SECOND CARNEGIE INQUIRY INTO POVERTY
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Tuberculosis:
The patients' perspective
by
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This is the third of three studies examining aspects of tuberculosis (TB) control in South Africa. The study sets out to ascertain the view of the consumer using TB services – the TB patient. Aspects such as the impact of contracting TB on employment opportunities and social lives, difficulties in getting treatment, and knowledge of TB, are studied in a sample population of urban Black working class TB patients. It is found that patients have difficulties in getting treatment at centralised points, and that health education is not effective at present. Poor socio-economic conditions also play an important role in the experience of the TB sufferer.
INTRODUCTION

Tuberculosis (TB) is one of the major health problems in South Africa. In order to attempt to control the disease a scientifically-based national TB policy is required, backed up by an adequate health infrastructure capable of implementing policy. The World Health Organisation, in discussing national tuberculosis programmes (1), emphasises that such programmes should, in particular, be convenient for the consumer rather than merely for those providing the service. However a review of the local literature reveals that the views of the consumer are seldom ascertained. In this study we attempt to discover what impact contracting TB has on the life of a group of urban Black working class people, how it affects their employment opportunities and social lives.

Health education is seen as an important aspect of TB policy (2), especially in the sphere of case finding, as knowledge of symptoms is regarded as the prerequisite for self-referral in good time. Therefore it was thought important to ascertain how much people knew about their disease and how they had acquired this knowledge.

Finally, non-compliance is often referred to as a serious problem in the implementation of TB policy. It is usually seen as a result of people not wanting to take treatment (3). Little
research exists on the problems patients experience in getting treatment. In this study, patients' views on the matter are ascertained.

METHODS

A random sample of 55 patients was chosen from the list of all TB patients receiving treatment at a local authority clinic in a Black residential area of Cape Town. The clinic serves a nearby squatter camp as well. The patients were interviewed in their homes by a trained interviewer using a previously tested questionnaire.

Response Rate

Of the 55 patients initially included in the sample, 7 had left the area and were excluded from the sample. Of the remaining 48, 6 were not able to traced giving a response rate of 87.5%.

RESULTS

Age and sex

There were 22 males and 20 females in the sample. 3 subjects did not know their ages. The age/sex distribution of the rest is shown in figure 1.

(Insert Figure 1)
Education level

Of the 28 adults (age greater than 18) in the sample, 10 (36%) had had no schooling at all. 10 had only primary school education and 8 had been to secondary school. The highest level of education attained was Std 8.

Employment

Of the 28 adult patients, only 5 males were currently employed. Of the 23 unemployed subjects, all 11 males and 5 out of the 12 females had been previously employed. 9 had been employed at the time they contracted TB and 7 of these lost their jobs for reasons associated with their disease. 2 other unemployed patients felt that, were it not for their disease, they would have been able to find employment again.

Financial Support

5 adults were still employed and supported themselves. Of the 7 who had lost their employment after contracting TB, 5 were supported by family, one by a friend and one received a disability grant. Of the 16 who were unemployed at the time of contracting TB, 14 were supported by family members, 1 by friends and one was living off his savings.

Of the 14 children, 2 had employed mothers who supported them, and 11 had unemployed mothers. Of these, 5 were supported by their fathers and 6 by other family members. 1 mother had had to
leave her job to look after her child when it developed TB and was now supported by the grandmother.

Apart from one foreman on a construction site, and one machine operator, all other subjects who had worked, had done so as unskilled workers.

Housing

The housing of the subjects included rooms in hostels (14 people), shacks (8 people), and houses rented from the Administration Board (18 people). 2 people lived in tents. The mean number of people per habitable room was 4,7 - excluding hostel dwellers. In the hostels there were an average of 6,2 people per room. The mean number of domestic contacts also suffering from TB was 0,4.

