

True status of smear-positive pulmonary tuberculosis defaulters in Malawi

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The article reports the results of a study to determine the true outcome of 8 months of treatment received by smear-positive pulmonary tuberculosis (PTB) patients who had been registered as defaulters in the Queen Elizabeth Central Hospital (QECH) and Mlambe Mission Hospital (MMH), Blantyre, Malawi. The treatment outcomes were documented from the tuberculosis registers of all patients registered between 1 October 1994 and 30 September 1995. The true treatment outcome for patients who had been registered as defaulters was determined by making personal inquiries at the treatment units and the residences of patients or relatives and, in a few cases, by writing to the appropriate postal address. Interviews were carried out with patients who had defaulted and were still alive and with matched, fully compliant PTB patients who had successfully completed the treatment to determine the factors associated with defaulter status.

Of the 1099 patients, 126 (11.5%) had been registered as defaulters, and the true treatment outcome was determined for 101 (80%) of the latter; only 22 were true defaulters, 31 had completed the treatment, 31 had died during the treatment period, and 17 had left the area. A total of 8 of the 22 true defaulters were still alive and were compared with the compliant patients. Two significant characteristics were associated with the defaulters: they were unmarried; and they did not know the correct duration of antituberculosis treatment.

Many of the smear-positive tuberculosis patients who had been registered as defaulters in the Blantyre district were found to have different treatment outcomes, without defaulting. The quality of reporting in the health facilities must therefore be improved in order to exclude individuals who are not true defaulters.

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Introduction

Malawi has had a National Tuberculosis Control Programme (NTP) since the country gained its independence in 1964 but, like many countries in sub-Saharan Africa, is now burdened with a large and growing tuberculosis (TB) problem, mainly as a result of the epidemic caused by human immunodeficiency virus (HIV). In 1984, the TB programme adopted the DOTS (directly observed treatment, short course) strategy and was supported in this endeavour by the International Union against Tuberculosis and Lung Disease (IUATLD); all districts in the country implemented this strategy over the following 1–2 years. The good recording and reporting system, which is inherent in the DOTS strategy, allowed the TB epidemic to be reliably monitored, and the number of notified cases rose from 5334 in 1985 to

20 630 in 1996 (Malawi NTP, 1996). As the NTP struggled to cope with the increasing number of cases and a deteriorating economic situation, national cure rates for smear-positive TB patients decreased from 86% in 1986 to 63% in 1992, and increased slightly to 68% in 1994 (Malawi NTP).

In Malawi, the TB registers are maintained by the district TB officers (DTOs). Each registered TB patient is given a unique registration number, and the name, age, sex, address, date of diagnosis, type and category of TB are recorded. Patients are treated with standardized antituberculosis regimens, depending on the type and category of TB. Newly diagnosed smear-positive pulmonary tuberculosis (PTB) cases receive 8 months of short-course chemotherapy, comprising 2 months of initial intensive treatment in hospital with daily supervised doses of streptomycin, rifampicin, isoniazid and pyrazinamide, followed by 6 months of unsupervised continuation therapy at home with isoniazid and thiacetazone or isoniazid and ethambutol. The drugs used in the continuation phase may be supplied to patients by the hospital or health centre. Sputum smears are examined after 2 months, 5 months and 8 months of treatment, and the outcome at the end of treatment is recorded according to the guidelines (see Table 1) established by the IUATLD and WHO (1, 2).

In the Blantyre district, which has 15 government health centres providing a TB service to the community, the cure rates in 1991 were less than 50%, with high default and transfer rates among

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patients (3). Although cure rates have improved since 1991, the recorded default rates are still unacceptably high at around 10–15%. Defaulters are an extra risk for the population because of possible contagion and the development of drug resistance by tubercle bacilli. The reasons for such defaulting in Malawi and other parts of sub-Saharan Africa are not known, but may include failure to report or record the cure or death of a patient, failure to collect the necessary drugs from the hospital or health centre because the patient was too ill, discontinuation of treatment by the patient after experiencing an initial improvement, and failure to notify the health care system that the patient had transferred to another health centre.

