

The social reality of migrant men with tuberculosis in Kathmandu: implications for DOT in practice

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Summary

OBJECTIVE To establish which of the many possible linkages between tuberculosis (TB), direct observation of treatment (DOTS), and the social reality of migrant workers in Kathmandu are the most relevant to the health outcomes and economic and social well-being of these populations, and which are amenable to possible interventions and high-yield policy changes.

METHODS Fourteen semi-structured in-depth interviews were conducted through an interpreter with male migrant TB patients aged 18–50 years recruited from three DOTS clinics in the Kathmandu valley in May 2005. The interviews were coded using constant comparison and analysed using a grounded theory method.

RESULTS The economic burden of TB treatment is far greater than the financial reserve of migrants. Consequently remittances sent to families are reduced and migrants remain in debt long after treatment completion, tied to the treatment location paying off high interest loans. Forced to attend clinics far away from their home, and isolated by the stigma associated with TB, migrants are vulnerable without social support networks. Migrants find that daily clinic visits are incompatible with working schedules and important cultural festivals, which forces them into defaulting.

CONCLUSION The needs of migrant workers with TB living in Kathmandu are not being adequately met. Current service provision needs to be reviewed to build in greater flexibility and support for migrant men.

keywords tuberculosis, migrants, qualitative study, Nepal, direct observation of treatment

Introduction

Tuberculosis (TB) is a major cause of illness and death worldwide, especially in Asia and Africa: in 2006, 9.2 million new cases and 1.7 million deaths from TB occurred (WHO 2008). The complex interplay between various socio-economic and cultural factors accounts for variable rates of TB infection and disease progression between the sexes (Hudelson 1996). Incomplete treatment of TB is dangerous for the individual and the community. The lengthy regime required to treat TB is a well-documented cause of non-completion of treatment (Duncan 2003) leading to prolonged infectiousness, disease relapse, multi drug-resistant TB (MDR-TB), and ultimately death (Cox *et al.* 2008).

Within Nepal, more than 40 000 people are estimated to develop active TB every year (Wares *et al.* 2000; Sharma 2004), and TB causes 8000–11 000 deaths per year (Sharma 2004). Diagnosis and treatment follows the World Health Organization's observation of treatment (DOTS) strategy, a key element of which is a requirement for

patients to attend a treatment centre daily for the first 2 months, and monthly for the remaining 6 months of treatment. Despite this strict approach, TB remains a growing problem in Nepal. Rates of MDR-TB rose from 1.1% in 1996 to 2.6% in 2006 (Nepal National Tuberculosis Programme 2007); recent increases in reported rates of extensively drug resistant TB (XDR-TB) further emphasize this concern (Gandhi *et al.* 2006).

In the urban areas of Nepal, the annual risk of infection has been estimated to be 4.5% compared to 2.0% in rural areas (Nepal National Tuberculosis Programme 2007). This is thought to be due to higher population density, migration, homelessness, and higher HIV infection in urban centres (World Health Organization 2008). Furthermore, many patients are diagnosed somewhere other than their rural homeland, and the national policy for referral for treatment when a patient moves does not always function (Wares *et al.* 2000).

Due to economic instability, over the past 150 years the migration of male workers between urban and rural settings and across borders to and from Nepal's

D. E. Kirwan *et al.* **Migrant men with TB in Kathmandu**

neighbouring countries has become a crucial component of Nepali culture (Blaikie *et al.* 2000). In the 2001 census, 89% of the migrant population was male, 85% of whom migrated for employment, compared to 36% of the smaller female group. Women migrants were more likely to migrate out of the country and, lacking the education and skills required for formal sector employment, to take jobs such as housemaids (Central Bureau of Statistics 2002). Typically migrants return to their rural birthplace for harvests or religious festivals.

Additionally, recent political instability resulted in further internal and external migration. This presents significant challenges for timely initiation, continuation, and completion of TB treatment (Wares *et al.* 2000). Migrants act as mobile vectors for TB and so interventions aimed at maximizing early diagnosis and treatment completion in this population will have a substantial impact upon TB control in Nepal.

The dynamic nature of this mobile population and the historical freedoms to travel in the region make it difficult to gather accurate data to quantify the extent of migration in Nepal. As a result, despite an effective national reporting and recording mechanism for TB data, surveillance amongst the migrant population is certainly somewhat unreliable. However, it is likely that migrants suffer disproportionately from TB, since TB and poverty are closely associated, and migrants form a highly marginalized and deprived sector of Nepali society (Blaikie *et al.* 2000; Baral *et al.* 2007). This is supported by studies of TB elsewhere that have shown increased TB infection amongst migrant workers (Cummings *et al.* 1998; Bhatia *et al.* 2002; Ho 2004).

