

## Non-adherence to tuberculosis treatment in the eastern Tarai of Nepal

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### SUMMARY

**SETTING:** Tarai districts, eastern Nepal.

**OBJECTIVES:** To identify potential methods of increasing adherence to tuberculosis (TB) treatment by determining factors that patients felt influenced adherence.

**METHODS:** New pulmonary TB patients registered from July to November 1998 with an outcome of non-adherence to treatment (NA) were identified from District TB Registers, traced and interviewed using a semi-structured questionnaire. An equivalent number of adherent (A) patients were interviewed.

**RESULTS:** Of 81 NA patients traced, 30 were interviewed, 16 had been incorrectly classified, age was incorrectly recorded in four, 13 had migrated and 18 were not found. The groups were similar in demographics, type and knowledge of TB. More A patients knew their diagnosis ( $P = 0.07$ ) and reported haemoptysis as an initial symptom ( $P = 0.03$ ). NA patients had longer travel

to a health facility ( $P < 0.001$ ), and fewer had been informed by health care workers (HCW) about the consequences of not completing treatment. The most common reasons given for stopping treatment were side-effects, HCWs' mistakes or behaviour, and health service failure. Desire for cure and knowledge that TB was curable were most the important reasons for completing treatment.

**CONCLUSION:** Non-adherence seemed related to treatment delivery failures. The health system needs strengthening in Nepal. Intensified HCW training and supervision, better health education for patients and families, more flexibility for treatment supervisors, adequate supplies for treatment centres and decentralisation of treatment delivery to the lowest health service level practicable are urgently needed.

**KEY WORDS:** non-adherence; tuberculosis; eastern Nepal

HEALTH BEHAVIOUR is unpredictable, and patients' behaviour often does not conform to the expectations of health care workers (HCWs) that they will follow the advice and treatment given. Adherence to any treatment, but especially to the long, complicated treatment for tuberculosis (TB), is determined by complex factors.<sup>1,2</sup> Cure of TB requires medication over long periods of time—even with so-called 'short-course' chemotherapy, which involves taking medication for at least 6 months—and leads to problems with treatment adherence.<sup>3</sup> Studies in many countries have demonstrated that it is almost impossible to predict which patients are not going to adhere to treatment and that the many reasons why patients do not adhere to TB treatment range from health care provider failures and deeply-held cultural beliefs among patients through to economic reasons.<sup>3-10</sup> The reasons vary in different settings, and are often country or culturally specific. In order to minimise non-adherence, it is necessary to ascertain the factors involved in a patient's decision to complete treatment or not in a specific setting.

The key to effective TB control is to find infectious cases and ensure that they are cured. To ensure cure, patients must receive correct treatment, take it correctly and be followed up bacteriologically. For the individual, non-adherence to treatment can lead to failure of treatment, further disability and possibly death, and for the community, perpetuation of the cycle of transmission, infection and disease. Worse still, non-adherent patients may develop and transmit drug-resistant TB, as irregular treatment increases the risk of developing drug-resistant disease.<sup>11</sup> If non-adherence is a major problem, it will be impossible for any TB programme to control the disease, as a cure rate of 85% must be maintained for 10-15 years to reduce tuberculosis incidence.<sup>12</sup>

TB remains a major public health problem throughout Nepal, especially in the highly populated lowland Tarai and the capital, Kathmandu. TB services are provided nationally by His Majesty's Government of Nepal's (HMG/N) Basic Health Services and international or national non-governmental organisations

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Article submitted 28 May 2002. Final version accepted 5 November 2002.

(I/NGO). Since 1994, an intensified National Tuberculosis Programme (NTP) has been implemented, with the internationally recommended directly observed treatment, short-course (DOTS) strategy being formally adopted in the NTP's Five-Year (1995–1999) Plan.<sup>13</sup> The five pillars of the DOTS strategy are: 1) political commitment to TB control activities; 2) case-finding primarily by sputum smear microscopy among symptomatic patients presenting to health facilities; 3) standardised short-course chemotherapy (SCC) given under direct observation (DOT); 4) adequate, uninterrupted drug supply; and 5) systematic monitoring and accountability for every patient diagnosed.<sup>14</sup> By late 1998, 71 treatment centres, mainly in the Tarai and the Kathmandu Valley, were implementing DOTS, covering about one-third of the population.

The aims of this study were to determine factors that patients felt influenced adherence to TB treatment in the eastern Tarai and to identify potential ways to increase treatment adherence.

