ISSN 0377-4910

ICMR BULLETIN

Vol.33, No.3 March, 2003

PEOPLE WITH TB: 'DOTS CURED ME, IT WILL CURE YOU TOO'

"Tuberculosis for which effective interventions exist remains an orphan and the world should be ashamed" — Kevin De Cock[1]

Directly Observed Treatment-Short course (DOTS) has been declared as the global strategy for tuberculosis (TB) control by the World Health Organization (WHO) since 1991. This strategy has shown to reverse the TB epidemic in many countries. Principles of the DOTS strategy have had many contributions from research carried out in India[2-7].

Scientific studies carried out on the treatment of TB in india[2] had shown the necessity and feasibility of giving drugs under supervision as also efficacy and safety of domiciliary treatment[7]. The evidences based largely on the effectiveness of DOTS in industrialized countries are indicative of the fact that DOTS would reverse the alarming trend in TB incidence throughout the world. It is thus evident that TB is amenable to management and cure when appropriate resources are provided.

The theme of the WHO for the World Tuberculosis Day (March 24) 2003 centers around 'people with TB' and the slogan 'DOTS cured me, it will cure you too' has been adopted to project the cured patient as a living proof that TB is curable. A programme manager from a district where DOTS has been successfully implemented has aptly said, " A cured tuberculosis patient is the best pamphlet " for advocacy of DOTS strategy for TB control.

The Revised National Tuberculosis Control Programme (RNTCP) in India is one of the largest programmes in the world and more than 800,000 TB patients have been treated under this programme with a success rate of more than 80%[8]. The DOT Providers (DPs) are primarily responsible for the success of the programme at the field level by giving a VIP status to the patient in the programme. This write-up is a reflection as to how patients and the DOT providers perceive their role in the DOTS programme.

Success of the RNTCP depends on the successful interaction between patients and the DOT providers. Because of the stigma attached to the disease it has become increasingly important to have a provider preferred by the patient. The RNTCP provides an opportunity for this through the decentralized approach at the governmental health system and even at the

Division of Publication & Information, ICMR, New Delhi - 110029

This issue commemorates the World Tuberculosis Day (March 24, 2003)

community level. For a large proportion of patients, the private sector is the first point of contact and the programme is making efforts to involve the private sector through a public-private mix. In Chennai city, a non-government organizatiqn (NGO) 'Advocacy for Control of Tuberculosis' is involved with the idea of inducting an array of community DPs on a one to one basis. The NGO has utilized the services of a variety of DPs from organized and unorganized sectors, ranging from housewives to other responsible members of the community, or other NGOs for the treatment of TB patients.

Scientists of the Tuberculosis Research Centre (TRC), Chennai have interviewed some of the tuberculosis patients and DOT providers from the urban and rural community where patients are being treated with the DOTS strategy. Some of the success stories as narrated by patients and DOT providers are reproduced here:

Experience of a patient - A tailor by profession

In the year 2000, I had cough and fever of one month duration. I attended a PHC and was told that I have developed TB. The treatment was started but could not be continued beyond I month as I had severe giddiness and vomiting. I felt better after stopping the treatment. My parents also said that my diagnosis might have been wrong and did not see the need to continue treatment.

However my cough and fever reappeared after about 2 year. Now I consulted a private practitioner who took an X-ray and said that I had TB. I was again referred to the Government hospital where sputum was examined and it was confirmed that TB had recurred Doctor scolded me for not having completed the treatment on previous occasion itself

The treatment was started again. This time my employer accompanied me to the hospital. He agreed to give the medicines under his supervision. Again I started getting vomiting and giddiness and was not able to work. I continued the treatment and attended the hospital as per the instructions of the health worker and was ultimately cured and got rid of the medicines. I am very thankful to the health staff for having motivated me to take the complete treatment as a result of which I was cured. I wish I had taken the treatment regularly on the previous occasion itself

Experience of a 30 year old male patient

I was suffering from cough, fever and reduced appetite for the past 2 months. I was shattered when I was diagnosed to have TB. The Doctor and the health staff informed me about the disease and motivated and convinced me for regular treatment.