The National Tuberculosis Programme (NTP) of Nepal carried out an in-depth external review of its services in October 2007 (Nepal National Tuberculosis Programme 2007). This reported that compliance with daily DOT is 'difficult or impossible' for many patients. Many patients suffered major hardship resulting from indirect costs caused by an inability to work because of fixed opening hours, cost of travel to centres, etc. The review acknowledged that adherence is a complex multifaceted issue involving socio-economic, health service, and other issues, and requiring solutions. Migrants were identified as a particularly challenging sub-group of patients. The review recommended a 'patient centred' approach taking into account the diverse and complex effects of tuberculosis on peoples' lives, and that the NTP provide support for those who are required to relocate to receive treatment.

However, there remains a scarcity of data to support formulation of policy for TB control among migrants. This study therefore aims to provide a better understanding of the difficulties migrants face during TB treatment, from

their own point of view. The study focuses on the male migrant population of Kathmandu, Nepal, since males comprise the great majority of migrants in Nepal, although a further study using female participants would be warranted as they are likely to generate contrasting factors for consideration.

Method

This qualitative study used a grounded theory approach, with data collected through in-depth interviews. Three DOTS clinics in the Kathmandu valley were selected as study sites: Patan Hospital, Patan; Helping Hands Clinic, Chabahil, Kathmandu; and Mitrapark Health Post, Mitrapark, Kathmandu. Purposive sampling was used, with participants meeting the following inclusion criteria: positive diagnosis of TB; receiving treatment at one of the above health facilities; male; aged 18–50 years (i.e. economically active); born outside Kathmandu; and considering themselves to be migrants to Kathmandu from rural Nepal. The final criterion, of migrant status, illustrates the strong sense of identity which residents of Kathmandu have as either migrants or local residents, and was felt to be the most appropriate definition of a 'migrant'. The participants were identified by health staff working in the DOTS clinics. Ethical permission for the study was obtained from the Institute of Medicine, Tribhuvan University, Kathmandu.

The grounded theory method used in data collection and analysis is appropriate for the aims of this study (Crabtree & Miller 1999) due to its ability to generate theory on the basis of emerging insights. Data was gathered using semi-structured in-depth interviews. A list of questions was constructed, checked for cultural appropriateness of the content and wording by a Nepali health worker, and adjusted accordingly. The revised version was used as a guide for the interviews. DK carried out the interviews, supported by a trained Nepali interpreter. As the participants were mostly illiterate, verbal consent to conduct the interview and permission to record were obtained prior to the interview and documented on an information sheet and consent form, and a guarantee of confidentiality and anonymity given verbally.

As soon as each interview was completed, it was translated and transcribed, and the accuracy of the translation and transcription checked by a person fluent in both Nepali and English. The transcript was analysed in conjunction with previous transcripts to develop emerging themes based solely on the data gathered. The analysis involved 'constant comparison': after every interview useful information in the data was identified and coded, then grouped together into sub-categories, and finally core

D. E. Kirwan *et al.* **Migrant men with TB in Kathmandu**

categories were identified. Subsequent interviewees were selected, and where appropriate interviews modified, to allow emerging themes to be tested. A target of 10 participants was selected as it was predicted that saturation would be reached by this time.

Results

Fourteen interviews were conducted between the 11 and 24 May 2005. After the first seven interviews, it was found that no new issues were being raised. The subsequent interviews focused on specific issues: the impact on patients' finances; relationships with employers; and impact on social life, and provided a deeper understanding of themes already identified. Ages of interviewees ranged from 20 to 49 years.

Final analysis and coding led to the identification of nine core categories and 20 sub-categories. The core categories are given in Box 1. Many of these factors apply to all patients with TB; but migrant respondents particularly stressed problems with economic impact, social support networks, and interactions with TB services. All three matters arose repeatedly during interviews and were used to explain isolation when dealing with the social consequences of TB. The following discussion will focus on these three areas.

Economic impact

All but one of the patients interviewed stated that their financial status had been significantly affected by their illness and/or treatment. A diagnosis of TB was found to incur three key categories of costs: illness-related costs, living costs, and employment related costs.

Although free diagnosis and treatment are provided at government health facilities, respondents reported additional costs of transport, visits to health providers and other medicines. These costs are significant for migrant patients on low wages. The study found that costs were

particularly high where private services had been used; many migrants use expensive private services as a result of their ignorance of local public service provision. The NTP is currently involved in developing a private-public partnership to improve access to TB services in Nepal which may help to reduce this disparity (Newell *et al.* 2004).

