PERCEPTIONS ABOUT THE FIGHT AGAINST TUBERCULOSIS

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A lot needs to be done to ascertain the perceptions of various groups about their respective roles in the fight against tuberculosis and to make attempts to dovetail these perceptions, so that all these groups feel committed to the programme. The fact that very little attention has been paid to study the perceptions of various groups, who ought to join in the fight against tuberculosis, confirms our top-down approach of thrusting programmes down, instead of taking the concerned people along.

I. SUMMARY

The fight against tuberculosis has to be a joint effort by the community, health providers and health planners. To effectively organise this in a systematic manner, an essential first step is to study the perceptions of each of these groups (and their sub groups) about their respective roles in the fight against tuberculosis. This paper highlights the serious lack of information about these perceptions, some gaps between perceptions of different groups and between perceptions and required action. As indirectly judged by the proportion of chest symptomatics for whom sputum examination has been ordered, none of the health providers (except sanatoria), seem to have the proper perception for a successful fight against tuberculosis. It is disheartening that the Primary Health Centres (PHCs) in a predominantly rural country, have an even more unhealthy perception than the unorganised private medical practitioners. While chest symptomatics perceive early diagnosis as important, the programme confines sputum examination to those with symptoms for more than two weeks. Available information shows that a large proportion of cases are cured after short treatment but the perception of the programme is that all cases would require uniform duration of treatment. The perception about development of resistance due to incomplete treatment does not seem to be correct, because there is no evidence of an increase in primary drug resistance. It is suggested that the present top down approach should be replaced by a managerial approach that takes the concerned groups along and develops a healthy alignment of all groups, which ought to be involved in the fight against tuberculosis.

II. INTRODUCTION

The fight against tuberculosis has to be a joint effort by the community, health providers and health planners. In the community, tuberculosis cases, chest symptomatics(CS) and various community leaders ought to play a part both individually and collectively. Health providers include the organised general health services and specific tuberculosis services (both government and non-government) and unorganised health clinics / practitioners using different systems of medicine. Health planners, in this context, consist of (1) those who plan and implement specific programmes for control of tuberculosis (Programme Directorate), (2) the supporting organisations (government and non-government) which provide data for planning and / or act as think tanks for programme formulation as well as evaluation and (3) the Ministry of Health and other organisations (mainly foreign) which provide funds for programme-oriented research as well as for formulation, implementation, and evaluation of the programme. To effectively organise systematic and collaborative efforts by all of them, an essential first step is to study the perceptions of each of these groups about their respective roles in the fight against tuberculosis. This has to be followed by all-out efforts to bridge gaps in such perceptions among these groups, wherever it exists, and the institution of a well planned programme for joint efforts to meet the overall goal of getting rid of tuberculosis. It is also essential to review how far the perceptions have led to well-planned actions. One basic problem is that hardly any study has been specifically planned to ascertain directly the perceptions of various groups about their respective role in the fight against tuberculosis. It is also doubtful whether there are plans to conduct such studies. This paper highlights the serious lacunae in information about perceptions of different groups about their respective roles in the fight against tuberculosis, some gaps between perceptions and between perceptions and required action.

III. PERCEPTIONS AT THE LEVELS OF HEALTH CARE DELIVERY

A. Funding Organisations

Perceptions of the Ministry of Health and other funding organisations are mainly confined to having an efficient and cost-effective tuberculosis programme.
They do not generally take direct interest in the finer details and depend upon the Programme Directorate (PD) to get the necessary background information as well as feedback from the programme. These ought to include information about perceptions of various groups about their respective roles in the fight against tuberculosis and about the efforts made to dovetail these perceptions so that all these groups work jointly to have a successful programme. But, these aspects seem to have escaped attention of this level.

B. Programme Directorate (PD)

The pivotal role in the fight against tuberculosis rests with the PDs at central and state levels. This has to be so with regard to various aspects of perceptions about the fight against tuberculosis as well. PDs, with the help of the supporting organisations, have to ascertain and dovetail the perceptions of various concerned groups and also guide them to have healthy perceptions, wherever necessary. The PD at the central level has the additional responsibility of ascertaining the perceptions of the PDs at the state level, as well as of the non-government organisations dealing with tuberculosis at national and state levels. It has to even out differences, if any, between it and all these organisations. Hardly any study has been carried out to ascertain the perceptions of PDs at state level and of non-governmental organisations at national and state levels. None of these thoughts about perceptions have received enough attention. To take up all such responsibilities, PD has to shed its image as an organisation that is concerned only with the technical, logistic, and financial aspects of the programme.

