

Back ground Paper IICASE HOLDING AND PATIENT COMPLIANCE & MOTIVATIONMARIE D'SOUZA

In India today we see a situation of extreme poverty of the masses and one of the highest rates of Tuberculosis in the world. For every 1000 population there are 16 persons with active tuberculosis lesions, 4 of whom are infectious. (sputum positive)

Yet it is said that success in treatment of Tuberculosis depends on quality and duration of chemotherapy.

It is also established that hospitalisation, rest and special diets are not needed in the majority of cases.

I will not consider here the fact that in developed countries the number of cases showed a decline when the standard of living improved. Nor will I dwell on the fact that the basic needs of food, water and health care are lacking for 80% of our population living in rural areas.

If success depends on quality and duration of chemotherapy then case-holding forms a very important part of TB control. 100% case-holding is however very difficult to attain.

The early sixties saw the evolution of the concept within the NTP of offering TB services as a part of comprehensive health care by the general services. This was done so that treatment centres could be nearer the houses of patients, who could take treatment without disrupting excessively their normal life. The belief that Tuberculosis is a problem of thickly populated cities and slums is a thing of the past. Pulmonary Tuberculosis is as prevalent in rural areas as in cities. And on the basis of distribution of population one can expect 2 to 3 cases in each village, with a higher rate in tribal areas.

CASE FINDING

Tuberculosis is classified as one of the biggest health problems among our vast ill-served rural population. So case-finding in the rural areas needs to be established and it is here too that CASE-HOLDING has to be given importance so that the best benefit can be drawn from the available resources of men, money and materials.

To-day every PHI is supposed to have a "microscoping centre" . . . though there is a query as to how efficient they are where established. Baily says that each PHI should diagnose nearly 2000 bacillary cases in a year. This can be achieved by examining the sputum of all new patients attending with symptoms of chronic cough.

If the real aim of case-finding is treatment, then that of case-holding is completion of treatment, while the aim of treatment is both relief of suffering as well as closure of sources of infection. The NTP stresses on the latter. It is the depth of suffering which makes people report to health centres (felt need) as well as influences the regularity with which treatment is subsequently taken (though this statement has been questioned).



Treatment efficiently administered and taken will relieve suffering and also have an epidemiological impact.

Efficient treatment requires free availability of drugs, suitable drug regimens, freedom from toxic reactions, regularity of drug intake and adequate duration of treatment. This implies health services easily accessible, daily, with health personnel who are capable and able to deal with patients with sympathy and consideration.

Unfortunately threefourth of patients who have a felt-need are being denied opportunities of getting their suffering alleviated due to faulty diagnosis. In many instances the sputum of patients with chronic cough is not examined. And of the patients who are diagnosed as having Tuberculosis 70% are lost during the entire course of treatment.

A moderately infectious Tuberculosis patient is capable of infecting 10 to 12 individuals within a periods of one year. This patient untreated has a survival time of 2 years (it is capable of infecting 24 individuals) Again, this patient treated irregularly has his life span prolonged and the number of people he infects keeps multiplying.

In terms of human suffering, the loss caused by TB is incalculable for the individual patient himself - physical, psychological, social, material and for his family too. Economically TB accounts for an estimated loss to the nation of Rs.1000 crores in man hours.

All this should make us realise the urgency of  
"Case - Holding"

#### NATIONAL TUBERCULOSIS PROGRAMME

A step in this direction was taken when the NTP brought treatment centres closer to patients homes. Further in order to ensure regular and adequate drug intake by patients for a period of atleast 12 months, a treatment organisation with limited supervision and machinery for defaulter retrieval has been provided. The main objective is detection of a maximum number of tuberculosis patients, specially sputum positive, and efficient treatment.

Here follows a synopsis of the programme

1. Every person reporting to the PHI with cough of more than 2 weeks duration is requested to give his sputum for examination. If sputum positive, treatment is started on the same day.

Every MPW is required to collect the sputum of eligible symptomatics (i.e. cough, fever or chest pain of more than 2 weeks or haemoptysis) prepare the smear and referral slip and hand it over to the PHI. The sputum positive cases are referred back to the MPW who is required to bring the patients to the PHI for check-up. The M.O. also communicated directly by post with sputum positive patients.