In the present study we investigated the status of patients with smear-positive PTB who had been registered as defaulters in the two principal hospitals which manage TB in the Blantyre district, and the possible reasons for their defaulting.

Patients and methods

The outcomes of 8 months of treatment of all smear-positive PTB patients who were registered between 1 October 1994 and 30 September 1995 in the TB registers at the Queen Elizabeth Central Hospital and the Mlambe Mission Hospital, Blantyre district, were studied. The name, age, sex, home address and treatment unit of patients who had been registered as defaulters were recorded, and a search was initiated to determine what had happened to them.

Between 31 December 1996 and 31 March 1997 the mortality records of patients admitted to the hospital for the intensive phase of treatment were inspected to determine whether those registered as defaulters had in fact died in hospital. The peripheral unit (usually a health centre) where the patients received the continuation phase of treatment was then visited to determine whether there were any records of the treatment outcome. If there was no such record or the patient was still registered as a defaulter in the health centre, attempts were made to trace the patient or a relative in the home or workplace. This required making journeys to villages by motorcycle. If there was still no trace of the patient, a letter was written if a post-office box number was present in his/her treatment unit records or the TB register.

In this way we investigated and documented the true 8-month treatment outcome of patients who had been registered as defaulters. According to the IUATLD and WHO definition (1, 2), true defaulters are patients who at any time during the course of treatment had not collected their drugs for two or more consecutive months. All defaulting patients who were still alive, or a near relative, were interviewed (using a structured questionnaire) to determine the following: the current health status of the patient or, if deceased, the date of death; any financial or other difficulties which prevented collection of antituberculosis medication; the distance from the home to the health facility and the

time taken to make this journey; and the presence of any other disease besides PTB. In order to determine the factors that could have been associated with defaulter status, a second interview, using another questionnaire, was carried out with the true defaulters and with a group of cured, fully compliant TB patients (matched for age and sex) who had been registered during the same period. This second interview, which was based on the health belief model (4–6), gathered information about demographic and socioeconomic variables, the patient's health-seeking behaviour and knowledge about antituberculosis treatment, the continuing availability of such treatment, the relations between the health care worker and the patient, the health status of the patient during the continuation phase of treatment, as well as ease of access to the health unit.

Results

A total of 1099 new smear-positive PTB patients were registered at the Queen Elizabeth Central Hospital and the Mlambe Mission Hospital during the 12-month study period; 126 (11.5%) of them had been registered as defaulters. Information about treatment outcomes was obtained for 101 (80%) of these defaulters (Table 1) through a home or village visit (100 cases) and by writing to one patient. Among patients whose treatment outcome was not a true default, we discovered a failure in communication between the district TB officer and the health centre in 70% of cases and between the patient and the health centre in the remainder.

Table 1. True 8-month treatment outcomes for 101 study patients who had been registered as defaulters

True outcome	No. of patients
Defaulted from treatment (i.e. patients who during their treatment had not collected drugs for two consecutive months)	22
Cured (i.e. patients who had completed treatment and whose sputum smear results were negative at the end of treatment)	27
Treatment completed (i.e. patients who had completed treatment but whose sputum smear results were not known at the end of treatment)	4
Died (i.e. patients who had died during the 8-month treatment regimen)	31
Transferred (i.e. patients who had transferred to another district and whose treatment outcome was unknown)	17
Total	101

Only 22 patients were true defaulters according to the IUATLD and WHO definition (1,2). At the time of the first interview, we found that 12 out of the 22 true defaulters had died since the end of their 8-month treatment period, 1 patient had moved out of the area, 1 patient had been wrongly registered in another unit and had defaulted again from treatment, and 8 patients were alive and well. In our first interviews we investigated 20 cases (the 8 who were alive and the relatives of the 12 patients who had died). The most important findings from these interviews are shown in Table 2. We also compared the 8 defaulters who were still alive with a group of age- and sex-matched cured patients who had been

fully compliant with their treatment. The main differences between the two groups were as follows: all 8 compliant patients were married, compared with none of the defaulters; and 7 of the compliant patients knew the correct duration of antituberculosis treatment, compared with none among the defaulters.

