# UNPAID COMMUNITY VOLUNTEERS — EFFECTIVE PROVIDERS OF DIRECTLY OBSERVED THERAPY (DOT) IN RURAL SOUTH AFRICA

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*Objective.* To illustrate successes and difficulties for the South African National Tuberculosis Programme in a rural area.

*Design.* Prospective cohort study.

*Setting.* Sekhukhuneland, Provincial Health Service Southern Region, Northern Province, South Africa.

*Subjects.* All patients diagnosed with tuberculosis (TB) in the catchment area of four rural hospitals between January 1997 and June 1999.

*Main outcome measures.* Standard outcomes for TB treatment as defined by the World Health Organisation. Treatment failure, treatment interruption and death were grouped as poor outcomes.

*Results.* One thousand four hundred and seventy-six people were diagnosed with TB. The majority (76%) had smear-positive pulmonary disease. Treatment was given by directly observed therapy (DOT) throughout in all but 15 instances. Excluding 10 subjects with known multidrug-resistant TB (MDRTB), 723 (66%) were cured, 68 (6%) completed treatment, 73 (7%) interrupted treatment, 37 (3%) failed treatment, 66 (6%) transferred out, and 134 (12%) died. Of the 920 initially smear-positive patients who survived the first 2 months to receive DOT in the community, 693 (75%) were supervised by unpaid community volunteers. Poor outcomes were no more common among patients supervised by these volunteers than among patients supervised by professional health care workers. Male gender (odds ratio 1.38, 95% confidence interval 1.02, 1.87) was significantly associated with a poor outcome.

*Conclusion.* Although there were difficulties, the national programme was successfully applied with no additional funds or facilities. Explanations for the high death rate and poor outcomes for men need to be found. Great efforts will be required to preserve the quality of the TB programme if it is devolved to primary care level.

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Worldwide, tuberculosis (TB) is a major cause of mortality and morbidity. Approximately 170 million people are infected and 4 million develop clinical TB each year.[1] The South African Department of Health has described TB as South Africa's 'number one health priority' and launched the South African National Tuberculosis Programme (SANTP) in 1995.[2,3] In 1997, 107 075 new cases of TB were registered in the country but the implementation of directly observed therapy short course (DOTS) has been difficult.[3-5] Many TB cases occur in the poor rural communities that make up nearly half of the population.[6] TB treatment is free in South Africa but effective models of care for these patients need to be developed.

Sekhukhuneland is a rural area situated in the Provincial Health Service Southern Region of the Northern Province. Its population of around 1 million suffers high levels of unemployment and most homes have no running water or electricity. Here we report obstacles to care and the outcome of treatment for patients presenting with TB to four hospitals in Sekhukhuneland (Jane Furse, Matlala, Maandagshoek, St Rita's) between January 1997 and May 1999.

## STUDY POPULATION AND METHODS

The study was based in four rural hospitals. In the districts in which the four hospitals are situated, all patients suspected of having TB were referred to hospital for assessment. Thereafter patients thought to have TB were diagnosed and treated according to the guidelines of the SANTP. Patients treated at these hospitals between 1 January 1997 and 31 May 1999 were included in the study.

New patients received regimen 1, namely 2 $HRZE_5/4\ HR_5$, while re-treatment patients received regimen 2, namely 2 $HRZSE_5/1\ HRZE_5/5\ HRE_5$ (H = isoniazid, R = rifampicin, Z = pyrazinamide, E = ethambutol, S = streptomycin. The large number before the drugs represents the number of months of treatment, the subscript after the drugs represents the number of days the drug was taken per week). Children received modified regimens that did not include ethambutol. Treatment was adjusted according to sputum acid-fast bacillus (AFB) smears after 2 and/or 3 months. Sputum was sent for culture if the patient was not responding appropriately to treatment. All treatment was directly observed for the full course. Details of all patients were entered in the national tuberculosis registers, kept on the TB wards of the four hospitals.