C. Supporting Organisations

The supporting organisations (both government and non-government) ought to study in detail the perceptions among various groups and formulate a process to even out differences in these, so that all the concerned groups would perform their functions with a common aim and not work at cross-purposes. These have to be submitted to the Programme Directorate (PD) for their consideration and implementation. However, the PD should mainly be responsible for motivating and funding such studies, as well as for utilising the study findings. Such aspects have not received the attention these deserve.

D. Perceptions at the Health Planning Level

At the stage of implementation of the planned programme, the planning level (particularly the PD) expects all health providers to diagnose tuberculosis cases by examining (repeatedly if necessary) sputum from all chest symptomatics (CS) who contact them, put them on treatment with a standard regimen, ensure regularity of such treatment and maintain proper records for each patient under treatment. If any of them is unable to carry out such diagnosis and treatment, he is expected to refer the CS to the nearest primary health centre (PHC) or the district tuberculosis centre (DTC). These perceptions are conveyed to health providers through training programmes, workshops and distribution of guidelines and other material. Information, Education and Communication (IEC) activities are also carried out to motivate community leaders, CS and tuberculosis cases in order to elicit their co-operation in diagnosis and treatment. How far these expectations regarding perceptions have been fulfilled is an open question.

E. Perceptions of Government Health Providers

There is hardly any published information about the perceptions of government health providers. During some studies (1,2) it was reported that the PHCs had felt that the Tuberculosis Programme had thrust some additional work on them without providing additional resources by way of staff, laboratory facilities and regular supply of material and drugs. It was observed (2) that PHCs, which should be the main pillars of the programme in rural areas (which form the bulk of the country), order sputum examination for only a negligible proportion (1.3%) of the rural CS who contact them. This would show that the perceptions about their respective role in the fight against tuberculosis could at best be summed up as a complete disaster. Sputum examination was ordered by the general hospitals for only 41.3% of CS contacting them. This indicates that their perceptions also needed improvement. Special tuberculosis facilities (DTCs and sanatoria) ordered sputum examination for 93.3% of the CS (but not 100%). Even among those, who were either diagnosed as having tuberculosis or had themselves recognised that they were suffering from tuberculosis (who may be referred to as probable tuberculosis cases - PTBs), only one out of eight (12.5%) contacting the PHCs were ordered sputum examination. This was so, even when about 70% of the PTBs had severe symptoms (3). These findings confirm that the perceptions of PHCs about their role in the fight against tuberculosis leave much to be desired.

F. Perceptions of Non-Government Health Providers

Published information about the perceptions of organised non-government health providers is conspicuous by its absence. Their co-operation is expected to be sought by the DTCs covering the area.
How far such efforts take the perceptions of this group into account remains a gray area. Among CS contacting non-government hospitals, the proportion for which sputum examination was ordered was as low as 34.2%, as compared to the expected 100% (2). Even among the PTBs, only 60.3% were ordered sputum examination (3). These findings indicate that these health providers did not have the perceptions necessary for a successful tuberculosis programme.

G. Perceptions of Unorganised Health Providers

This is another group for which published information about perceptions is conspicuous by its absence. The size, nature and spread of this group make it very unwieldy. But, it cannot be denied that they play a major role, because about two-thirds of CS approaches them first for getting relief from their symptoms (2). Some studies have shown that among private medical practitioners (PMPs), only 20% carried out investigations before starting treatment and 60% directly gave treatment employing 80 types of regimens. Most of these regimens were expensive, inappropriate and non-standard (4, 5). Majority did not give importance to sputum examination (6). These indicate that their perceptions are quite different from that of the PDs. A large number of published papers describe (in text book style) the role PMPs ought to play, but not the results of any dialogue with them. Hardly any attempt has been made to ascertain (a) their perceptions about their role in the fight against tuberculosis and (b) what should be done to dovetail their perceptions with those of the PD, if necessary. Attempts are being made to formulate different models for their co-operation with the programme. It is hoped that these models would give adequate attention to the role perceptions of health providers practising all systems of medicine and to bridge differences between these and the perceptions of the heath planners. Among the CS contacting PMPs, as low as 14.4% were ordered sputum examination (2). Even among the PTBs, only 31.2% were ordered sputum examination (3). Because about two-thirds of the CS contact them first, these findings indicate a serious shortfall in perception.

IV. PERCEPTIONS AT COMMUNITY LEVEL

A. Leaders in the Community

As stated earlier, IEC activities were carried out to provide perceptions to (or impose these on?) the community leaders, CS and cases so that they would co-operate in diagnosis and treatment. But whether they have developed these perceptions in the process or they continue to have their own perceptions has not been studied. Further, there is hardly any published data about the activities of the community leaders in the fight against tuberculosis, even to make an indirect guess about their perceptions. Fortunately, information about the action taken by CS and cases is available, which could be used to indirectly judge their perceptions or expectations.