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2. The sputum negative patients who are suspects are sent to the nearest Government Health Institute with facilities for X-ray/ MMR/ Screening.
3. NTP has 5 drug regimens  $R_1$  to  $R_5$  for sputum positive patients. Those who are sputum negative are treated with  $R_1$ . Drugs are supplied free of cost.
4. At initiation of treatment the patient is motivated by the M.O. and health visitor in the clinic with emphasis on completion of treatment. Repeat motivation is done at each collection every month.
5. If the patient does not collect the drug within 2 days of the appointed date, a postal reminder is sent and if there is no response for 7 days, then home visits and fresh motivation about importance of regular treatment is given.
6. There is an effective "transfer" system which enables any patient to receive treatment from any peripheral centre convenient to him.
7. A new patient put on treatment becomes eligible for first follow-up exam and sputum exam at 6 months. X-Ray exam is optional. Second follow-up exam is due after 12 months when both X-Ray and sputum exam can be ordered.

#### Default:

The above is what the NTP requires. Whether these requirements are achieved is the big question. And achievements vary from state to state. From reports it appears that the NTP functions very poorly in the north of the country, a little better in the south.

It is not surprising that as a result there is a very high defaulter rate - 70% of patients diagnosed as having Tuberculosis.

Banerji defines 'defaulter' as one whose actions even after being provided "optimal" services go against his own welfare or against the welfare of the community or both.

In this sense there are very few patient defaulters because the major impediments to acceptance of NTP appear to be organisational, managerial and technical rather than behavioural factors or short comings in motivation of patients. Therefore there are more organisation defaulters.

This is proved by the many instances where recommendations laid down by NTP are not carried out.

Very often patients are not told the result of the sputum exam on the same day. A study has shown that 11% positive causes do not return to learn the result of their exam. ~~Why~~ should they? Since no indication or motivation is given and the drugs

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given for their cough have not been effective. After all patients are not worried about TB bacilli in sputum. They are worried about fever, cough, chest pain, anorexia, loss of weight, children starving, loss of sexual potency, etc. They expect to be cured quickly and so decide to go elsewhere for "better" treatment.

In fact it has been shown that 52% of infectious Tuberculosis patients seek medical help of their own accord and of these 90% are sent away with cough syrups and tonics.

It tells badly for the health professionals who are not properly trained/motivated. Add to this the fact that many of them resort to private practice or corruption. Why should any patient have confidence in them? The same can be said of para-medical personnel, inadequately motivated, trained and utilised, mal-functioning or lacking (eg. lab technician) Lack of proper supportive supervision, as opposed to inspection, adds to the problem.

Lack of communication on the part of organisational personnel leads to misunderstandings,. This is further heightened by rudeness and results in default., specially so among the poor who are the larger number and yet are pushed aside while preference is given to the middle class;:

Often a patients arrive at the PHI to find it closed - either the doctor is away for a meeting so the rest of the staff also take a holiday, public holidays are suddenly declared on the radio, a camp is organised and all the staff are involved / no one attending to the general health services, much less to Tuberculosis patients.

Drug regimens are prescribed but no health education or motivation is given in many instances. Patients are asked to return after a week or two because the drugs are exhausted. When they do return they find that the colour and form and even the number of the tablets has changed (eg. INH 100 mg 3 tabs. changed to INH 300 mg 1 tab) No explanation is given and literate as well as illiterate patients are not sure whether their drugs have been given correctly. They dare not question the health personnel and often consume the wrong dosage.

Not all the fault lies with the PHI. They are ~~influenced~~ influenced by decisions from above. Highest priority is given to Family Welfare Programs, with ample funds and monetary inducements to promoters etc. Though on the 20- Point Programme, low priority is given to TB.

Drug manufacturers have their part to play too in default. There is not much margin of profit in the production of first line drugs and only one third of the required quota is manufactured. While second line drugs, not included in the NTP, are available easily on the market. Add to this the wrong prescribing habits within the country by private practitioners systematically adding tonics and other fanciful tablets, as also free sale of TB drugs by chemists without prescription. How is a patient to judge whether 2 or 3 kinds of tablets given at the PHI are enough to cure him of his disease when his neighbour takes 5 or 6 kinds, wrapped in silver foil, prescribed by a private practitioner.



All the above adds up to organizational default. Is it surprising then that there is lack of patient complinace and motivation?

This leaves just a few instances of patient "default". Though, can he be said to "Default" when he is not provided with 'optimal' services?

Studies show that drop-outs are maximum within the first 3 months of treatment irrespective of the type of regimen the patient is on. However a large proportion of these drop-outs resort to subsequent treatment either immediately or after some time either at the same PHI or at other health institutions public or private. Studies also show that relief of symptoms, as commonly believed, was not a cause of default.

Distance of patients home from the treatment centre exerts a continuous process of selection. Patients living more than 5 Kms. from treatment centres take treatment irregularly. Add to this the monsoons when travel is difficult as bus services are stopped and even walking on mud roads requires an effort. Emigration in search of work is another cause of default.

