

ROLE OF NON-GOVERNMENTAL ORGANISATIONS IN TUBERCULOSIS CONTROL*

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Summary. Our experience over the last 18 months has given us hope that NGOs have great potential as an effective task force in augmenting the efforts of the government in tuberculosis control activities. They have been successful in identifying and referring chest symptomatics to us. In the near future, we hope to test out strategies for utilising their services in case-holding and supervised administration of chemotherapy.

INTRODUCTION

It was only about three years ago that WHO made a categorical statement that tuberculosis will never be brought under control by the efforts of the government alone.

The National Tuberculosis Control Programme is based on sound epidemiological and practical considerations. It is disheartening that this programme has not had the desired effect and tuberculosis today is alive and causing more deaths worldwide in adults than all other infectious diseases combined.

The Tuberculosis Research Centre has made many landmark contributions in tuberculosis research, especially in the introduction of short course chemotherapy for domiciliary treatment in the District TB Programme. We took great pride then that treatment of tuberculosis was made easier and brought within the reach of the common man. However, all these developments have not had the desired effect on the control of the disease and only 50% of patients started on treatment complete the full course of treatment under the programme.

Where have we gone wrong?

Go in search of people,
Begin with what they know,
Build on what they have.

No people-oriented strategy is worth its name unless the people understand the reasons for it and have a say in how it is applied. The responsibility of

the leaders at all levels of the health infrastructure is to place confidence in ordinary people and to entrust to them the cause of health

The non-governmental organisations (NGOs) have the reputation of working closely with the community. They have been effective in reaching out to people and have been successful in the implementation of various welfare schemes. The Tuberculosis Research Centre, therefore, has, in collaboration with the Tamil Nadu Slum Clearance Board entered into an arrangement of working with the NGOs to find out how they could get involved in the tuberculosis control programme. It was most encouraging when the NGOs felt the need to join us in our fight against tuberculosis, and after a series of meetings with representatives of NGOs, certain thrust areas were identified.

Strategy

The identified thrust areas have been classified from three phases;

Phase I - Case-Finding.

For case-finding, the strategy adopted has been:

- * Introduction of training programmes for animators and grass roots level workers of NGOs in order to
 - (a) equip them with skills necessary to identify chest symptomatics,
 - (b) create tuberculosis awareness in the community and
 - (c) organise health camps to screen chest symptomatics.

Phase II - Case-Holding

The strategy for case-holding will be.

- * To study the feasibility of using NGOs in defaulter retrieval for which a protocol is being

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developed and a pilot study is being planned.

Phase III - Chemotherapy

The Revised National Tuberculosis Programme envisages Directly Observed Therapy (DOT) as the cornerstone of tuberculosis control in the future. We plan to study the feasibility of using NGOs for drug delivery and DOT.

Against this background, a training programme on tuberculosis for animators and grass roots level workers of various NGOs was initiated.

Content of Training

Our training programme was based on a training module developed by the Social Work Section of the Tuberculosis Research Centre. The module outlines the objectives of the training programme, clinical aspects of tuberculosis, explained in simple terms by a medical doctor and the sociological aspects of tuberculosis highlighted with the help of role play. We found the role play to be a very effective means of communicating the social problems associated with a disease like tuberculosis. The role play is enacted by a team of social workers. The scenario is that of a woman with tuberculosis and the impact it has on herself, her husband and her family. It brings out the fears and stigma attached to the disease, the problem of non-compliance with treatment and the role of a health worker in motivation and follow-up of the patient in completing treatment successfully. After this, there is an Open House discussion where the participants are given sufficient time for questions, presenting their view points and for making suggestions on how they could get involved in the control programme, in their particular areas of work. Before the start of the programme, the participants are asked to fill in an awareness questionnaire on tuberculosis to give us an idea of their level of awareness. And at the end of the programme they are given a "form" to evaluate the training programme and for making suggestions.

So far, we have conducted 18 training programmes for 517 participants. The participants were programme officers, community development organisers, teachers, AIDS educators, multi purpose workers and animators.

Community Awareness Campaigns

Simultaneously, we also launched Community Awareness Campaigns, where different groups such as women, street children, school teachers, youth and domestic maids, etc. were targeted. Through these campaigns 973 people were reached.