Migrants have very few savings to help them cope with financial upset. Some patients reported having to spend all of their savings during their illness, with subsequent reduction of remittances affecting dependent relatives back home. TB may consequently affect their own living standards or may eliminate surplus income rendering them unable to save money, either for their own use or to send back to family members as remittances.

The absence or rapid consumption of savings also meant that migrants were forced to resort to borrowing early in their illness from relatives, friends, or employers. Loan repayment subsequently caused long-term financial problems that they expected would last much longer than their illness.

In some situations where patients were too ill to work, other family members were forced to earn money; one patient's wife was working full time as a direct result of his illness. As he attributed becoming ill to over-working, he expressed concern that his wife might also get TB through over-work, causing them further financial problems.

Two participants were students, and in both cases, their illness had significantly affected their studies. One patient and his family agreed that both the illness and the inconvenience of the daily visits were affecting his study. This patient's family was suffering financial hardship, and he was partly being supported by remittances from a brother working abroad. He expressed guilt and so planned to leave school to help his brother in supporting the family after completing treatment.

Employment

Because of the daily visits to DOTS centres, respondents generally found it necessary to inform their employer of their TB. Although initially reluctant to disclose their illness, most patients reported a favourable reaction from their employer including unpaid leave from work or financial assistance. However, the temporary nature of migrants' employment renders them particularly vulnerable to job losses, and some respondents were forced to resign and were left with no income. One interviewee lost his job as a result of the incompatibility between clinic opening times and his working hours. Others described friction with employers and a reluctance to disclose their TB status for fear of dismissal, leading in some cases to poor compliance with treatment. The concern about

Box 1 Core factors affecting migrants with TB in Kathmandu

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|----|------------------------------------|
| 1. | Economic impact |
| 2. | Employment and education |
| 3. | Health and wellbeing |
| 4. | Effects due to status as a migrant |
| 5. | Interactions with TB services |
| 6. | Impact on family |
| 7. | Stigma |
| 8. | Conflict |
| 9. | Other factors of interest |

disclosing their TB status was also influenced by their perceived likelihood of finding another job.

Interest rates on loans from employers were reported to be low. Repayment, however, often depended upon the patient recovering sufficiently to enable them to work. They were then tied to the place of employment on very low wages. Saving to pay back such a debt takes a long time, affecting the liberty of migrant workers to return to their home at regular intervals for cultural and religious Nepali festivals.

Social support networks

A strong social network is vital to the coping strategies of patients with TB. Many examples were given of occasions when they had relied on others for practical help, e.g. with affording food and accommodation, in addition to help coping with the psychological aspects of TB. Accounts were also given of occasions when these networks were absent.

However, many respondents reported having a weak social network, sometimes attributed to their migrant status. The development of social infrastructure takes time and is labour-intensive, and respondents reported that creating a circle of friends and contacts was a low priority for individuals on short contracts.

There were also reports of social networks weakening further as a result of TB. For example, one patient said that his colleagues and employer blamed his illness, and therefore his inefficiency at work, on him. Another patient felt that his employers and relatives 'are afraid of his disease, so they are treating him so differently'. Such views caused patients to conceal their illness from others, thereby isolating them from the support network they relied upon.

To gain the benefits of social support, some migrant workers would have preferred to return to their birthplace or go elsewhere for at least part of their treatment, but believed that the Nepali DOTS policy did not allow patients to transfer their treatment to a different clinic. This contributed to discontinuation of treatment.

Interaction with TB services

Migrants arrive in Kathmandu with little knowledge of the available TB services. Many patients decided where to access health care based on information gained by word of mouth so again, social networks and time spent in Kathmandu were found to be crucial. Respondents also cited illiteracy and a non-Nepali mother tongue as two additional examples of problems significant to migrants accessing TB services.

Patients who found daily visits convenient tended to be those who were not working, those whose working hours

were compatible with the visits or were flexible, or those with family members who, where permissible, could be sent to collect medication on their behalf.

Other patients complained of conflict between their working hours and the opening hours of clinics they were obliged to visit daily as part of the DOTS strategy. Examples were given of having to work extra hard at work to obtain permission to leave early, and reliance on friends to cover for absences from work. One migrant described both missing work because of the visits, and missing his medication because of his work, resulting in him being scolded by both his employer and the health staff. It can be inferred that the way in which medication is currently being distributed does not suit many patients' lifestyles, and some patients would benefit from more flexibility.

A common complaint was that, as a result of daily observation of treatment, patients were unable to visit their birthplace for short periods for important occasions in the Nepali calendar such as religious festivals. Current policy in Nepal restricts treatment to one clinic, so it is not possible for travelling patients to register as temporary visitors elsewhere. Patients said that they would like the option of receiving enough medication for short periods so that they could visit their village. Some patients complained of having been denied this option, while others had been given it; one patient had been given medicine for 9 days on production of his travel ticket. Although this is not formally allowed it appears that some health workers interpret the policy in a flexible, patient-centred manner, assessing each patient individually and deciding who they can 'trust' to take their medicine, and who they cannot. This could be included as an option in order to ensure standardization.