## STUDY POPULATION AND METHODS

### Setting

The population of the six Tarai districts in the Eastern Development Region is 3.4 million ( $\approx 70\%$  of the regional total), with district populations ranging from 270 000 to 800 000. The East-West Highway bisects the eastern Tarai, and a good network of both tarmac and gravel roads serves the area. In 1996/1997, 85% of the 4500 new cases in the region were reported from the six Tarai districts.<sup>15</sup>

The HMG/N Basic Health Services (BHS) in the study setting are based on a network of zonal (3) and district (4) hospitals, primary health centres (17), health posts (59) and sub-health posts (360). Nationally almost 45% of households can access a health facility within a travel time of 30 minutes, and this applied to the study setting.<sup>16</sup> Each health institution level has a specified staff complement, ranging from the medical superintendent of the zonal hospital to a village health worker in the sub-health post. The NTP is implemented through the BHS structures and supervised via a network of regional and district TB/Leprosy Assistants. Health services are also provided by (I)NGOs, the private sector (especially in the urban areas) and a privately funded medical college. The Britain-Nepal Medical Trust (BNMT) supports the NTP in the areas of training, quality control of smear microscopy and programme evaluation.

Non-DOTS treatment centres use either the 12-month standard long-course chemotherapy (LCC) regimen or the 8-month unsupervised SCC regimen.\*

\* LCC regimen: 2SHT/10HT; unsupervised SCC and DOTS: Cat I 2EHRZ/6HE, Cat III 2HRZ/6HE, retreatment regimen 2SHRZE/1HRZE/5HRE. S = streptomycin; H = isoniazid; T = thioacetazone; E = ethambutol; R = rifampicin; Z = pyrazinamide. The numbers indicate the duration of the treatment phase in months.

The pattern of TB treatment regimens and service delivery varies in the six study districts: the LCC regimen is still used in three districts, whilst the other three utilise a mixture of unsupervised SCC or daily directly observed SCC (DOTS), as DOTS was not implemented across a complete district at once, but rather in a number of health facilities within the district. Hence the treatment regimen that a patient received depended on which health facilities' catchment area they lived in. Overall the DOTS strategy covers 26% of the study districts' populations. Treatment outcomes differ between the different regimens and delivery patterns. Cure rates with LCC are 25%, with non-adherence<sup>†</sup> at around 40%. Cure rates and non-adherence rates stand at respectively 65% and  $\leq 20\%$  for unsupervised SCC and 70–90% and  $\leq 10\%$  for DOTS SCC.

## METHOD

The study was of a non-randomised, exploratory nature, using semi-qualitative research methods. Ethical permission for the study was given by the Nepal Health Research Council and the NTP.

### Identification of treatment centres

Nine centres were to be selected, comprising one health post (HP) and two primary health centres (PHC) from each of three groups of centres offering the following different treatment regimens: 1) unsupervised LCC; 2) unsupervised SCC; and 3) daily directly observed SCC (DOTS). Each unit needed a minimum of 50 new cases registered for treatment per quarter.

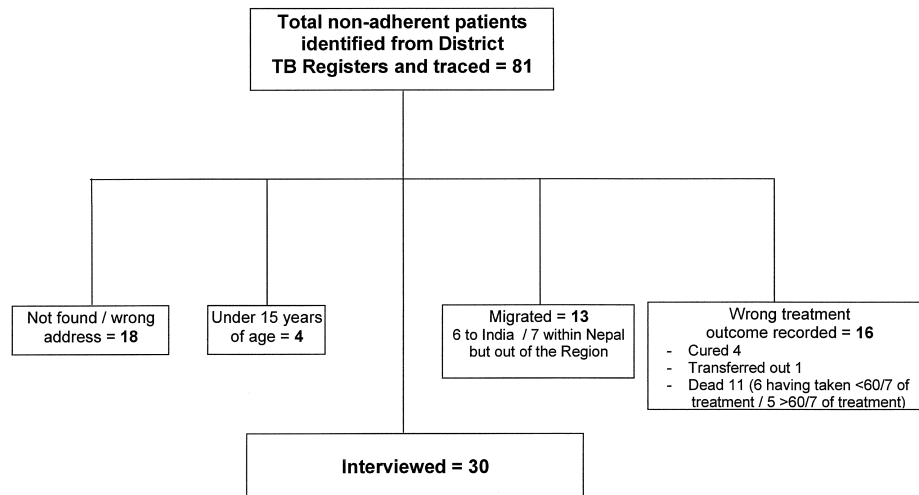
The initial selection criteria of treatment centres could not be followed fully due to the absence of PHCs in the districts where LCC was being offered, and as the treatment sub-centre of one selected PHC was a sub-health post, not an HP.