Patients stayed in hospital for the first 2 months of treatment and were discharged from hospital if they were physically and mentally fit for supervised ambulatory care. They were taken home by hospital transport, escorted by one of a team of nurses with special skills in organising DOT. Having located the patient's home, a decision would be taken on the most appropriate person to support treatment. The prime consideration at this point would be convenience for the patient, and since very few patients had any means of

transport, DOT providers had to be within walking distance of the patient's home. If the patient lived near a primary health care (PHC) clinic, a PHC nurse undertook DOT provision. If not, an alternative DOT provider, usually a shopkeeper, was asked to supervise treatment. Occasionally patients refused a particular provider or a shopkeeper refused to undertake supervision, but this was very unusual. Supervision by a family member was usually the last option. The provider was instructed by the accompanying nurse and given a month's supply of drugs. The record card was kept and completed by the provider. Each month the TB nurse delivered treatment to the DOT provider and checked that the treatment documentation card was complete. The visit was also used to support the patient and the DOT provider and to trace treatment interrupters. At the end of treatment all patients returned to hospital. At this attendance at least two sputum samples were examined and the TB register was completed.

Outcomes of treatment were those defined by the World Health Organisation (WHO)/International Union against Tuberculosis and Lung Disease (IUATLD) and used in the SANTP.[7] For some analyses 'cured' or 'treatment complete' were combined as 'satisfactory' outcomes, whereas 'treatment failed' or 'died' or 'treatment interrupted' were 'poor' outcomes. Multidrug-resistant TB (MDRTB) is TB caused by organisms resistant to both isoniazid and rifampicin.

Data from the TB register were transferred into a database (Microsoft Access).[8] Univariate analyses and multivariate forward stepwise logistical regression were done using SAS statistical software.[9]

## RESULTS

A total of 1 476 patients with TB were identified. Ninety-two per cent (1 358) presented with intra-pulmonary disease, of which number 1 114 (82%) were sputum smear-positive. Ten who were known at the beginning of treatment to have MDRTB were excluded from further analyses. The median age of patients with smear-positive pulmonary TB (PTB) was 36 years (range 0.4 - 95 years). Twenty-six (2%) were less than 15 years old. Men made up 62% of patients and were, on average, 8 years older than women (men 42 years, women 34 years). One hundred and seventy subjects had previously been treated for TB.

### Treatment outcomes

Treatment outcomes for smear-positive patients are shown in Table I. The overall cure rate was 66% and varied widely (52 - 72%) between hospitals. After 2 months 153 (16%) previously untreated patients with smear-positive PTB still had a positive sputum smear. Of the remainder, 21 (2%) had interrupted treatment, 24 (3%) had not had a smear done, 76 (8%) had died and 25 (3%) had transferred out. This left 634 (68%) who were proved to have a negative smear after 2 months. Results were similar for re-treatment patients except that 38 of 171 (22%) had a positive smear after 2 months.

**Table I. Treatment outcomes for 1 104 patients with smear-positive pulmonary tuberculosis**

| Treatment outcome | *N* | % |
|---|---|---|
| Cured | 726 | 66 |
| Dead | 134 | 12 |
| Transferred out | 66 | 6 |
| Treatment complete | 68 | 6 |
| Treatment failed | 37 | 3 |
| Treatment interrupted | 73 | 7 |
| Grand total | 1 104 | 100 |

Risk factors for poor treatment outcome were assessed among 1 038 patients with smear-positive PTB. Two hundred and forty-four subjects with a poor outcome were compared with 794 with a satisfactory outcome. Those transferred out (66) were excluded. Risk factors evaluated included sex, age, hospital and whether the patient had previously been treated. In multivariate analysis only male sex (odds ratio 1.38, 95% confidence interval (CI) 1.02, 1.87) was significantly associated with a poor outcome. Table II suggests that this difference was because of higher numbers of men failing and interrupting treatment.

Risk factors for poor outcome were assessed among the patients with smear-positive PTB who survived until hospital discharge. Particular attention was paid to who supervised treatment.