Social Implications of TB

Of the 28 subjects who had families present in Cape Town, 24 reported that there had been no change in their family's attitudes since they or their child had contracted TB. In the remaining 4 cases, the family's attitude had changed unfavourably. Only 4 subjects reported that their friends' attitudes towards them had changed.

Diagnosis

Not one of the subjects reported that they had suspected that they or their child had TB, when they first felt ill. The only
common reason that people gave for consulting doctors at the time of diagnosis was coughing (45%). No other single sign or symptom was reported by more than 5 people. The other symptoms and signs were very varied. 4 subjects were contacts. When people felt ill, they went to the following health services:

- Private practitioner 9 (24%)
- Provincial paediatric hospital 6 (16%)
- Day Hospital 11 (30%)
- Local authority clinic 5 (14%)
- Provincial hospital 6 (16%)

4 subjects were contacts.

Problems in getting treatment, and side effects

11 of the 14 mothers (or grandmothers) with children suffering from TB complained of problems in connection with getting daily treatment. These related mainly to the distance which had to be walked to the clinic. 2 subjects had to take their other children with them to the clinic. 2 subjects who were working, had difficulty in getting to the clinic in time before going to work.

11 of the 28 adults reported problems. These also related mainly to the distance they had to walk to the clinic each day. Some people had to walk for an hour each day to reach the clinic. 3 people found the walk difficult for health reasons. One woman had a small baby that she had to take with her and one man found that he was late for work each day as a result of having to go to the clinic first. He feared that he would lose his job.
20 subjects reported no problem in getting their treatment daily.

23 patients reported no side effects from the treatment. The remaining 19 reported side effects, mainly of a gastric nature.

**Knowledge of TB**

a) Signs and symptoms

The subjects were asked how they would identify someone suffering from TB. 9 (21%) could not give an answer. The commonest signs and/or symptoms of TB mentioned were lethargy/lassitude, pallor and loss of weight. Only 2 people mentioned cough. No one spoke of haemophysis or nightsweats.

b) Spread

16 (38%) subjects knew that TB could spread. 7 knew that this occurred by coughing, 1 thought it was spread by using common cutlery. The remaining 8 did not know the mechanism of spread.

c) Seriousness

29 (69%) thought that TB was a serious disease. Of these, 20 based their information on the fact that they had been or knew someone who had been very ill with TB. 9 knew that TB could be a fatal disease.
d) Prevention of TB

Only 9 (21%) of the sample knew that TB was a preventable disease. The ways suggested in which TB could be prevented were utilisation of health services (5), changes in personal habits, e.g. alcohol consumption (3) and eating good food. Knowledge of prevention is not related to educational level. (CHI MANTEL-HAENSZEL = -0.96) Only 1 mother of the 14 children in the sample knew that TB is preventable.

e) Duration of treatment

No-one in the sample knew for how long they or their child would have to take treatment before being cured.

f) Source of information about TB

5 people said that they had been told about TB by the clinic, 2 had learnt about it at school and one had heard about it on the radio. The remaining 34 denied that anyone had ever instructed them about TB. In particular everyone in the sample denied that they had been told about TB by the health visitor attached to the clinic.

g) Awareness of environmental issues

People were asked why they thought that their residential area had a high incidence of TB. Only 4 people responded, the rest saying that they did not know. Of these 4, 2 mentioned personal habits such as smoking, drinking and use of health services.
mentioned the lack of houses, overcrowding and the fact that people were living in shacks.

**Comparison of results with those of other studies**

Three other studies (4,5,6) have been done in South Africa to assess the knowledge of attitudes of people towards TB. Moloantoa's sample consisted of Black patients receiving treatment for tuberculosis at a hospital and clinic close to Pretoria. The others, Lubbe, used two community-based samples of urban and rural Blacks who were not TB patients. The sample populations were comparable to that of this study with regard to age and sex distribution. Education levels were also similar although these were not reported in Lubbe's rural study. 95% of the Cape Town subjects and 82% of the Pretoria ones were labourers. Occupation was not reported in the other two studies.