### Identification of patients

Inclusion criteria were as follows:  $\geq 15$  years of age, registered as a Category I or III pulmonary TB (new smear-positive or -negative) case in the district where the treatment unit was situated (i.e., not a 'transfer in' case). A non-adherent patient was defined as a patient who was more than 60 days late in collecting medicines.<sup>18</sup>

Patients who had a treatment outcome of 'non-adherence to treatment' reported in the 1st quarter of the 2055/2056 Nepali calendar (July–November

<sup>†</sup>Traditionally, patients have been said to be non-compliant with treatment. This has the connotation that the patient is subservient to the provider. As many of the reasons for non-compliance have been shown to be due to weaknesses in health service provision, the term 'compliance' is seen as inappropriate. Hence the term 'non-adherence', which reflects the active role of the patient in regard to treatment, is used in this article to denote patients who do not complete their TB treatment as prescribed.<sup>17</sup>



**Figure** Flowchart of the identification, selection and interview of non-adherent cases.

1998) were identified from the District TB Registers of the selected treatment centres. Identification and selection was continued until 10 non-adherent patients had been interviewed from each of the three groups. An equivalent number of patients who were adherent to treatment were also identified and interviewed: consecutive adherent patients in the TB register at each treatment unit were identified and selected for interview. Recruitment continued until a total of 30 adherent patients had been interviewed.

#### Data collection

A semi-structured questionnaire using open and closed questions was developed. The questionnaire was pre-tested by the field researchers (AKA & RD) on patients at the Nepal Anti-Tuberculosis Association Chest Clinic in Biratnagar. The required revisions were made to the questionnaires prior to the field work.

After identification, non-adherent patients were traced. If a patient was not found on the initial visit, a maximum of two repeat visits were made. If they had moved within the district, they were traced and interviewed. If they had no forwarding address or had moved outside the district, basic information was recorded from secondary sources (family members or neighbours). Once a patient had been traced, and verbal consent had been given, the field researchers conducted one-to-one interviews with the individual to explore the reasons for non-adherence. At the same time the interviewer encouraged the patient to return to treatment. The same interview process was followed for the adherent patients selected as controls.

The field work for the study took place during January–March 2000. In the first 2 weeks, weekly review meetings of the field researchers (AKA and RD) and research co-ordinators (DFW and SS) were

**Table 1** Patients by treatment group

	LCC	Unsupervised SCC	DOTS SCC
Non-adherent			
Total identified	35	47	33
Interviewed	10	10	10
Not found/wrong address	3	10	5
Wrong outcome recorded in TB Register	3 (3 deaths)	3 (3 deaths)	10*
Died having taken <60/7 of treatment	2	2	2
Died having taken >60/7 of treatment	1	1	3
Migrated	4	4	5
To India	3	1	2
Within Nepal, but outside the region	1	3	3
Under 15 years of age	1	2	1
Adherent			
Total identified	13	10	15
Interviewed	10	10	11
Not interviewed	3 (not found)	—	4 <sup>†</sup>

\* 4 cured/1 transfer out/5 deaths.

<sup>†</sup> 2 internal migrants, 1 wrong address, 1 wrong name.

LCC = long-course chemotherapy; SCC = short-course chemotherapy; DOTS = directly observed treatment, short-course strategy.

**Table 2** Socio-demographic and disease characteristics of interviewee groups

	Non-adherent (n=30)	Adherent (n=31)
Median age in years (range)	36.5 (16–80)	40 (17–68)
Male:female	22 (73%):8 (27%)	22 (71%):9 (29%)
NPTB+:NPTB–	16 (53%):14 (47%)	17 (55%):14 (45%)
Haemoptysis reported as an initial symptom	10*	19*
Type of disease as reported by interviewee		
Pulmonary	6 <sup>†</sup>	13 <sup>†</sup>
Extra-pulmonary	5	6
Not known	19	12
Sputum smear result as reported by interviewee		
Positive	12	14
Negative	6	8
Not known	12	9
Category I:Category III <sup>‡</sup>	10 (50%):10 (50%)	14 (67%):7 (33%)
Illiterate/Class 1–5	17 (57%)	14 (45%)
Unemployed/unskilled <sup>§</sup>	22 (81%)	19 (66%)

\* Mantel-Haenszel test ( $P = 0.03$ ).

<sup>†</sup> Mantel-Haenszel test ( $P = 0.07$ ).