The treatment was provided at an ICDS Centre close to my house. I am thankful to the ICDS teacher and other staff for having cured me of 'TB by DOTS. Now I Know the symptoms of the disease and have sent some other villagers who were coughing to the PHC where I had treatment. Three Patients of them were diagnosed as having TB and were started on treatment. I told them to be regular for treatment. All the above patients got cured of the disease. I am even willing to take the responsibility of giving medicines to other patients if an opportunity is given to me.

The above experiences by the patients point to the significance of DPs in the success of programme, and to the fact that the cured patients themselves are willing to help other patients. Drugs are essential for successful treatment of patients but still an important aspect that motivates the patient to complete the treatment is the human bond developed between patients and provider during the treatment period due to their frequent interactions.

Having seen the satisfactory experiences of the cured patients it is necessary to examine the perspective of the DOT Providers from various strata of the community.

Experience of a community DOT provider

In a rural area, a caretaker of a cycle stand near a railway station was providing DOTfor about 7 patients.

Since those patients had to pass by my shop they found it convenient to collect the drugs from me.

I feel so proud to be of use of these patients and was happy to see them improving. At the moment I am not having any patient to give medicines but I am eagerly waiting to continue to be a DOT provider.

Experiences of DOTS Provider – An ICDS teacher

I am an ICDS teacher, but also trained as Village Health Nurse (VHN). I never managed a TB patient before DOTS programme was started. After the training in RNTCP, I was eager to help the patients. I have managed 5 patients so far. All of them took medicines as DOT and 4 patients were cured. One patient defaulted and could not complete the treatment.

I am very much convinced about the success of DOTS for curing the patients. I am so happy that I could prevent the spread of disease in the community by curing 4 patients. These patients, if left untreated could have infected other 10-15 persons each. I am willing to treat more patients. I got full cooperation from my husband and some times even he acted as a DOT Provider in my absence.

These examples give an idea of the successful participation of the community in the TB control programme that has helped the patients for successfully completing their treatment. The attitude of the provider helps the patient to complete treatment and get cured. Many of the cured patients have expressed their willingness and happiness to give medicines for other patients in their area to help them also get cured.

Why Should We Need DOTS?

It is clear from the above illustrations that despite all the criticism and antagonism DOTS have come to stay in the control of tuberculosis.

The key to achieve a high cure rate among TB patients is regular and complete treatment in a specified time period. TB being a chronic disease and requiring long duration of treatment, it has always been a challenge to ensure adherence to treatment.

Adherence to treatment in most diseases requiring long-term treatment is inversely proportional to the length of treatment[9]. This holds true in TB management also especially where patients are supplied with drugs for self-administration. When a patient with pulmonary TB feels better there is no compelling reason to continue to take medicines[2].

According to Annik Rouillon former Executive Director of the International Union Against Tuberculosis and Lung Diseases (IUATLD) –todefault is the natural reaction of normal, sensible people: a person who continues to swallow drugs or have injections with complete regularity in the absence of encouragement and help from others is the abnormal one[10].

As one cannot predict which patients are likely to be regular for treatment it becomes mandatory to give each and every patient, drugs under direct observation. Controlled clinical trials at TRC, Chennai have demonstrated that >95 % cure can be achieved if drugs are administered under supervision and thus DOT has been a major contribution to the DOTS strategy followed world-wide.

Epidemiological evidences suggest that decrease in cases results from an interruption in the spread of infection because of better rates of completion of treatment and expanded use of DOT[11].

This strategy is very patient friendly as the treatment is brought as close to the patient as possible. Treatment is made convenient to the patient with regard to timing of attendance, distance to be travelled, and choice of DOT provider. The flexibility to choose the DOT provider makes the patient feel more comfortable as far as the stigma is concerned. In the RNTCP there is decentralization of the treatment services from district to sub district level and patient can avail the treatment even at the community. Another positive aspect of DOTS is its cost effectiveness[12,13].

Who Could be a DOT Provider?

Generally it is believed that giving the drugs to patients is the responsibility of pharmacist or the nursing staff. The concept of decentralization is entrusting the responsibility of giving medicines to any individual with sympathy, care, helping tendency and make the patient feel secure.

