence to treatment and successful treatment outcome. In many areas patients are admitted to hospital for the first 2 months of treatment or travel daily or three times weekly to a health centre for DOT. This can result in considerable social costs to the patient, an economic burden on the family, and may discourage adherence. Organized community groups, peer groups, chosen members of the community, and family members all have the potential to act as supervisors to ensure completion of treatment and hence cure.

Support and motivation of patients

TB treatment is long, symptoms typically disappear well before treatment is complete, and the drugs used may cause side-effects. Community members are well placed to help support and motivate patients during treatment. This may be done by raising awareness of the benefits of completing treatment, providing general support, and directly observing patients taking their medication.

General support

In leprosy control and AIDS care programmes, home visits by community members and self-help groups are two strategies used to support patients treated in the community. Sharing fears, beliefs and experiences with others with the same disease may be beneficial. Family support is also clearly critical. Support for patients to promote adherence to treatment should be built into all TB control programmes. In addition to enlisting family support, community members can be approached to volunteer as house-to-house supporters for TB patients, and the patients themselves encouraged to establish self-help groups.

Case detection

Not all people with TB come forward for treatment. Case finding in the community may help NTPs that already achieve high cure rates to make progress towards the WHO target of 70% case detection. Community-based surveillance has been shown to be sustainable in some settings, as community health workers (CHWs) know their local community well. CHWs may be involved by referring TB suspects for diagnosis, delivering sputum specimens to health care facilities and collecting results. It is important to clearly define the role of the CHWs in each setting, and diagnosis and prescription of treatment must remain the responsibility of the health professional.

Increasing community awareness

Many health programmes have used informal and formal ways of raising awareness. Leprosy control
Programmes have shown that schoolteachers and students can provide health education and motivate patients to continue treatment. School children have successfully encouraged families to practice hand washing and use latrines. More formally, CHWs were more suitable than physicians as educators to increase compliance in guinea worm eradication programmes. Lessons from sanitation programmes indicate the importance of the content of the messages with a focus on individual benefits rather than ideal behaviours or community benefits.

The common symptoms of TB are non-specific and TB is also often perceived as a chronic, incurable disease. TB programmes could use a variety of community members to help spread messages to TB patients to raise awareness of the benefits of completing treatment. Messages via the mass media can complement those given by community members. Messages could encourage patients to complete treatment in order to restore full participation in society and prevent relapse or drug resistance. TB control programmes could take advantage of existing community resources to enhance community knowledge of TB. Community members already directly involved with TB patients could collaborate with health workers to provide patients with accurate information regarding length of treatment and known side-effects. Various community members, including village leaders, schoolteachers, CHWs, religious leaders, trade unions and women’s organizations, have the potential if mobilized to successfully raise awareness of the signs and symptoms of TB and the availability and benefits of its treatment. However, awareness campaigns will only have a positive impact if diagnosis is available and treatment is readily accessible.

Access to drugs

TB treatment and control requires an uninterrupted drug supply. Distribution of drugs is an acceptable, effective and sustainable function for a CHW, and it may empower the community by providing access to treatment, enhancing the status of the CHW, and addressing the true needs of communities. Interestingly, communities may attach a higher value to CHWs that provide drugs than to those that focus on preventive and promotive care only. Thus involving the CHWs in TB drug distribution may enhance their status and hence the impact of other programmes. Practical lessons that have been learnt from community-based drug distribution programmes include:

- Programmes are dependent on good drug supply at central stores down to district and health centre level.
- Communication between drug distributors and stores is essential.
- Programmes planned by the community are more likely to be sustainable than those planned by health professionals.
- The higher the level of participation the greater the success of the programme.
- Home visits for drug delivery, while apparently very convenient, are not always welcomed by patients with stigmatized diseases (including TB).
- Community members are able to evaluate the appropriateness of house-to-house versus central distribution and change their strategy accordingly.

Review of published studies describing schemes of community contribution to TB care

Table 1 shows a summary of important features of published studies describing schemes of community contribution to TB care. On account of the low priority often given to research on NTP service delivery, there may have been under-reporting of community tuberculosis care projects. Published reports show good results with community contribution to tuberculosis care in various cultural settings. There may, however, be considerable publication bias, with under-publication of reports of projects failing to show successful community contribution. A limitation of many of the published reports is that they refer to pilot projects with relatively small numbers of patients. The challenge remains of showing the more widespread applicability of the community approach to tuberculosis care, maintaining good results with much wider population coverage.