<sup>‡</sup> Remaining cases were treated under LCC and were thus not categorised.

<sup>§</sup> Old age pensioners were excluded from the totals (NA 27/A 29).

NPTB+ = new smear-positive pulmonary TB; NPTB– = new smear-negative pulmonary TB; LCC = long-course chemotherapy.

held at BNMT's headquarters in Biratnagar. Team meetings were then held every 2 weeks.

The data from the questionnaires were collated manually, and where appropriate statistical analyses was performed using Student's *t*-test and the  $\chi^2$  test. A *P* value of <0.05 was taken as statistically significant.

## RESULTS

Treatment centres were selected as follows: LCC, three HPs in one district; SCC, one sub-HP and two PHCs in two districts; DOTS, one HP and two PHCs in two districts.

Of the 81 NA patients identified and traced, 30 were interviewed, 16 had been incorrectly classified as non-adherent in the District TB Register, 13 had migrated, 18 were not found (leaving no information on their whereabouts), and four were found on interview to be under 15 years of age (Figure, Table 1). For those with an incorrect address or treatment outcome, discrepancies in the recording of these details were found between the District TB Register and patients' treatment cards in about half. Thirty-eight adherent patients were identified and traced, and 31 were interviewed (Table 1\*).

With regard to age, sex ratio, type of disease, treatment categories, literacy rates and employment status, no significant differences between the non-adherent (NA) and adherent (A) groups were found (Table 2). More patients in Group A knew their correct diagnosis (Table 2), and significantly more reported haemoptysis as an initial symptom ( $P = 0.03$ ). No differ-

ences were found in relation to other initial symptoms reported, illness supposed (NA 8, A 5 answered 'TB'), whom first contacted (family NA 25, A 26) and first HCW visited (private doctor NA 11, A 14; government doctor at PHC or hospital NA 10, A 10).

There were no differences with regard to mean time from first symptom to presentation to a government HCW or from diagnosis to starting treatment, treatment (or not) at nearest health facility, method of transport to health facility, and travel costs to health facility (Table 3). A significant difference was found in mean travel time to health facility ( $P < 0.001$ ).

Reasons for not being treated at the nearest health facility were: TB treatment not available at nearest health facility (NA 4, A 7); sent by hospital staff to health post despite hospital being nearer to patients' home (NA 5); and patient's father knew PHC staff and sent his son there for treatment (NA 1).

The overall mean time to default amongst non-adherent patients was 80 days (range 6–210) (Table 3). Although the DOTS group appeared to default earlier, the difference compared to the LCC and SCC groups was not statistically significant.

As regards information reportedly given to patients by HCWs during treatment, no differences between NA and A interviewees were found on five points: free TB drugs provided by the government health services; total duration of treatment; number of daily tablets that needed to be taken; frequency of drug collection from health facility; and what to do in the case of side-effects from the TB drugs (however, 21 in each group had not been informed what to do if they had side-effects). A significant difference was found, however, with regard to the consequences of not completing TB treatment, with eight NA patients

\* An additional adherent patient was interviewed as a result of number 30 and 31 being traced and interviewed simultaneously by the two field researchers who were working separately in the field.

**Table 3** Health facility presentation and other characteristics of interviewees

	Non-adherent (n=30)	Adherent (n=31)	P value (t-test)
Mean time from first symptom to presentation to a government HCW (days)	120 (range 3–365)	127 (10–730)	0.86
LCC	145	116	
SCC	126	111	
DOTS SCC	110	133	
Mean time from diagnosis to treatment initiation (days)	3.9 (1–22)	3.7 (1–18)	0.87
Treated at nearest health facility	20	24	0.35 ( $\chi^2$ test, Mantel-Haenszel)
Mode of transport to health facility			
Bus	9	11	
Foot	6	11	
Other	15	9	
Mean travel time to health facility (mins)	102 (5–150)	51 (10–300)	<0.001
Mean travel costs to health facility (NR)	8.9 (0–60)	8.5 (0–80)	0.90
Mean time to default (days)	80 (6–210)		LCC:SCC 0.69
LCC	81 (7–210)		LCC:DOTS 0.58
SCC	92 (10–210)		SCC:DOTS 0.33
DOTS SCC	66 (6–180)		

HCW = health care worker; LCC = long-course chemotherapy; SCC = short-course chemotherapy; DOTS = directly observed treatment, short-course; NR = Nepalese rupee.