Discussion

The true outcome of 8 months of treatment was determined for 80% of the patients who had been registered as defaulters. The remaining 20% could not be traced because either their addresses in the TB register were incorrect and our inquiries in their villages did not help or our letters sent to their post-office box numbers were not answered. Of the 101 patients who were traced, only 22 were true defaulters. The true default rate was therefore considerably lower than that given in the TB register. The possible causes for the different treatment outcomes and suggestions for corrective measures are summarized in Table 3.

About one-third of the registered defaulters had in fact completed their treatment and many of them were cured. The DTO was not aware of this because either the officer had not visited and checked the results in the treatment unit registers, or the patient's transfer to another health centre had not been communicated to the DTO (one-fifth of the cases). Failure in communication between districts was also a problem, and this accounted for a small number of defaulters who should have been registered as "transferred" to another health centre. About one-third of the defaulting patients had died. Over 70% of tuberculosis patients registered for treatment at the Queen Elizabeth Central Hospital were HIV-seropositive (7); therefore, since the mortality rates among HIV-infected TB patients in sub-Saharan Africa are high (8-11) it is not surprising that many "defaulters" were in fact patients who had died. In the rural areas, with few telephones and difficulties in communication, it is unlikely that relatives would travel to the nearest health centre to report the death of a patient when there is no incentive to do so. Health centre staff are supposed to follow up all defaulters, but owing to transport difficulties, increasing workload, lack of motivation, concerns about safety in remote areas, and poor record-keeping, few of them do so. Ways to improve communication between health facilities within a district and between different districts must therefore be found.

We investigated the reasons why patients defaulted. Although only a small number of our defaulting patients could be compared with compliant cured patients, we found that unmarried status and ignorance of the duration of antituberculosis treatment were characteristic of defaulting behaviour. The public should be given more information about tuberculosis, especially the total duration of treatment and the need to complete the full course,

Table 2. Results of interviews with 8 study patients and relatives of 12 patients who had died, concerning 20 defaulters

No. of defaulters	20
No. of males/females	14/6
Mean age (years)	38.9 ± 13.0
Mean time to obtain the medicine (minutes)	147 ± 118
Mean distance to hospital/health centre (km)	7.7 ± 4.7
Mean survival time (months)	11.2 ± 6.5
Were there difficulties in obtaining medicine in general?	
Yes	89.5%
No	10.5%
Were financial problems incurred to obtain medicine?	
Yes	55.6%
No	44.4%
Were there difficulties in obtaining medicine due to patients' physical problems?	
Yes	36.8%
No	63.2%

Table 3. Possible causes and treatment outcomes for 79 patients who had incorrectly been registered as defaulters, and possible corrective measures

Treatment outcome	Possible causes	Corrective measures
Cured or treatment completed (<i>n</i> = 31)	DTO not visiting health centres ^a	Regular DTO visits to health centres ^a
	Health centres not communicating with DTO	Educate health centre staff about communicating the results of treatment outcome
Transferred (<i>n</i> = 17)	DTOs failing to communicate with each other	Quarterly DTO meetings at regional level
Died (<i>n</i> = 31)	Difficulties in relatives providing information to health centres	Better follow-up by health centre staff would result from having adequate transport, staff numbers and training

^a DTO: district tuberculosis officer.

via intensive health education through health care workers and the use of posters, leaflets and flyers in the local language. Malawi is a poor country, and it is therefore unlikely that substantial socioeconomic and demographic improvements can be made in the near future.