The “Community TB Care in Africa” project

This section summarizes progress in the “Community TB Care in Africa” project coordinated by WHO in collaboration with the following agencies: United States Centers for Disease Control (CDC), the United States Agency for International Development (USAID), the International Union Against Tuberculosis and Lung Disease (IUATLD), the Royal Netherlands TB Association (KNCV), and the United Nations Joint Programme on HIV/AIDS (UNAIDS).
<table>
<thead>
<tr>
<th>Year of publication of study</th>
<th>Country</th>
<th>Location</th>
<th>Setting</th>
<th>No. of patients evaluated</th>
<th>Form of TB</th>
<th>Treatment supervisor</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>1978a</td>
<td>Philippines</td>
<td>Two rural slums One urban slum</td>
<td>Rural Urban</td>
<td>175</td>
<td>Sm+ PTB New and re-treated</td>
<td>Lay volunteers</td>
<td>90% cure</td>
</tr>
<tr>
<td>1990b</td>
<td>Philippines</td>
<td>Manila</td>
<td>Urban</td>
<td>144</td>
<td>Sm + PTB</td>
<td>Church group volunteers</td>
<td>80% success rate</td>
</tr>
<tr>
<td>1997c</td>
<td>Bangladesh</td>
<td>17 thanas</td>
<td>Rural</td>
<td>1525</td>
<td>New sm + PTB</td>
<td>Members of rural advancement committee with financial incentive</td>
<td>Cure rate &gt; 85%</td>
</tr>
<tr>
<td>1997d</td>
<td>Haiti</td>
<td>Artibonite Valley</td>
<td>Rural</td>
<td>138</td>
<td>New sm + PTB</td>
<td>Lay persons and former patients. Financial incentive</td>
<td>87% success rate</td>
</tr>
<tr>
<td>1996e</td>
<td>South Africa</td>
<td>West Cape</td>
<td>Rural</td>
<td>105</td>
<td>All forms</td>
<td>Farm workers and volunteers</td>
<td>High rates of adherence to treatment (no results of treatment outcome given)</td>
</tr>
<tr>
<td>1997f</td>
<td>South Africa</td>
<td>KwaZulu Natal</td>
<td>Rural</td>
<td>535</td>
<td>All forms</td>
<td>Community health workers, lay people volunteers</td>
<td>&gt;85% success rate in survivors</td>
</tr>
<tr>
<td>1997g</td>
<td>Nepal</td>
<td>Four national demonstration centres</td>
<td>Rural</td>
<td>270 new sm+ cases 310 other forms</td>
<td>All forms</td>
<td>Community workers, social workers</td>
<td>&gt;85% cure rate</td>
</tr>
<tr>
<td>1997h</td>
<td>Indonesia</td>
<td>North and Central provinces of Sulawesi</td>
<td>Rural</td>
<td>1797</td>
<td>New sm+ PTB</td>
<td>Health care workers (50-60%) Women organization volunteers (50-60%)</td>
<td>88% cure rate</td>
</tr>
<tr>
<td>1996i</td>
<td>China</td>
<td>12 provinces Rural and urban</td>
<td>Rural and urban</td>
<td>55,213 new sm+ cases 57,629 previously treated sm+ cases</td>
<td>New and previously treated sm+ PTB</td>
<td>Village doctor</td>
<td>90% cure rate among new sm+ PTB cases and 81% cure rate among previously treated sm+ PTB cases</td>
</tr>
</tbody>
</table>

Table 1 was originally published in the following paper and is reproduced with kind permission of the Int J Tuberculosis Lung Dis, Maher D, Van Gorkom J, Gondrie P, Raviglione M. Community contribution to tuberculosis care in countries with high tuberculosis prevalence: past, present and future. *Int J Tuberculosis Lung Dis* 1999;3(9):762–768. Summary of important features of published studies describing schemes of community contribution to tuberculosis care.


Olle-Goig JE, Alvarez J. Control of tuberculosis in a district of Haiti: directly observed vs non-observed therapy. *Int J Tuberculosis and Lung Dis*. 1997;1:68.


The HIV-fuelled TB epidemic is outstripping the ability of health services to cope with a very large increase in the number of cases of TB in many countries in sub-Saharan Africa. Since NTPs are often not achieving adequate case-detection and treatment outcomes, it is necessary to explore ways of complementing government health service provision of TB care.