**Table 4** Interviewees' knowledge of tuberculosis and treatment (most gave more than one response to several of the questions)

Question	Answer	Non-adherent (n = 30)	Adherent (n = 31)
How do you catch TB? How is TB spread?	'Eating the food or food remains of a TB patient'	21	25
	'Via breathing, coughing or via sputum of a TB patient'	20	23
	'By sleeping in a TB patient's bed or sleeping with a TB patient'	12	14
Symptoms of lung TB?	Cough	26	25
	Fever	26	23
	Coughing up blood	17*	25*
How is TB cured?	'Take treatment regularly'	23	23
	'Take a complete course of treatment'	10	8
What happens if a patient does not complete the full course of treatment?	'May die'	26	25
	'Disease may come back or need to take treatment again'	21	22
	'Get worse/not cured'	11	7
	'Pass disease on to others'	6	3

\* Mantel-Haenszel test,  $P = 0.03$ .

stating that they had not been informed compared with one A patient (Fisher's exact 2-sided test,  $P = 0.01$ ).

There were no significant differences in responses to the questions: 'How do you catch TB?'; 'What is the cause of TB?'; 'Can TB be passed on to other people?'; and 'How is it spread?' (Table 4). Interviewees often answered the same question with more than one option. Cough and fever were the most commonly mentioned symptoms of 'lung TB'. More A interviewees named 'coughing blood' as a symptom ( $P = 0.03$ ).

All except one A patient thought that TB was curable by 'taking treatment regularly' and 'taking a complete course of treatment' (Table 4). When asked, 'How long is the treatment?', of those cases treated with SCC/DOTS, 12 NA and 17 A patients answered correctly (8 months), and 4 NA and 5 A patients treated by LCC gave the correct duration of 12 months. There was no difference when interviewees

were asked, 'What may happen if a patient does not complete the full course of treatment?'. This contrasts with the significant difference found in regard to the information reportedly received by the patients from HCWs during treatment in relation to 'What happens if the patient does not complete the TB treatment?'

The most common reason (11/32\*) given by non-adherent patients for stopping taking their treatment was treatment side-effects such as vomiting, stomach problems and itching (Table 5). Nine of the 11 interviewees reported that they had not been informed by their HCWs about what to do if they experienced side-effects. In the DOTS group, five of the seven interviewees who mentioned this gave 'side-effects' as the factor that led to their stopping treatment.

\* Total 32, as some respondents mentioned more than one factor in reply to the question.

**Table 5** Factors that encouraged non-adherent patients to stop taking their treatment (some respondents gave more than one factor)

Factor for non-adherence	DOTS SCC	Unsupervised SCC	LCC	Overall
Related to side-effects of TB drugs	6	2	3	11
HCWs' mistake or behaviour	4	3	1	8
Couldn't afford the investigations and/or treatment ordered by the HCWs.	2	—	—	2
Pregnant patient told by HCW to stop TB drugs otherwise the baby would be born disabled.	1	—	—	1
Told by the HCWs at the first visit that he did not have TB.	—	—	1	1
Patient ill so sent his son to collect the drugs; HCW refused to give the son his drugs.	—	1	—	1
Patient doing exams requested a week's supply of drugs; when HCWs refused, patient bought drugs from private pharmacy.	1	—	—	1
HCW asked for money for a new treatment card and to do a sputum test.	—	1	—	1
Lost her treatment card, thought that she could not get her drugs and that HCW would shout at her as had happened previously, so stopped taking the treatment.	—	1	—	1
Health service failure	—	2	2	4
No drugs at the PHC, told to buy drugs at a private pharmacy.	—	2	—	2
Self-transferred to the hospital nearby, took full treatment, i.e., completed treatment and not non-adherent	—	—	1	1
No improvement, saw a government hospital doctor who transferred her to a DOTS centre, took 8 months of LCC treatment, i.e., completed treatment and not non-adherent.	—	—	1	1
Patient choice	1	1	2	4
Did not like taking TB drugs, argued with HCWs, bought drugs from a private pharmacy for 3 months.	—	—	1	1
Felt better after 2 months of treatment and stopped taking the treatment.	1	—	—	1
Switched to buying drugs from private pharmacy after 3 months; took 12 months treatment in total.	—	—	1	1
No improvement, villagers told him that he did not have TB, so stopped taking the treatment.	—	1	—	1
Private doctors	—	1	1	2
No improvement, saw a private doctor who told her that the government drugs did not work and that she should buy them from a private pharmacy, which she did for 3 months, then stopped.	—	—	1	1
Government doctor told patient that he needed 8 months of LCC treatment, but private doctor said he only needed 3 months. Felt better after 3 months and stopped taking the treatment.	—	1	—	1
Miscellaneous	—	1	1	2
Could not cross the river to reach the HP during the monsoon season.	—	—	1	1
Disabled patient's mother collected drugs; when she had to move away no-one collected his drugs afterwards.	—	1	—	1
Expense	1	—	—	1
Couldn't afford the transport costs.	1	—	—	1

HCW = health care worker; HP = health post; PHC = primary health centres.

