

# WHY TUBERCULOSIS PATIENTS IN A HEALTH UNIT FAILED TO PERSEVERE WITH THEIR TREATMENT<sup>1</sup>

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*A problem which is impeding tuberculosis control in the Health Unit at Magdalena, Peru, as it does in any health service, is lack of regularity in attendance for treatment on the part of ambulatory patients, a large percentage of whom abandon their treatment. In 1967, the bronchopulmonary service in this health unit had several hundred patients; 90 per cent of these followed the course of treatment regularly. The other 10 per cent were recalcitrant.*

## Introduction

It is clear that the failure of tuberculous patients to persevere with their treatment not only rules out their complete recovery but helps to make them active agents in the spread of the disease in the community. Health workers frequently try to argue theoretically that lack of health education is the one and only reason why tuberculous patients are reluctant to submit to treatment, and take measures of an exclusively educational kind. This in our opinion is like making out a prescription without first diagnosing the ailment, or blindly adopting a solution to a problem without ascertaining its underlying cause. This approach is mistaken and almost invariably leads nowhere; hence our concern that it should not be perpetuated. Before offering advice on what should be done in health services to ensure that tuberculous patients are restored to health by means of regular treatment, we have made a study which has enabled us to pinpoint the factors underlying the problem. The knowledge we have acquired will be used in due course to seek solutions which will really fit the problem, and these will not be purely educational in nature.

The present article describes how the research was carried out and what results were obtained.

The School of Public Health was anxious that medical students studying health education and the behavioral sciences in postgraduate courses should participate directly in planning the educational component of public health programs. The topic selected for this experiment, to be carried out by means of a carefully planned educational operation, was the problem of patients of the Health Unit at Magdalena who do not persevere with their treatment regularly. We were called in to advise the group of medical students<sup>4</sup> taking part in the preparation and execution of the study.

It was agreed that a thorough investigation should be undertaken beforehand in the hope that it would throw light on the underlying causes of the problem, and subsequently a study would be made based on patients, contacts, and health personnel. The investigation of each of these sources of information meant analyzing the purpose of the study, its content, the methods to be used, and the background of those responsible for carrying it out.

## Study of the Patients

The study of the patients was to be based on information sought directly from them and on observation of their family surroundings. The

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purpose would be to obtain more complete information from contacts and health personnel; to ascertain the precise reasons why the treatment was abandoned; to find out what the patients knew about their illness; and to isolate the positive factors which might help to solve the problem. The points to be studied were to be: what the patient thought about his illness; the resources he had for treatment; and the obstacles in the way of his attending the clinic.

The device to be used for the survey would be the interview, this being chosen for a number of reasons: first of all, the greater likelihood of obtaining truthful statements and overcoming the patient's reluctance to answer questions, and the possibility of framing the questions with a certain flexibility so as to elicit additional information not asked for; the difficulty of using other methods because of the low cultural level of the patients; and finally, the fact that the interview method was feasible with the personnel resources available.

It was not intended that the study should be carried out on all the recalcitrant cases, but only on 20, each of the five members of the investigating team being detailed to interview four of them. The sample was to be made up of patients living close to the School of Public Health and the Health Unit at Magdalena, and as far as possible it was to include cases representing various age groups, occupations and educational levels, and including both sexes.

Stress was placed on the importance of correct questioning, and the following recommendations were made as to the best way of obtaining information: questions should be of the "open-ended" type, so as to elicit the varying opinions of those interviewed on the subject of the survey; questions which in any way suggested the answers should be avoided; when necessary, oblique questions should be asked—for example, in trying to ascertain the patient's income he need not necessarily be asked how much he earned, since this could be arrived at by inquiring as to his occupation and deducing his income from that.

Subsequently a list of questions was drawn up by way of suggestion, not to be recited by heart when the questioner came to interview a patient. These were questions concerning the patient's knowledge of what was wrong with him: whether the disease was contagious, how long his treatment would take or how he could be cured, why he did not take the drugs given him or attend the clinic; what was preventing him from being cured; how far he lived from the consulting room; what he thought about the hours of consultation; whether he had his employer's permission to attend the clinic; whether the drugs had any side-effects and what form the discomfort took; whether he traveled a great deal, and whether he continued his treatment while he was away from home.