B. Perception of CS

Some studies have shown that 85% to 90% of CS visited health providers for relief of symptoms (2, 7). About 40% did so within 7 days of onset of symptoms, about 70% within 15 days and about 80% within 30 days (2). On an average, they took 1.7 actions and visited health providers about 8 times. Evidently such prompt and multiple actions show that their perceptions are encouraging for the fight against tuberculosis.

C. Perception of Cases/PTBS

Earlier studies had shown that about 50% of cases had taken action to seek relief (8, 9). Among the PTBs in a more recent study (3), which could indicate the behaviour of cases, all had taken action. The first action was taken after an average interval of 14 days, with 78% taking action within 15 days. Such universal action and the prompt action by more than three-fourths of PTBs indicate that there has been a vast improvement in the perception of cases in the recent studies.

V. PERCEPTIONS ON COMMUNICATING WITH CASES/PTBs

A. Results of Sputum Examination

All those from whom sputum has been collected expect that the results would be told to them when they would visit next. But, out of those examined, only 68% of CS and 76% of PTBs were told the result (2, 3). Thus the perception of the health provider, which had collected the sputum, was not conducive enough to examine all the collected smears and inform the results, to satisfy the perception / need of those from whom sputum was collected.

B. About Treatment

The programme expects all diagnosed cases to take the prescribed treatment for the prescribed duration. But, it is widely known that substantial proportion of cases do not take complete treatment. Evidently, there is a wide gap between the perceptions of the programme and that of patients with regard to duration of treatment.
VI. DISCUSSION

The almost total absence of information about the perceptions of various groups (other than the PD at central level) about their role in the fight against tuberculosis is very discouraging. As indirectly judged by the proportion of CS for whom sputum examination has been ordered, none of the health providers, except the special tuberculosis facilities (mainly sanatoria), seem to have the proper perception for a successful fight against tuberculosis. It is disheartening that the PHCs (which ought to have been in the forefront of the fight against tuberculosis in a predominantly rural country) have an even more unhealthy perception than the unorganised PMPs. While the PMPs had ordered sputum examination for 14.4% of CS and 31.2% of PTBs, the corresponding proportions for PHCs were much smaller - only 1.3% and 12.5% respectively (2,3). Is it possible that the PHCs are having a non-cooperative (or even hostile?) attitude, because of their feeling that tuberculosis work has been thrust on them without providing additional staff and supplies? In any case, their approach seems to have made them unpopular with the rural CS, with only about one-sixth contacting PHCs (providing free service) first, as compared to about two-thirds contacting PMPs (which charge for their services). The corresponding proportions for second action were 7% and 59% respectively and for third action, 11% and 44% respectively. It is also significant that only 0.0%, 2.4% and 0.0% of the urban CS had contacted DTC for first, second and third actions respectively, eventhough two out of the four towns included in the study (2) had a DTC. Whether this unpopularity is also a reflection of their lack of proper perception needs to be investigated. Since these rural and urban health facilities were expected to give free services, the high level of unpopularity, as observed, is indeed surprising. It may be relevant to mention here that during interviews, some CS had stated that they had to incur expenses without providing additional staff and supplies? In any case, their approach seems to have made them unpopular with the rural CS, with only about one-sixth contacting PHCs (providing free service) first, as compared to about two-thirds contacting PMPs (which charge for their services). The corresponding proportions for second action were 7% and 59% respectively and for third action, 11% and 44% respectively. It is also significant that only 0.0%, 2.4% and 0.0% of the urban CS had contacted DTC for first, second and third actions respectively, eventhough two out of the four towns included in the study (2) had a DTC. Whether this unpopularity is also a reflection of their lack of proper perception needs to be investigated. Since these rural and urban health facilities were expected to give free services, the high level of unpopularity, as observed, is indeed surprising. It may be relevant to mention here that during interviews, some CS had stated that they had to incur expenses at the PHCs (2). This aspect also needs to be investigated.

In one study, more than two-thirds of CS had been found to contact a health provider within 15 days of onset of symptoms (2), showing that they did perceive early diagnosis as important for them. But, perception of the programme is that sputum need not be examined for CS with symptoms of less than two / three weeks duration. This serious and hitherto unrecognised disparity in perceptions has to be looked into and corrected, in order to avoid frustration among CS and to make diagnosis as early as possible.