The desire to be cured and to continue caring for their families, and the knowledge that TB was curable were the most common factors given by the adherent interviewees that encouraged them to complete their treatment (Table 6).

**Table 6** Factors that encouraged adherent patients to complete their treatment (some respondents gave more than one answer)

Factors encouraging adherence	No. of patients
Knowing/thinking that TB was curable	20
Wanting to be cured	9
Wanting to survive so as to continue caring for their families	9
Counselling/advice of the health care workers	6
Free treatment	1
Not wanting to pass the disease onto others	1
Knowledge that if they stopped their treatment they might die or the TB may return	1

## DISCUSSION

Although it is based on a small sample, this study highlights the complexity of the issue of adherence to TB treatment. Adherence should be seen as a chain of responsibilities, including patients' behaviour (patient adherence), HCWs' treatment of patients (HCW adherence), and decision-makers' and society's behaviour (system adherence).<sup>19</sup> Factors related to all three were discovered in the study, but were linked mainly to HCW and system adherence.

A significant number of patients reported to be non-adherent were in fact not so. Inaccuracies between reported and actual treatment outcome are not an uncommon event in developing countries.<sup>20,21</sup> In this study, however, most such patients had the correct information recorded on their treatment cards, which was then transcribed inaccurately into the District TB Register, leading to incorrect reports being submitted. These errors lie within the responsibility of the HCW (District

TB/Leprosy Assistant) in charge of completing the TB Register and cohort reports, i.e., HCW adherence.

The non-adherent and adherent groups of interviewees were similar in many respects. However, adherent patients seemed better informed about their disease: more knew their diagnosis correctly and significantly more reported haemoptysis as an initial symptom that presumably underlined the presence of serious illness and the need for treatment. Both groups showed fairly good knowledge about TB, but significantly more non-adherent interviewees reported that they had not been informed by their attending HCW about what would happen if they did not complete their treatment.

Despite this seemingly good knowledge of the disease and treatment, the non-adherent patients did not seem to act upon this knowledge. The most common reported reason for non-adherence was related to the drug side-effects. Worryingly, a high number (7/10) of the non-adherent DOTS group reported that they had not been informed by the HCWs what to do if they had side-effects, and a high proportion (5/7) subsequently gave 'side-effects' as the reason for defaulting. The same lack of information about what to do in the case of side-effects was seen in the other two treatment groups and, interestingly, also in the adherent group. Logically, this type of information would only become important in relation to treatment adherence if a patient actually had side-effects, otherwise it would not appear important. Again, giving or not giving this type of information is within the HCWs' area of responsibility, i.e., HCW adherence.

The second most common reason for non-adherence was grouped under the heading 'HCWs' mistakes or inappropriate behaviour'. When added to the findings discussed in the above paragraph, the importance of the interaction between the HCW and the patient seems crucial to treatment adherence. Factors mentioned by interviewees demonstrate serious breakdowns in the HCW-patient relationship. The finding that HCWs respond aggressively to patients, especially towards those who presented late for treatment, is not new in Nepal.<sup>22</sup>

By contrast, only a few of the reasons given for non-adherence appeared to be related to the patient, i.e., patient adherence. Two of the four patients who stopped their NTP treatment themselves (one after an argument with an HCW) actually continued taking TB treatment, choosing to purchase the drugs from private pharmacies, and one completed a full course of treatment. Interestingly, even though travel time for the non-adherent interviewees was significantly longer (although not more costly in monetary terms), only one patient gave transport cost as the cause of non-adherence. Quality of care has been found to be an important determinant in people's choice of health facility, and can lead to bypassing free public health facilities in favour of fee-paying services.<sup>23</sup>

Care, however, should be taken before generalising these findings, due to the small number of cases interviewed in the study. The non-randomised sampling method may also have introduced hidden biases in the group of patients interviewed. In addition, educational, cultural and socio-economic differences between the interviewers and interviewees may have influenced the interviewees' responses. The interviewers were educated urban researchers, while the interviewees were mainly rural illiterate/semi-literate unemployed or semi-skilled workers. Even with both interviewers being male, the male:female ratio amongst the interviewees closely mirrored the sex ratio reported by the NTP in case notifications. Although not documented in the study, it is generally felt that females who commence treatment often adhere to treatment better than males. It must also be said that many interviews were done in the presence of patients' family members or friends. Culturally this would be expected, but again this may have influenced the replies given by the interviewees. Finally, the reasons stated for default by the interviewer have been taken as a statement of fact. This, however, cannot be validated, and must be accepted as a limitation to the study findings.