Of 1 104 patients with smear-positive PTB, 909 survived the intensive phase and were allocated treatment supervisors. Of those not surviving the intensive phase, 100 had died, 53 had transferred out and 27 had interrupted treatment, 6 were not supervised and for 9 the mode of supervision was not recorded. Twenty-one transferred out in the continuation phase leaving 888 for analysis. Of these, 779 had satisfactory outcomes and 109 poor outcomes. Unpaid community volunteers supervised 77% of patients and nurses based in

**Table II. Treatment outcomes by gender for 1 034 patients with smear-positive pulmonary tuberculosis***

| | Female | | Male | |
|---|---|---|---|---|
| Treatment outcome | *N* | % | *N* | % |
| Cured | 305 | 75 | 421 | 66 |
| Dead | 52 | 13 | 82 | 13 |
| Treatment complete | 18 | 4 | 50 | 8 |
| Treatment failed | 9 | 2 | 28 | 4 |
| Treatment interrupted | 20 | 5 | 53 | 8 |
| Grand total | 404 | 100 | 634 | 100 |

* Patients transferred out (66) have not been included.

PHC clinics supervised nearly all the rest. Analysis of this group revealed that gender, age, hospital, previous treatment and treatment supervisor did not predict poor outcome. In particular there was no significant difference in outcome when family members, other community volunteers (usually shopkeepers) or professional health care workers (usually PHC nurses), supervised DOT (Table III).

**Table III. Treatment outcome by supervisor**

| | Outcome | | | | | |
|---|---|---|---|---|---|---|
| | Poor | | Satisfactory | | | |
| Treatment supervisor | *N* | % | *N* | % | OR | 95% CI |
| Professional health care worker | 30 | 14 | 177 | 86 | 1 | - |
| Other community volunteer | 58 | 11 | 455 | 89 | 1.32 | 0.82, 2.13 |
| Family | 21 | 13 | 147 | 88 | 1.19 | 0.65, 2.16 |

## Discussion

The 66% cure rate and 7% treatment interruption rate for smear-positive PTB patients are better than the figures of 60% and 18% recorded for the rest of South Africa in 1997.[3] In a review of the TB services in Sekhukhuneland in 1996, the cure rate was estimated to be 40% and very few patients were receiving DOT.[10] Unlike other similar studies, no additional funds or facilities were provided, nor were any payments made to patients or supervisors in the community.[11]

Several factors may have contributed to the relatively high cure rates and low default rates. Nearly all patients were treated in hospital for the first 2 months. This ensured close supervision and guaranteed drug provision during the period of high bacillary load and consequently could be expected to reduce the risk of the development of drug resistance. A team of nurses, working between the hospital and the community, transferred all patients to conveniently situated DOT providers. The transfer of patients between health facilities has been identified as particularly risky with regard to treatment interruption.[12] We believe, therefore, that the link between hospital and community provided by these nurses was vital.

As far as we could tell DOT coverage was almost complete. A few patients did not receive DOT either for social reasons or because they were referred from another area where their treatment had not been supervised. Like other successful programmes, this programme had dedicated nursing and medical staff with access to transport.[13] These staff took responsibility for the service and attempted to correct problems with drug supply and transport before they affected patient care. Furthermore, the TB nurses were able to visit patients in their homes. This task is particularly difficult for clinic-based PHC nurses who frequently have no transport and yet serve widely dispersed rural populations. The sense of identity and common purpose of the small team of nurses in each hospital was vital to the success of the programme.[14] Although the bulk of the work was done by the nursing teams, a doctor with an interest in TB was required to support the nursing teams, to speak for the service and to assist in diagnosis, particularly in patients with smear-negative or extrapulmonary TB. A full-time doctor was not required in each hospital; in the present programme one of us covered four hospitals, and subsequently as the nursing teams grew in experience and confidence, the programme was extended to a fifth hospital.

We encountered several difficulties. Transport was a recurring problem, reliable transport being essential for community services. The credibility of the TB services, and the trust between medical staff and patients, depends on the regular delivery of drugs and on visits to patients and their supervisors. Enough cars were available but they were drawn from a pool in each hospital and the maintenance of the cars and the organisation of the pools were very poor. In addition, we found the national TB register to be unnecessarily complicated; the nursing staff found it difficult to complete and required training to maintain accuracy and consistency. Arrangements for transfer were inadequate, patients transferred out of the area were not provided with transport, there was no proper hand-over, and it was not possible to obtain information on the outcome of their treatment. Patients transferred in from other hospitals often arrived with inadequate information such as sputum smear results.