In the RNTCP onus of cure is on the health system. A good DOTS provider ensures a good programme. There is great flexibility in the revised programme of giving the patients the right to choose a provider convenient to him. Anyone who is acceptable and accessible to the

patient, and accountable to the health system could be the DOTS Provider. These factors help to bring the treatment closer to the patient so that he is able to complete the treatment. More than qualification, it is the attitude of the provider towards the patient that matters.

A person will qualify to become a DP if he/she is able to undertake the following activities.

- Give drugs to the patients under direct observation.
- Mark the attendance in the treatment card.
- Visit patient and motivate him/her to come back for treatment after default.
- Remind the patient for timely sputum examination.

These activities do not require any high academic qualifications. Once the providers have been selected they should be given on-the-spot training regarding duties of a DP as mentioned earlier.

Who is a Successful DP?

A DP is successful if the patient completes the treatment in the prescribed period. This requires a DP to be vigilant and committed. The highest challenge lies in motivating the patient to continue treatment once the sense of well-being creeps in after about a month or two of commencing the treatment. The DP should take immediate action if patient defaults for treatment or for follow up sputum examination, and ensure treatment completion/cure.

Linking of DOTS Providers

Treatment under DOTS requires a system where each patient will be administered drugs under observation and for that we need a network of DOTS Providers. Regular and complete treatment is essential for cure of TB and prevention of both relapse and emergence of multi-drug resistant tuberculosis (MDR-TB). Direct observation ensures right drugs, with right dosage at right interval.

The government has identified multi-purpose workers (MPWs) as DPs. Because of the multiplicity of their responsibility there is a need to decentralize their responsibility as a DOT provider at the community level. Hence it becomes imperative to select DPs from the community to make the treatment convenient to the patients. Community DOT Providers (CDPs) are not under the direct control of the PHI. The government DPs (GDPs) are the crucial link between community and the health system. A foolproof link needs to be established between MPWs and CDPs for effective DOTS.

Once a CDP has been identified in consultation with the patient, he/she will be briefed about their role in the management of the patient. After the treatment box is handed over to CDP, it is still the responsibility of the MPW to visit the CDP at least once a week for supervision and updating of the original card kept at the PHC. Based on this information, the medical officer will take necessary action as and when required.

Although it is easy to widen the network of CDPs. it is very crucial to supervise their work. Good supervision is the essence of any successful programme.

Supervision helps to:

- Motivate the providers and maintain their initial enthusiasm.
- Check the correctness of documentation
- Clarify their doubts, if any.
- Provide on-the-spot training when needed.

The slogan "Dots cured me it will cure you too" will be a strong and useful signal emanating from a benefactor in the community. Cured patients could be used as a powerful tool to provide DOTS as they are the satisfied customers and their services might be better accepted by the patients as the stigma is likely to be less. In any marketing strategy celebrity endorsement policy is widely practiced. to promote the product. This has been found successful in the management of many public health problems. As in DOTS programme a patient is considered A VIP projecting them as celebrities who have enjoyed the benefits of DOTS will help to build confidence in the new patients as well as among the community.

One of the most successful marketing policies by marketing giants is the 'satisfied costumer approach'. A cured patient can be a good advocate and a good DOT provider as he has gone through the whole routine and he can share his experiences with new patients. He can be a good health educator to the patient. Stigma, long duration of treatment, etc. are major barriers in the treatment of TB from patients point of view. A successfully treated patient has experienced these barriers and conquered the stigma and inconvenience of daily visits.

Their involvement in the DOTS programme will give enormous confidence to new patients.

Despite all the advances in the treatment of TB and in-depth knowledge of genomics of the organism, we are far away from control of the disease. The renewed political commitment and other important strategies like diagnosis mainly by sputum microscopy, decentralization of treatment services, training and good documentation and most importantly, DOT, have started showing good results. It is the l0th anniversary of the DOTS strategy implementation and approximately 10 million patients have been successfully treated world-wide. Every cured patient will reduce the number of people getting infected every year, people dying of TB, an avoidable death. Jacob Kumaresan, former Executive Secretary of Stop TB Partnership has aptly said "By now we should be starting to turn the tide against TB. After all we have tools so let us finish the job".

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This write-up has been contributed by Dr. Aleyamma Thomas, Dy. Director (Sr. Grade), Tuberculosis Research Centre, Chennai.