Despite the above considerations, the study highlights areas for concern that require action. The improved treatment outcomes seen since the introduction of the DOTS strategy in different settings have been much discussed, with considerable focus on the DOT aspect of the strategy. In relation to treatment adherence, however, this study indicates that strengthening the health system is just as crucial, not just in terms of buildings, supplies and reporting systems, but also in improving staff motivation and capacity. The importance of staff, community, motivation and a feeling of ownership of the programme in the success of the DOTS strategy in Nepal has recently been highlighted.<sup>24</sup>

Interestingly, although a number of adherent interviewees suggested that HCWs should intensively supervise patients because they may be discontinuing treatment for some reason, none of the DOTS group interviewees gave the reason of daily DOT as the factor that encouraged their non-adherence to treatment. Although the DOTS group appeared to default earlier than the other two groups, their time of default would also have been detected earlier due to the more frequent attendance required under the DOTS strategy, i.e., every day during the intensive phase for DOT.

Although as yet small in scale compared to India, the private health sector in Nepal is growing. The influence of private doctors was demonstrated in the study by the fact that two patients stopped their NTP treatment on the advice of private doctors, and subsequently received sub-optimal treatment. The NTP needs to engage the private health sector in dialogue, provide information about the TB programme and assist in improving the standard of TB treatment provided in the private sector.

The first response of HCWs in Nepal, when asked

about how to address the problem of non-adherent patients, is often that a tracing system needs to be initiated (verbal discussions between authors and HCWs). There may be a small role for a default tracing system, as it may encourage some patients to return to treatment and may pick up some concealed deaths. Its most important role, however, may be to bring into therapy those patients who have not started treatment despite being diagnosed (primary defaulters).<sup>25</sup>

However, in contrast to the above often-stated need for a tracing system for late or default cases, this study highlights that the majority of factors leading to non-adherence lie within the realm of HCW and system adherence. If alternative actions had been taken, such as HCWs informing patients about side-effects and what to do if they occurred, especially at the initial visits, it is possible that many of the non-adherent cases interviewed in the study would have been averted. If so, then the need for systems and resources for tracing late and defaulting cases would be much reduced.

#### *Suggested actions*

Intensified HCW training and supervision is required, with a better understanding of the recording and reporting systems to reduce errors. Training needs to include communication skills to improve communication between HCWs and patients and family members, especially in view of the need for a careful initial interview with the patient to accurately record registration details.

Better health education should be provided to patients and family members. The knowledge that TB was curable and the desire to be cured were strongly highlighted by the adherent interviewees. Transmission of knowledge between HCW and patient appears to be crucial. Although lack of knowledge has been shown to be a factor in the non-adherence of patients to TB treatment,<sup>26,27</sup> this study demonstrates that knowledge alone does not guarantee adherence. Health education that solely aims to transmit information is not enough: it should also be directed at behavioural change.<sup>3</sup> Good health education early in treatment may also encourage those who migrate to present to a health facility on reaching their destination.

Some flexibility should be delegated to the DOT supervisors, such as the authority to increase the duration of drug supplies or give the drugs to a relative in exceptional circumstances (e.g., an acute illness leading to the temporary inability of patients to collect their drugs themselves). Adequate logistics support for treatment units must be ensured, especially of drug supplies, in order to enable HCWs to supply drugs to patients on time. Finally, treatment delivery should be decentralised to the lowest possible level of the health service to enable easier patient access to treatment.

#### *Acknowledgements*

The authors wish to thank all those patients who gave their time to be interviewed. We also wish to thank Dr Dirgh Singh Bam, Direc-

tor, National TB Centre, His Majesty's Government of Nepal National TB Programme, Kathmandu, for his support and advice to the project, the HMG/N health staff of the Districts who gave their assistance to the field researchers, and to the members of BNMT's TB Sub-Committee and Ms Diane Waring for their help and support with this project and paper.

The study was financed by the BNMT TB/Leprosy Control Programme, with donor funds from the Department for International Development and the National Lottery Board, UK.