Since interviews with patients in their homes provided direct evidence of the problems of their family surroundings, a guide was prepared so that systematic note could be taken of such matters as the amenities of the household, the degree of overcrowding, the condition of the sanitary facilities, lighting, electrical appliances, and other belongings with a view to deducing the patient's economic situation.

Subsequently, at a special meeting, the group making the study drew up the following guidelines for interviewing: choose the right moment for conducting the interview; let the interviewer identify with the patient so as to gain his friendship and confidence; in explaining the purpose intended, use simple language and converse in a friendly manner which does not seem like an interrogation; in recording the patient's replies following the interview, make use as far as possible of his actual words and try not to distort his views; finally, if the information required is not forthcoming in a single visit, try to secure another interview, avoiding criticizing or arguing with the patient.

#### Data Furnished by Patients

When the patients were asked what they knew about their illness, 60 per cent said they had "a spot on the lung," 15 per cent had

nothing to say, and 25 per cent stated that their ailment was not infectious—which not only indicates their ignorance, but illustrates the danger of the patients themselves spreading the disease.

With regard to the length of the cure, 70 per cent thought it would take a long time, irrespective of whether the disease was in the early stages or chronic. Thirty per cent had no views. This would appear to have a somewhat negative effect on readiness to undergo treatment.

On the question why they did not take the medication given them, 40 per cent said they forgot; 30 per cent said that the drugs had unpleasant side-effects; 20 per cent gave lack of money to buy the drugs as their reason; and the other 10 per cent said there were no facilities for giving injections.

The handling of patients by the health service personnel is not all it should be, and this too helps to explain why treatment is given up. This suggests that the training of staff to perform their daily tasks efficiently must not overlook practical instruction in human relations.

With regard to the most convenient hours of attendance for treatment, 50 per cent of the patients favored 8 to 10 a.m.; 40 per cent had no preference; and 10 per cent did not want any fixed timetable. Thus the consultation schedule is no obstacle to the normal treatment of patients, since the health service functions at the hours chosen for their treatment by the patients themselves.

When they were asked whether at their place of work they were given permission by their employer to attend the clinic, 30 per cent replied that they were not and 70 per cent that they were. This suggests that lack of cooperation from employers can only be overcome by appropriate educational efforts on the part of the health service.

The most frequent complaint made by patients about the drugs was that they caused heartburn, indigestion, vomiting, and nausea.

Inquiries into the occupation of patients revealed that 25 per cent were itinerant

vendors, 30 per cent worked at home, 25 per cent had no occupation, and 20 per cent were casual workers.

#### Data Obtained from Contacts

When asked what precautions they took to avoid "catching the disease," 60 per cent of the contacts replied that they had a periodic medical check-up; 30 per cent said that the patient's belongings were kept apart; and 10 per cent said that they ate properly. These replies make it clear that the health education of contacts has not been successful, possibly for want of proper planning, in giving them adequate guidance as to the essential steps to be taken to prevent the disease from spreading within the family circle.

When asked why the patients did not follow their treatment schedule regularly, 50 per cent of the contacts cited the lack of the wherewithal to buy drugs and good food; 20 per cent blamed the distance between the patient's home and the clinic; 20 per cent spoke of the unhelpful attitude of the clinic; and 10 per cent had no explanation to offer.

Sixty per cent of the contacts said that although they were anxious to help with the patient's treatment, they could not do so because they were out of work and they thought the clinic should help the patient until he was able to work.

As to the reasons why patients gave up the treatment, 20 per cent of the contacts cited the patient's conviction that his disease was incurable; 30 per cent his irresponsibility; 20 per cent lack of money; and 30 per cent the fact that he had lost his job because of his illness.

With regard to the occupation of the contacts, 20 per cent were itinerant vendors, another 20 per cent worked at home, 10 per cent were workers not in receipt of social security, 20 per cent were out of work, and 30 per cent were students.

The survey team reported that 31 per cent of the contacts had an electric iron, 50 per cent a radio, 15 per cent a television set, and 45 per

cent an electric blender. Eighty per cent had water and sanitary facilities but had no separate bath or shower, and the other 20 per cent had no basic services whatever.

The family households of cases had an average of 5.6 members, of whom two contributed to the upkeep of the household. This illustrates a fact already known, namely, that tuberculosis is a disease which seeks its victims among persons of low income not earning enough to provide for the restoration of the patient's health.