FOLLOW - UP

We contacted the NGOs which had received training to find out the effect of our programme. Below is highlighted some of the work done by them :

Guild Plan International

This is an integrated community development project targeting 10,000 families, each family comprising 4 to 6 members. We had initially trained their Programme Development Officers of seven clusters. These clusters are made up of neighbourhoods (the word slum is no longer used). Subsequent to our training programme, the Guild Plan International requested us to extend our training to all the clusters for the grass roots level workers.

After we completed the training programme, these animators carried the message of tuberculosis through various awareness campaigns to different target groups in the community. What is encouraging is that they used their own innovative communication skills for this purpose. One such technique was a "Villu Paattu" (Song-Drama) sequence with the help of school children in the age group of 7 to 14 years. The script was written by the animators and the social implication of tuberculosis was illustrated very effectively. These children not only helped in creating awareness of tuberculosis in schools but also in their community.

The Guild Plan International also organised two health camps at two strategic points in Chennai. A team from TRC comprising doctors, social workers, nurses and a statistician conducted the camp. About 500 people including children were screened on each day of the camp. Sputum was collected for testing from those with symptoms suggestive of tuberculosis and these patients were referred to TRC for further investigations.

Asha Nivas

It is an NGO that concentrates on the marginalised and exploited women and children in 110 areas of Chennai covering a population of 65,000 people, ie around 130 families. The animators and teachers of this organisation underwent training and subsequently arranged awareness programmes in the areas under their coverage. In each area, they covered about 20-30 women and about 40 young people who they felt were an important target group, through whom information on tuberculosis could be disseminated into the community.

Shankara Institute of Community Health

This NGO's sphere of activity covers seven villages on the outskirts of Chennai. Their health projects have mainly been in the areas of nutrition and maternal and child welfare. A training programme was held for the Multi-purpose Health Assistants who had some degree of awareness of tuberculosis but had only realised the seriousness of the problem after our training. Their first step was to create awareness of tuberculosis in their different villages. With this in mind, they assembled the people of the community late in the evening, a convenient time for both men and women. Using a videoplayer they screened a popular feature film to capture the attention of the people. This was followed by a film depicting a puppet show on tuberculosis

The multi-purpose workers also organised four women's groups comprising about twenty women in each group. They conducted awareness programmes on various topics of interest, viz. nutrition demonstrations, income generating schemes, immunization etc. and then talked about the various aspects of tuberculosis. They felt that the women, as a target group, were very effective as they had good influence in the community.

Another interesting feature launched by this team was a 'combing up' operation in the village. In order to do this, they had to first conduct a door-to-door survey in seven villages with a combined population of 4500 people. Six multi-purpose workers conducted the survey. They went to each household to get information. They were able to detect 67 cases of tuberculosis, both old and new.

All these cases were on irregular treatment.

The multi purpose workers then contacted the nearest health facility and arranged for a medical team, comprising a doctor and a laboratory assistant, to visit the village. The symptomatics were asked to assemble in two strategic places convenient to the seven villages. It was encouraging that all the 67 patients turned up for sputum examination. Twenty of them were negative and the doctor felt that there was no need for further investigation. Forty seven continued to have symptoms and they were referred to the nearest facility for further investigations.

It is gratifying to note that the activities of the Shankara Institute have been sustained and they have kept upto date. Their health workers have kept track of the patients they have identified and are monitoring their treatment. On the 27th of October, this NGO organised a health camp to screen chest symptomatics that they had identified from seven villages covering a population of 16,000. A total of 230 symptomatics were screened and were investigated with X-ray and sputum examinations. Of the 30 sputum examinations done on the spot, one was positive. It was heartening to note that the District Tuberculosis Officer was good enough to attend the camp and the sputum positive patient was started on treatment right away. She also volunteered to make the requisite drugs available to the health workers of this NGO so that they could supervise the treatment for this patient and for others that might be identified in the future.

To quote Dr. S.P. Pamra in his article 'The Role of Voluntary Organisations in Tuberculosis Control', "while it is the Government's responsibility to provide the facilities. it should be the responsibility of the voluntary organisations to ensure full and proper utilisation of these facilities and to involve the community in general in the control programme" The Shankara Institute has taken the first step in this direction with the help of the DTO, and we hope that their efforts will be sustained. It should be brought out that all the NGOs which have undergone training have been sending chest symptomatics from their areas to the TRC. So far, 123 chest symptomatics have been sent, of which 14 tested positive for tuberculosis. One of them is a child - ten years old - who was diagnosed as having brain tuberculosis.