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## RÉSUMÉ

**CADRE :** Les districts de Tarai dans l'est du Népal.

**OBJECTIFS :** Identifier les méthodes potentielles d'amélioration de l'adhésion au traitement de la tuberculose (TB) en déterminant les facteurs perçus par le patient comme influençant l'adhésion.

**MÉTHODES :** Les nouveaux cas de TB pulmonaire enregistrés entre juillet et novembre 1998 avec comme résultat l'absence d'adhésion au traitement (NA) ont été identifiés dans les registres de TB du district, recherchés et interviewés en utilisant un questionnaire semi-structuré. Un nombre équivalent de patients avec adhésion thérapeutique (A) ont été interviewés.

**RÉSULTATS :** Parmi les 81 patients NA recherchés, 30 ont pu être interviewés, 16 avaient été classés incorrectement, l'âge avait été noté de façon incorrecte chez quatre, 13 avaient déménagé et 18 n'ont pas été retrouvés. Les groupes étaient similaires en termes d'aspect démographique, de type et de connaissance de la TB. Un plus grand nombre de patients A connaissaient leur diagnostic ( $P = 0,007$ ) et ont signalé des hémoptysies comme premier symptôme

( $P = 0,03$ ). Les patients NA avaient des durées de déplacement plus élevées vers les services de santé ( $P < 0,001$ ) et un plus petit nombre avaient été informés par les travailleurs de la santé (HCW) des conséquences du non-achèvement du traitement. Les raisons citées les plus fréquemment de l'arrêt du traitement étaient les effets secondaires, des erreurs ou le comportement des HCW et les déficiences du service de santé. Les raisons les plus importants de terminer le traitement sont le désir de guérir et la connaissance du fait que la TB est guérissable.

**CONCLUSION :** La non-adhésion semble liée aux déficiences d'administration du traitement. Le système de santé doit être renforcé au Népal. Les besoins urgents identifiés sont l'intensification de la formation et de la supervision des HCW, une meilleure éducation des patients et des familles en matière de santé, une plus grande flexibilité attribuée au superviseur du DOT, des fournitures adéquates au centre de traitement et la décentralisation de l'administration du traitement vers le niveau du service de santé le plus bas.

## RESUMEN

**MARCO DE REFERENCIA :** Distritos de Tarai, en el este de Nepal.

**OBJETIVO :** Identificar métodos potenciales de identificación del cumplimiento del tratamiento de la tuberculosis (TB) determinando los factores que influyen sobre el cumplimiento, percibidos por el paciente.

**MÉTODO :** Los casos nuevos de TB pulmonar registrados entre julio y noviembre de 1998, con la mención no cumplidor del tratamiento (NA), fueron identificados en los Registros de TB de Distrito, localizados y entrevistados utilizando un cuestionario semiestructurado. Se entrevistó un número equivalente de pacientes cumplidores (A).

**RESULTADOS :** De los 81 pacientes NA localizados, 30 fueron entrevistados, 16 habían sido clasificados incorrectamente, la edad había sido incorrectamente registrada en cuatro, 13 se habían mudado y 18 no fueron encontrados. Los dos grupos eran similares en cuanto a los aspectos demográficos, tipo y conocimientos sobre la TB. Un número mayor de enfermos A sabía su diagnóstico ( $P = 0,07$ ) y señalaron una hemoptisis como síntoma inicial ( $P = 0,03$ ). Los pacientes NA tenían un

mayor tiempo de trayecto para acceder al centro de salud ( $P < 0,01$ ) y un menor número había sido informado por los trabajadores de la atención de salud (HCW) de las consecuencias si no completa el tratamiento. Los motivos dados más frecuentemente para suspender el tratamiento fueron los efectos adversos, los errores o la conducta de los HCW y las deficiencias de los servicios de salud. El deseo de curar y el conocimiento que la TB es curable eran los motivos más importantes que contribuían al cumplimiento del tratamiento.

**CONCLUSIÓN :** El no cumplimiento del tratamiento parece estar en relación con las deficiencias de los servicios que proporciona el tratamiento. Es crucial el refuerzo del sistema de salud en Nepal. Son necesidades urgentes intensificar la formación y la supervisión de los HCW ; mejorar la educación para la salud de los pacientes y de sus familias ; delegar una mayor flexibilidad a supervisores del DOT ; obtener un adecuado abastecimiento de los centros de tratamiento y descentralizar la administración del tratamiento hacia el nivel más bajo practicable de los servicios de salud.