This study may raise questions about the reliability of data for other treatment outcomes. Cure rates and treatment completion rates can be verified from the patients' treatment cards, and sputum smear results from the laboratory records. Details of patients who move to another district should be recorded in the TB registers. These treatment outcomes are likely to be correct, although we have not specially investigated this. Deaths cannot always be verified if the patient died in the village, and

further research to assess whether death rates are accurate is probably warranted. ■

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Résumé

La véritable situation des tuberculeux non observants à frottis positif au Malawi

Pour faire face à la charge de plus en plus lourde que représente la tuberculose, de nombreux pays d'Afrique subsaharienne comptent sur leurs programmes nationaux de lutte antituberculeuse. L'un des éléments essentiels de la lutte antituberculeuse consiste dans la notification et le suivi des non-observants au cours du traitement. Au Malawi, le taux de non-observance varie de 10 à 15%. Au cours de la présente étude, nous avons cherché à déterminer quelle était la situation véritable des malades atteints de tuberculose pulmonaire avec frottis positif qui avaient été enregistrés comme non-observants dans les deux hôpitaux antituberculeux du district de Blantyre, en nous efforçant de trouver des raisons pouvant expliquer leur comportement.

Nous avons examiné les résultats de 8 mois de traitement chez tous les cas de tuberculose pulmonaire avec frottis positif consignés entre octobre 1994 et septembre 1995 sur les registres de la tuberculose de ces hôpitaux. Nous avons relevé l'identité de ceux qui étaient notés comme non-observants et nous les avons suivis par des visites à domicile ou, à défaut, en consultant les statistiques de mortalité des hôpitaux ou les dossiers des centres de santé. Nous avons interrogé les malades qui étaient de véritables non-observants selon la définition de l'OMS ainsi que les proches des malades qui avaient déménagé ou étaient décédés, afin de nous faire une idée de leur état de santé et de connaître les raisons qui les avaient amenés à ne pas observer le traitement. Nous avons ensuite procédé à un deuxième interrogatoire, basé sur une modélisation des croyances en matière de santé, des véritables non-observants et d'un groupe témoin de la même période, constitué de malades guéris (appariés par sexe et par âge).

Sur les 1099 malades que nous avons identifiés au cours de la période étudiée, 126 (11,5%) avaient été enregistrés comme non-observants, mais 22 d'entre eux (dont 8 encore en vie) ont pu véritablement être qualifiés

comme tels. De fait, environ un tiers des non-observants enregistrés étaient allés jusqu'au bout de leur traitement et un grand nombre avait guéri. La principale raison des erreurs d'enregistrement tenait à une mauvaise communication entre le Service antituberculeux distal concerné et les centres de santé. L'insuffisance de la communication entre les districts était également en cause, de même que l'absence de suivi des malades par les centres de santé. Au départ, nous avons interrogé 20 personnes: les 8 non-observants encore vivants et 12 proches des malades décédés. Au cours d'un second interrogatoire, nous avons comparé les 8 malades non observants à des patients guéris et parfaitement observants. Environ 90% des malades ou de leurs proches ont déclaré avoir eu des problèmes financiers ou diverses difficultés pour obtenir leurs médicaments. Comparativement aux patients guéris, les véritables non-observants se caractérisaient par le fait qu'ils étaient célibataires et n'avaient aucune idée de la durée normale de leur traitement.

Parmi les non-observants répertoriés, nombreux étaient les malades décédés. Dans des zones rurales avec des problèmes de communication dus notamment au sous-équipement téléphonique, on ne pouvait guère s'attendre à ce qu'un parent se rende jusqu'au centre de santé le plus proche pour y déclarer le décès d'un malade, s'il n'était pas poussé à le faire. L'absence de suivi des malades non observants par les centres de santé s'explique par les problèmes de transport, l'accroissement de la charge de travail que cette activité aurait produit, un manque de motivation et la mauvaise tenue des dossiers. Il importe donc de trouver le moyen d'améliorer la communication entre les établissements de soins, tant entre districts qu'à l'intérieur d'un même district.

En ce qui concerne les difficultés financières et les problèmes pratiques auxquels les non-observants ont eu

à faire face, on peut remarquer que le Malawi est un pays pauvre, dont la situation socio-économique et démographique n'a guère de chance de s'améliorer dans un proche avenir. Toutefois, en pratiquant une éducation

sanitaire intensive, il devrait être possible de corriger l'ignorance qu'ont les non-observants de la durée normale du traitement antituberculeux.