A WHO-coordinated mission in 1995 assessed TB care in community-based organizations in several countries and recommended operational research to evaluate the potential of community organizations to contribute to the delivery of effective TB care, as part of NTP activities. Since 1996, WHO has coordinated a project evaluating the community contribution, through NTPs, to effective TB control in sub-Saharan Africa. The project has involved eight district-based projects in six countries badly affected by TB/HIV (Botswana, Kenya, Malawi, South Africa, Uganda and Zambia). The main focus of the project was the community contribution to effective TB care by supporting TB patients throughout treatment until cure, including directly observing the initial phase of treatment. The aim of the project was to demonstrate that decentralizing the provision of TB care beyond health facilities and into the community can contribute to effective NTP performance. The project outcomes are effectiveness, acceptability, affordability, and cost-effectiveness of TB care.

The project resulted from an assessment in 1995 in four countries in sub-Saharan Africa of the quality of TB care in several community and home care programmes, most of which had a focus on HIV/AIDS care. The assessment showed that the quality of TB care was generally low on account of the lack of links between the community and home care programmes, the district general health services and the NTP, but that nevertheless these programmes had the potential to contribute effectively to TB care, provided these links were developed. The project to evaluate community contribution to TB care as part of NTP activities began in 1996 with mobilization of funding, identification of project sites and investigators, and development, review and approval of project proposals. After preparation and training, district-based projects began implementation of community TB care interventions in early 1998. Project investigators (PIs) of the eight projects presented their results at a “lessons learned” workshop in 2000.

In all projects the intervention was the introduction of trained and supervised or supported community members (community TB treatment supporters) in supporting TB patients and directly observing their treatment. TB patients thus had the option of community Directly Observed Treatment (DOT), in addition to health facility DOT (as an in-patient or out-patient). The initial emphasis in the projects was on improving treatment outcomes rather than intensifying case-finding.

Implementing the option of community DOT involved addressing the following issues:

- How to identify and mobilize the appropriate community organization.
- How to develop links between general health services, NTP and the community organization.
- How to train and supervise or support community members.
- How to develop and introduce recording and reporting systems in the community.
- How to distribute anti-TB drugs and prevent potential abuse (particularly of rifampicin).
- How NTPs can face the challenge of extending their current management responsibilities when harnessing community contribution to TB care.

Results

Projects achieved satisfactory rates of treatment success, taking into consideration the high case fatality in new sputum smear-positive pulmonary TB cases of up to 20% recorded in high HIV prevalence populations. The pilot sites involving community contribution to care were generally lower cost, less hospital dependent, and more cost-effective than the controls which relied on the traditional approach of hospitalization of patients during the initial phase of treatment.

Policy recommendations

Project Investigators (PIs) from the “Community TB Care in Africa” project met in Zimbabwe in 2000 to share results, consider lessons learned and formulated the following policy recommendations:

NTPs should:

1. extend TB care to the community where health services are providing the basic elements of TB control, but failing to ensure adequate access;
2. identify suitable community TB treatment supporters in consultation with the community and ensure their effectiveness by:
   a. training and supervision,
   b. establishing effective referral links with general health service and NTP staff,
   c. preventing "drop-out";
(3) ensure effective systems extended into the community for recording and reporting, and for supply of anti-TB drugs;
(4) monitor community contribution to TB care using the standard NTP performance indicators, information on the numbers of patients choosing different DOT options, and quality of care indicators;
(5) develop costed plans for expansion of the community approach, including clear criteria for choosing the districts targeted for expansion.

Ministries of Health should:
(1) ensure adequate financing, on account of the new costs involved in harnessing community contribution to TB care;
(2) coordinate the efforts of NTPs, donors and NGOs to ensure sustainability;
(3) consider opportunities for collaboration between NTPs and HIV/AIDS programmes, including community provision of integrated HIV/AIDS and TB care.

Conclusion

Review of the published literature and the results of the "Community TB Care in Africa" project confirm the value of the community-based TB care approach, mainly in improving successful treatment outcomes. WHO is mobilizing technical and financial support to enable NTPs to mainstream community contribution to TB care as part of routine NTP activities. Where NTPs have high rates of treatment success, it is useful to promote community involvement in improving case-finding.

References