As already noted, some migrant workers would have liked to return to their birthplace to complete their TB treatment. However, some patients were either unsure of whether there were DOTS facilities available in their birthplaces or knew that there were not, and as a consequence had remained in Kathmandu to complete their treatment when otherwise they may have returned to their village. Two patients explained that the nearest DOTS facilities were 1 or 2 days away from their village, and they would have to find temporary accommodation nearby if they returned. They could not afford to do this, and had therefore remained in Kathmandu. One patient even explained that he could not return to his village because, even though there are government DOTS facilities available there, the health centre that distributes them charges money illegally, which the patient could not afford.

As this shows, the DOTS regimen not only affects whether or not a patient can visit his birthplace, but also where he lives; these patients were forced to remain in

D. E. Kirwan *et al.* **Migrant men with TB in Kathmandu**

Kathmandu because their treatment was either inaccessible or unaffordable in their birthplace. This further exacerbates the economic consequences of TB as these patients still have to pay rent that they could have avoided by returning to their villages.

Family

As alluded to previously and of particular concern is the impact of TB on migrants' families. Substantial economic problems arise: for example the direct and indirect costs of DOT; and increased pressure on other family members to earn when a patient is unable to work. Many of the patients expressed a worry about effects on their family if they did not recover or were unable to return to work. Respondents also had concerns about transmitting the illness to family members. As both TB and migration are associated with socio-economical disadvantage and poor living conditions, these concerns are not unwarranted. Furthermore, children may have to leave school due to economic consequences of a parent's illness. One patient wished to educate his child, but was worried that this would not be possible due to the financial difficulties that he was suffering.

Discussion and conclusions

This study examined the social reality of the male migrant with TB in Kathmandu. The findings demonstrate that both TB and DOT have a substantial social impact on migrant patients living in Kathmandu, and that their needs are being far from adequately met.

Specifically, daily visits for DOT are often impractical and inconvenient. There is a need for greater flexibility with the treatment regimen to accommodate the particular needs of this population, including their wishes to leave Kathmandu for short periods, and for a treatment regimen compatible with their working hours.

There is also a necessity for improved access to treatment in rural areas, and collaboration between rural and urban treatment centres. Improved systems for referral-for-treatment and monitoring and tracing referrals would permit patients to travel between the location of their employment and their home villages. This would lessen the adverse impact of DOT on their lifestyles, thus enhancing patient autonomy and quality of life whilst facilitating completion of treatment.

The lack of social support to migrants needs to be acknowledged as a problem for this group of patients, and measures must be put in place to provide support for the patients and their families. This could include education of employers regarding TB and DOT, and

further information on available TB services targeted at migrant workers.

Further policy development should include measures to reduce costs to the patient; research into developing a private-public partnership is a good example of how this is already taking place. Increased flexibility of treatment centre opening hours would allow patients to maintain employment whilst complying with their treatment. Alternatively, more patient-friendly approaches to treatment supervision could be considered: possibilities include community- or family-based DOT, both of which have been shown to be effective in Nepal (Newell *et al.* 2006). Financial provision to mitigate loss of earnings during illness could be considered in Nepal for those patients who are worst hit by economic problems.

The method excluded important groups within the migrant population of Kathmandu, including women and individuals with symptoms of TB who are not currently receiving treatment. Further research may be necessary to identify additional issues affecting these groups.

There is substantial migration of poor people across Asia and Africa, and these people are highly vulnerable to TB because of their crowded living conditions and poor nutrition. While the findings presented here refer to male migrants in Kathmandu, it seems likely that the issues that arise are relevant to migrants more widely. There is a growing body of evidence describing the explicit needs of migrant populations globally (Tang & Squire 2005; Munro *et al.* 2007; Long *et al.* 2008; Wang *et al.* 2008). Migrants are increasingly identified as poorly educated and economically and socially vulnerable, and at high risk of TB infection as a result of factors such as their crowded living conditions and poor nutrition. Despite this, however, TB programmes make little or no extra provision for their countries' floating populations.

Interventions such as better information and signposting of government facilities, and limited flexibility in treatment delivery, could be provided at little extra cost. Moreover, these provisions would benefit all patients, not only migrants. The findings of this study should therefore give an impetus to all TB control programmes to provide more patient-centred care focusing on the varying patient needs found within the different geographical areas they have responsibility for.

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D. E. Kirwan *et al.* **Migrant men with TB in Kathmandu**

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