Thirty per cent of the contacts questioned said that the sick family member had gone away for a change of climate and to be cured. This indicates that a considerable sector of the population attributes curative powers to the climate, and suggests the need to correct such erroneous ideas by means of a systematic educational campaign.

Sixty per cent of the contacts stated that the patients released from the hospital continued their treatment at the clinic; 30 per cent said they attended consulting rooms for this purpose; and 10 per cent said that patients abandoned the treatment.

An essential piece of information sought was how the disease had been detected. To elicit this the contacts were asked why the patient in their family had gone to the clinic. Thirty per cent replied that he had gone to the health service to get a medical certificate; the other 70 per cent said it was because he had felt ill. None had gone to the health service of his own accord for a general check-up; practically all of them had only done so when the symptoms of the disease began to be felt. This indicates the urgent need for an effective health education campaign in the community to make the people realize the importance of having a periodic check-up if tuberculosis is to be diagnosed and treated in time.

With regard to the attitude of the patient on being informed that he must undergo an operation, 60 per cent gave up the treatment; 30 per cent shied away from a surgical operation; and 10 per cent changed to another clinic.

To judge by this, another equally important reason for failure to persevere with the treatment is the patient's fear of being operated on.

#### Data Furnished by the Health Personnel

According to the information given by the health service staff, the following causes may explain why patients do not continue with their treatment: failure to understand that it is absolutely essential to consult the health service; shortage of money to buy drugs and to pay fares; apparent lack of interest on the part of the specialist staff; the patient's mistaken view as to the influence of climate in effecting a cure; the side-effects of drugs; and the false notion some patients have that their illness is incurable.

When asked who was responsible for health education, 30 per cent of the staff of the bronchopulmonary service questioned put the responsibility on the chief medical officer, and 70 per cent on the public health nurse. This underlines the need for briefing all personnel, without exception, to the effect that one of their basic functions is to impart health education.

The study likewise showed that 60 per cent of the staff of the bronchopulmonary service thought that examination of the sputum was sufficient for an accurate diagnosis of the disease; 30 per cent thought that a proper diagnosis required X-ray photographs; and the other 10 per cent considered that the standard radiographic examination served the purpose. This illustrates the need for adequate instruction of personnel concerning the most effective way of diagnosing tuberculosis.

The study revealed that the basic health instruction that personnel can give to patients covers the following points: the fact that tuberculosis can be cured; the need for uninterrupted treatment; the infectious nature of the disease; and the assurance that the patient need not necessarily stop working. In practice, this instruction is not imparted, or if it is, the

patient does not grasp it or assimilate it properly, since one of the main causes of breaking off treatment—as demonstrated in the course of this very study—is this ignorance on the part of tuberculous patients. To solve the problem, the health personnel suggested that effective health education should be imparted by means of home visits to recalcitrant patients.

With regard to conditions contributing to the spread of the disease, 40 per cent of the health personnel questioned considered ignorance about the disease to be a factor in helping to spread it; 30 per cent cited overcrowding; 10 per cent poor nutrition; and 20 per cent failure to comply with the recommendations of the medical service.

The health service personnel were fully aware that lack of regularity in the treatment of patients is a problem standing in the way of control of the disease. Fifteen per cent of those questioned stated that there were patients who gave up their treatment completely; the remaining 85 per cent said that the attendance of many patients at the clinic was very spasmodic. The survey team felt that health education is the only solution to this problem. No recommendations were put forward in regard to the solution of the other factors underlying the problem.

As regards the reason why treatment was ambulatory, 40 per cent of the health service personnel questioned said that it was because the rules laid down by the authorities required it; 50 per cent said it was the most effective and economical method of curing the disease; and 10 per cent said it was because it was impossible to treat every case in a sanatorium.

When asked what were the most appropriate occasions for imparting health education, 35 per cent felt that it should be given in the course of home visits; 30 per cent at any time when treatment was being given; 20 per cent when the nurse had the time; and 15 per cent had no views on the subject.

All this indicates the urgent need to make the staff realize—30 per cent had the right idea—that advantage must be taken of all

contact between public health workers and patients to impart instruction, and that this should form an essential part of the duties of every one of these workers.