Poverty has a large part to play. How is patient to pay for bus fare, corrupt practice, X-Rays etc. when he draws no income because of his inability to work.

#### CASE-HOLDING

Improvement in case-holding demands that technical and organisational methodology of case-holding will have to be improved, and methods of preventing default, specially organisational, must be intensified. For with proper organisation case-holding could increase by 40%.

Studies have shown that there is a positive interaction between good organisation, low default rate and effective treatment, each supporting the other. In 1983 the Government of India launched the new National Health Policy in co-ordination with the new 20-Point Programme of which Point 14 says "substantially augment universal primary health care facilities and control of Leprosy, TB and blindness".

Government funds need also to be provided (as in the NFPP) to "motivate" professional and para-medical health personnel. For example, CHVs and MPWs bringing sputum positive patients to PHIs could be "rewarded". While patients themselves who complete treatment could be given a gift.

Government has the money to spend on research and treatment of Ischaemic Heart Disease Cancer, Diabetes, Chronic Renal Failure, as also CHOGM, Asian Games etc. so why not on treatment of TB?

Health personnel, in general, definitely need better orientation, and up-dating as regards TB treatment. The para-medical workers also need



Patients support each other in taking treatment. So meetings could be held of patients in each village, where common problems could be discussed, misunderstandings cleared and difficulties solved where possible. They also help to remind each other of visits due to the PHI besides supporting each other in cases of corrupt practice by health personnel or getting their rightful demands met. This has been my experience in one village.

Studies need to be conducted to improve community participation in TB control.

One factor which promotes patient compliance and motivation is sputum examination done periodically. In one study where sputum exam was done on 3rd, 6th and 9th month after initiation of treatment, drug collection went up in the period immediately following it. A physical check-up with weight taking at every drug collection each month would also probably help. At present, in many instances the patient is just sent to the dispensing window-where he is merely told "Come again next month". Is this enough motivation?

In case of patients sent for X-Ray exam., proper instruction to reach the Health Institution, person to contact, fee to be paid, etc. should be clearly given. The Referral Centre should also make clear to the patient that he is being referred back to the referring centre, presumably more convenient, for treatment. In case of transfer to another PHI, more convenient for the patient, he should be similarly clearly informed of the person to contact at the transferred address.

#### OUR ROLE

What role can we of MFC and the Voluntary Health Sector play in Case-Holding? There are some that feel that the Government HI cannot handle the TB control program alone. NGOs and other have to pool in.

As long as NGOs are treating middle class and rich patients their pooling in will certainly help. They should follow the guide-lines laid down by the NTP ~~as~~ . . . . which are good as sputum positive patients are concerned. In the case of sputum negative patients it would be well to remember that X-Ray alone is not enough to confirm diagnosis of TB. Studies have shown that defaulters among these "cases" based on radiological findings is very high and that they need strong and more effective motivation. Also as many as 98% of sputum negative so called X-Ray positive cases continued to be sputum negative after 3 years.

The question arises when treating poor patients. Should they be refused treatment by NGOs? . . . . specially when they profess to be meant for the poor? Financially they would go under, I think, if they give free treatment to the poor. On the other hand the poor cannot afford the whole course of treatment and would soon become defaulters . . . . . with eventual increase in suffering. One solution could be a closer relationship with the NTP, which through the DTC Centre, is willing to supply free drugs on fulfillment of certain conditions.



Another solution is to make sure that poor patients really make use of the PHI services. They have a right to free treatment and we could help them get it. One way to do so that we, at Janseva, have found helpful is a slide show on TB which, besides emphasising completion of treatment also informs the community on the different steps TB suspects will have to go through for diagnosis eg. sputum exam., possible X-Ray, the form, filled in by the doctor, they will have to take to the referral centre, and bring back filled in, signed and stamped, and eventually, free treatment.

When some patients were asked a fee at collection of drugs - they refused to pay saying 'we are from Janseva' they were never posterred again.

The same slide show helped motivation . . . and yet we had patients defaulting in spite of home visits by us.

We should realise that even the most refined advertisemental techniques using deep motivation, subliminal perception, etc. have never claimed 100% success. Personally, I feel that we of MFC and others in the Voluntary Sector should bring pressure on the Government., so that sufficient funds are provided to carry out effectively the National tuberculosis Programme. This would mean an increase in work load 3 times the present, and hence increase in personnel, with proper training, etc.

Above all, pressure has to be brought on the Government to in turn pressurise the Drug Manufacturers into producing the necessary quota of first live drugs based on a realistic calculation of the number of patients to be treated.

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