Questions arise as to how sustainable this case holding strategy is. In 1997 the annual antenatal clinic HIV sero-prevalence survey showed that the Northern Province had a relatively low prevalence of 8.2%. By 1998 this had risen to 12% and it was predicted that the explosive development in KwaZulu-Natal, where HIV may account for 50% of TB cases, would be replicated in all the other provinces.[15,16] The rise in incidence of HIV is likely to be associated with an increased TB burden and pressure will increase for early hospital discharge. However, representatives of the WHO have warned against early discharge of sputum smear-positive TB patients to inadequate community services.[17,18]

The model of TB management described in this paper may be criticised for not being sufficiently integrated with PHC services. WHO guidelines recommend that sputum testing and antituberculosis chemotherapy be organised by PHC nurses.[7] In the model reported in this paper TB patients are not diagnosed at clinic level and follow-up is co-ordinated by nurses whose sole responsibility is TB control. The reason that TB care has not been fully devolved is that in our experience primary care clinics in this area have erratic drug supplies and slow and unreliable laboratory turnaround times.[19] Furthermore, the conflicting demands on PHC nurses make it difficult for them to gain sufficient knowledge of the TB programme to allow wholesale transfer of TB services from the

hospital.[17,20] The challenge over the next few years will be to integrate with the HIV and sexually transmitted disease (STD) programmes and to move the focus of diagnosis towards primary care without compromising treatment outcome and sputum examination. It is to be hoped that newly appointed district TB/HIV/STD co-ordinators will facilitate this process; however, they will need considerable vigour to maintain the TB service in the face of a host of competing pressures.

In rural areas of South Africa such as the area in which we were working it is not possible for most patients to have DOTS provided by clinic-based PHC nurses. This is because the majority of patients do not live within walking distance of a clinic.[21,22] Among TB patients in Sekhukhuneland, 75% were supported by volunteers near their homes. DOT providers received no payment or direct rewards. DOT provision may have increased status or brought in a little extra trade for shopkeepers, but goodwill and a desire to do something for the community seemed to be the principal motives. This system meant that there had to be a mechanism for DOT providers to be instructed in their role. Health service transport is based in the district hospitals and PHC nurses do not have access to vehicles. As a result, there seemed little alternative to dedicated TB nurses going out in transport from the hospitals to advise and supply the DOT supporters. Fortunately we have confirmed the finding of Wilkinson,[21] namely that the strategy of DOT provision by community volunteers is at least as effective as DOT provided by PHC nurses.

Treatment outcomes were worse for men. This was particularly related to higher treatment interruption rates, an effect that has been observed elsewhere in rural South Africa and elsewhere.[23,24] Possible reasons for the high interruption rates are the need to find employment outside an area where the unemployment rate is around 60%, and alcoholism, which is common, particularly among men.

We have now observed a 13 - 14% death rate in 2 consecutive years for patients with TB on treatment.[25] This death rate contrasts with an average of 4% among patients being reported to the WHO worldwide and 6% in sub-Saharan Africa.[26] Seventy-five per cent died within 2 months of starting treatment and 55% within the first month. This suggests that they were very ill on arrival at the hospital.

Potential causes of the high mortality are HIV infection, the tendency for patients to attend traditional healers before coming to the hospital and asbestos exposure. Local HIV infection prevalence is relatively low compared with other parts of southern Africa but many people have worked in or around asbestos mines. Another concern is the fact that our system relies on the district hospitals for confirmation of diagnosis. The difficulties associated with travelling up to 70 km to reach the hospital may mean that patients present with advanced clinical disease. We hope to explore these possibilities in further studies and also wish to develop means of safely devolving diagnosis into PHC settings.

We have shown that a well-organised TB service, employing the DOTS strategy, can achieve reasonably high cure rates and low default rates in a rural environment. Similar results have been reported in at least two other rural areas in South Africa.[21,22] These areas have in common hospital-based diagnosis, doctors and nurses dedicated to TB work who liaise with PHC services, and the use of community volunteers to achieve comprehensive DOT provision. The approach clearly has the potential for good case holding, but its general application and accessibility to rural communities (case-finding) remains in doubt. As South Africa tries to develop a high quality primary care-based health service, the lessons from these TB programmes in rural areas should not be forgotten.

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