In the ICORCI study, in spite of making an average of about 8 visits to more than one health provider, sputum examination was found to have been ordered for only 23.1% of actions taken by CS (2). Even for PTBs, who closely resemble cases, this proportion was about 50% only (3). Sputum examination was ordered for only 35% of PTBs at first contact, though 52% of them had severe symptoms. Further, among PTBs, the proportion with severe symptoms had increased steadily from 52% at first action to 73% at third action. This increase shows that the health providers, contacted by the PTBs, did not provide the service expected by PTBs, either because of deficiency in their perception or gaps in its implementation. Out of the reportedly diagnosed cases in the study, about 60% were diagnosed by PMPs (mostly without sputum examination) and had probably included wrong diagnosis (2). Such services, which do not meet the needs of CS / PTBs, are bound to weaken their perceptions and seriously damage the programme. Further, about half of the private doctors, who had referred their patients to public health service, had found these to be unsatisfactory, 40% as average and 10% would never refer their patients due to bad treatment (10). Attempts at rectifying provider behaviour are likely to be more productive than that of disciplining patients (11), but are given a low priority, owing probably to staff resistance or to the convenience of finding a scapegoat in the patient. Being a predominantly rural country, first priority has to be given to rectifying the behaviour of PHCs. A proper dialogue (with an open mind) is necessary for understanding their perceptions and changing these to the extent necessary, instead of thrusting the work on them through administrative orders.

The disparity in perceptions between the cases and the programme regarding treatment has been solely attributed to default by patients. This has, however, to be reviewed against the following:

(a) Most of the advanced countries had controlled tuberculosis before the advent of chemotherapy.
(b) A longitudinal survey showed that about one-third of cases had been cured without chemotherapy (12).
(c) The proportion of cases that did not have relapse after two years was 91% and 96% after five-month treatment (13,14) and 60% to 89% after four-month treatment with different regimens (15). Even among those who had only three-month treatment, the vast majority (80%) did not have relapse (14).
(d) A five-year follow-up showed that 65% of “lost to treatment” cases, with no subsequent treatment, did not relapse (16) and could be considered cured.
The perception of the programme that all cases are alike and need uniform duration of treatment is not supported by the above data. A large proportion of cases are cured after short treatment and do not continue treatment, which was no longer required for them. These findings support the perception of the so-called defaulters and not the perception of the programme, that all cases would require uniform duration of treatment. Further, it may be relevant that “comprehensive management of TB must take the total person and not only his physical disease”(17) and that “in terms of practical management, pulmonary TB can be as much a disease of the personality as it is of the lungs”(18).

A surprising finding, which has been overlooked so far, is that the “success rate” of 81% at the end of treatment under Revised National Tuberculosis Control Programme (RNTCP) with Directly Observed Treatment (DOT) (19) is not different from 80% under the three-month treatment after two years (14) and is less than 91% & 96% after two years under 5 month treatment (13,14) and 84% & 89% after two years under 4-month treatment with two regimens viz., SHRZ/ HRZ and SHRZ/HR respectively (15). After two years, the success rate under RNTCP is likely to be even smaller than under the 3-month treatment and raises serious questions about RNTCP and DOT.

If the perception of the PDs regarding development of resistance was true, there would have been a phenomenal increase in resistance in the country, because of substantial “irregular and incomplete” treatment, which had supposedly existed for many years all over the country. But there is no clear evidence of an increase in primary drug resistance, which is an indicator of tuberculosis control efforts in the past, during the period from 1956 to 1995 (20). Further, prevalence of MDR-TB also is reported to be at a very low level in most of the regions in India. Another interesting observation made is that, when compared to global level, prevalence of primary drug resistance is found to be marginally less in India.

Another important aspect is that research elsewhere and contributions by foreign organisations and experts also had played a substantial part in the evolution of the programme. But no information is available about the perceptions of these contributors about the fight against tuberculosis and how these have influenced the planning, implementation and evaluation of the programme. The personality, background and expertise of these contributors from different parts of the world, which would have influenced their perceptions, did vary from time to time, on account of replacements. Such changes could have also affected the programme. While some of these, no doubt, had a positive influence on the programme, certain negative or retrograde influences could not be ruled out. These aspects need to be studied and kept in mind in order to stabilise the evolution of the programme.

In conclusion, it may be re-emphasised that lot needs to be done to ascertain the perceptions of various groups about their respective roles in the fight against tuberculosis and to make attempts to dovetail these perceptions, so that all these groups feel committed to the programme. Even more unfortunate and unscientific is the reluctance to question and modify a perception, even when the data indicate that it needs to be changed. The fact that very little attention has been paid to study the perceptions of various groups, who ought to join in the fight against tuberculosis, confirms our top-down approach of thrusting programmes down, instead of taking the concerned people along. While a business management gives utmost importance to the preferences and even vagaries of the customer and makes all out efforts to modify these, government programme management refuses to have even a dialogue with the beneficiaries and others who have a role in the programme. Instead, it never tires of dictating to them about what they should do. A radical change in management, resulting in a healthy alignment of all the relevant groups, is called for.

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