Resumen

Situación real de los pacientes con tuberculosis pulmonar y frotis positivo remisos a cumplir el tratamiento en Malawi

Muchos países del África subsahariana tienen programas nacionales de lucha antituberculosa para hacer frente a la creciente carga de tuberculosis (TB). Una parte esencial del control de la TB consiste en la notificación y el seguimiento de los pacientes remisos durante la terapia; en Malawi, la tasa de abandonos varía entre un 10% y un 15%. En el presente estudio investigamos la situación real de los pacientes con tuberculosis pulmonar (TBP) y frotis positivo que habían sido registrados como remisos a cumplir el tratamiento en los dos hospitales principales para casos de tuberculosis del distrito de Blantyre; se analizaron asimismo las posibles razones del abandono.

Examinamos los resultados de ocho meses de tratamiento de todos los pacientes con TBP y frotis positivo que figuraban en los registros de TB en esos hospitales entre octubre de 1994 y septiembre de 1995. Tras identificar a los pacientes remisos registrados, procedimos a hacer un seguimiento de los mismos, bien acudiendo a visitarlos a su domicilio, o bien, cuando ello no era posible, examinando los registros de mortalidad de los hospitales y los registros de los centros de salud. Entrevistamos tanto a pacientes que eran verdaderos remisos, según la definición de la OMS, como a familiares de pacientes que habían cambiado de domicilio o habían muerto, al objeto de conseguir información sobre su estado de salud y sobre las posibles razones del abandono del tratamiento. Se llevó a cabo una segunda entrevista, basada en el modelo de creencias de salud, entre los remisos verdaderos y un grupo testigo de pacientes curados (armonizado por edad y sexo) del mismo periodo.

De los 1099 pacientes identificados durante el periodo de estudio, 126 (11,5%) habían sido registrados como remisos, pero sólo 22 resultaron serlo realmente, y de éstos ocho seguían con vida. Casi un tercio de los remisos según los registros habían terminado en realidad su tratamiento y muchos estaban curados; otra tercera

parte había fallecido. La razón principal de los errores de registro era la deficiente comunicación entre la Oficina de TB distrital responsable y los centros de salud. La mala comunicación entre los distritos también era causa de problemas, al igual que la incapacidad para efectuar un seguimiento de los pacientes desde los centros de salud. Inicialmente llevamos a cabo 20 entrevistas: con los ocho pacientes remisos que seguían con vida, y con 12 familiares de pacientes fallecidos. En una segunda entrevista se procedió a comparar a los ocho pacientes remisos con pacientes curados que habían seguido fielmente el tratamiento. Casi un 90% de los pacientes o sus familiares señalaron que habían tenido problemas económicos o de otro tipo para obtener los medicamentos. En comparación con el grupo curado, los remisos verdaderos eran en general personas solteras y que no sabían cuánto debía durar el tratamiento.

Muchas de las personas consideradas remisas según los registros habían fallecido. En las zonas rurales, con pocos teléfonos y malas comunicaciones, era improbable que un familiar viajase hasta el centro de salud más cercano para notificar la muerte de un paciente, cuando no tenía ningún incentivo para ello. El personal de los centros de salud no podía realizar un seguimiento de los pacientes remisos debido a los problemas de transporte, la gran carga de trabajo, la falta de motivación y los fallos del sistema de registro. Por consiguiente, hay que hallar la manera de mejorar las comunicaciones entre los establecimientos de salud de cada distrito y entre los diferentes distritos.

En lo que respecta a los problemas financieros y prácticos afrontados por los pacientes remisos, cabe señalar que Malawi es un país pobre y que es improbable que su situación socioeconómica y demográfica mejore en un futuro próximo. Sin embargo, la ignorancia constatada entre los pacientes remisos respecto a la duración correcta del tratamiento podría remediarse mediante una educación sanitaria intensiva.

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