With regard to health education activities within the service, 40 per cent said that the best means was the interview; 30 per cent favored group discussions; and 30 per cent the use of educational films. These replies show how necessary it is for personnel to be made to realize clearly that health education should not use any specific teaching method or device exclusively or unilaterally, but a suitable combination of these, according to the nature of the topic and the groups taking part in the learning process. Another fact revealed by all these replies is the need to make staff change their way of thinking so as not to overestimate the value of educational films. This appeal to the senses cannot in any circumstances replace the educator or other educational methods, and should be used merely to give backing or objective corroboration to the information provided by other educational media.

It seemed important to ascertain whether the decision to break off treatment was in any way due to offhand treatment on the part of the staff. To elicit this information the question had to be put in a roundabout way, since direct questioning would not have brought out the truth. Thus, instead of being asked how they treated patients attending the health service, the staff were asked whether complaints or representations were often made by patients, what was the reason for the complaints, and what was done about them. The replies obtained were as follows: 20 per cent said that complaints were frequent; 30 per cent that they were very frequent; 40 per cent said there were not many complaints; and 10 per cent said there were none. Ninety per cent of the personnel questioned said that the reason for complaints was that the patients themselves were impolite and ill-mannered; they also said that the complaints were looked into. There is no doubt that complaints are not all the fault of the patients, which suggests that the

bronchopulmonary service should try to exercise a strong influence on the patients by treating them with kindness, friendliness, and courtesy.

### Conclusions

The following conclusions emerge from the study:

1) The reason why treatment is broken off in certain cases is not necessarily to be put down to faulty education; there are also other contributory factors.

2) If uninterrupted treatment is to be achieved in all instances, a systematic health education plan with well-defined objectives must be supplemented by efforts to solve the other problems which affect the issue.

3) In order to plan and develop the educational component of the Tuberculosis Control Program, it is essential to determine the social and cultural factors which influence the incidence and treatment of the disease.

4) Any teaching program on the subject of tuberculosis must be based on a prior investigation of opinions, practices, and attitudes in regard to the disease.

5) Apart from enabling health education to be conducted in the light of the needs and interests of the public, such an investigation will make it possible in due course, by means of an evaluation, to assess any changes in views and practices that the educational efforts may have brought about.

6) Educational activities carried on as part of the Tuberculosis Control Program should without any question be focused on patients, contacts, and health service personnel so as to bring about effective changes in their attitude toward the diagnosis, treatment, and control of tuberculosis.

### Summary

A survey conducted at the Health Unit in Magdalena, Peru, among tuberculosis patients, their contacts, and the health personnel treating them, reveals several reasons why many patients are irregular in their attendance for treatment or give it up. One of the most important reasons given was the lack of health education, although it was stressed that this was not the only reason.

The study included 20 selected recalcitrant patients, their contacts, and the health service personnel. Five investigators interviewed four patients each. When asked what they knew about their illness, 60 per cent of the patients said they had a spot on the lung, 25 per cent did not think the disease was infectious, and 15 per cent did not know. Regarding the length of time required for cure, 70 per cent thought it took a long time, irrespective of whether the disease was in the early stages or was chronic. Regarding the reason for not taking medication, 40 per cent said they forgot, 30 per cent blamed side-effects, 20 per cent lack of money to buy drugs, and 10 per cent lack of facilities for injections.

As to precautions taken by contacts, 60 per cent said that they underwent a periodic check-up, 30 per cent that the patient's belongings were kept separate, and 10 per cent that they ate properly. The reasons they gave for irregularity of treatment were lack of money, 50 per cent; distance from the clinic, 20 per cent; unhelpful attitude of the staff, 20 per cent. The remaining 10 per cent mentioned no difficulties.

The health service personnel attributed the interruption of treatment to failure to realize its importance, lack of money, indifference of personnel toward the patient, a mistaken belief in the curative power of climate, the side-effects of drugs, and the patient's conviction that his illness was incurable. Thirty per cent of the personnel considered that the chief medical officer should be responsible for educational work, and 70 per cent considered it the duty of the public health nurse.

The data collected from these three sources indicate that interruption of treatment is not due to educational reasons alone. Health education must be adapted to existing beliefs, practices, and attitudes regarding tuberculosis in order to bring about changes of attitudes not only among cases and contacts, but also in the health personnel responsible for their treatment.