The knowledge that TB was an infectious disease was highest among the urban Black of Lubbe's study (85%). In the other three studies, less than 50% of the subjects were aware of the infectiousness of TB. Knowledge of the common symptoms of TB was very varied in the three studies in which it was measured. 67% of the rural Black population sample, 25% of the urban Black population and 21% of the Cape Town sample were unable to answer the question at all. The corresponding figures for knowledge of cough as a symptom of TB are 28%, 68%, and 5%. The percentages of the samples who knew that TB was a droplet-spread infection varied from 33% (5) to 11% (6). The three commonest sources of information about TB were mass media, health services and
schools, although the percentage of the sample who had received information from these sources was low, ranging between 39% and 2%.

DISCUSSION

Socio-economic factors

Employment

Contracting TB has a serious effect on the economic lives of patients. Only 5 of the 14 patients employed at the time they contracted TB were still working. 7 had lost their jobs as a direct result of contracting TB. This occurred in spite of it being official policy to treat as many people as possible at work. Similar results were found in a previous study, where it was found that only 5% of adults on TB treatment received treatment at work. It is also possible that some of the patients unemployed at the time of diagnosis might have been able to find re-employment were it not for the fact that they were on TB treatment. Although this was not a focus of the study, 2 subjects volunteered this information.

Financial support

The high rate of unemployment among TB patients throws a heavy burden of support onto family members. Only one patient received a disability grant.
Housing

Poor housing, particularly overcrowding, is known to be associated with TB. 10 subjects lived in inadequate housing (tents or shacks). There was a high degree of overcrowding.

Community acceptance

Very few people felt that their disease had affected their relationship with friends and family.

Health services

Passive case finding is seen as the most important method of case finding in South Africa. This study shows that no one in the sample suspected that they had TB. People present to curative health services complaining of a variety of symptoms. Although coughing was prominent among these, people did not seem to associate it with TB.

Often non-compliance is seen as the fault of the patient. In this study over 50% of the sample had problems in getting treatment. It became clear that distance from the clinic was an important factor. Although health services, particularly at the local authority level, are fairly well distributed in Cape Town, having to walk daily to a clinic was a problem, particularly for mothers with children.
Health education

Knowledge about TB is important for a number of aspects of TB policy such as passive case finding and prevention. People showed very little knowledge of the signs and symptoms of TB, its prevention, or the duration of treatment. This is not surprising in view of the fact that 81% of the sample had never been exposed to any formal health education. In particular, very few people felt that they had been taught about TB at the clinic. Also the low educational level of the patients makes it necessary to carefully assess education techniques to make sure they are appropriate.

CONCLUSIONS

In this study we have attempted to present a patient's perspective of TB. It would seem that there are a number of weaknesses in the implementation of present TB policy. These are:

1) insufficient attention given to socio-economic factors, i.e. whether TB can be controlled while people live in overcrowded circumstances with very limited means of support;

2) the problems of having to get treatment at a centralised health service are underestimated. Treatment at home or at work would be of great assistance, particularly to women with small children and people in employment;

3) the ineffectiveness of health education at present. Continuing evaluation of both methods and results is required.
REFERENCES


2. Glatthaar E. Tuberculosis control in South Africa: 'Where have we gone wrong?' and 'A look at the future'. S A Med J 1982; Special Issue p.36.


Figure 1: Age and Sex Distribution of Study Population

NUMBER OF SUBJECTS

MALES

FEMALES

AGE INTERVALS
These papers constitute the preliminary findings of the Second Carnegie Inquiry into Poverty and Development in Southern Africa, and were prepared for presentation at a Conference at the University of Cape Town from 13-19 April, 1984.

The Second Carnegie Inquiry into Poverty and Development in Southern Africa was launched in April 1982, and is scheduled to run until June 1985.

Quoting (in context) from these preliminary papers with due acknowledgement is of course allowed, but for permission to reprint any material, or for further information about the Inquiry, please write to:

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