Health services research at work for national health policy

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Citation for published version (APA):
ten Asbroek, A. H. A. (2006). Health services research at work for national health policy
How did you get here?
Twenty-six journeys on the road to tuberculosis treatment in rural Nepal


Submitted for publication
Abstract

The fact that tuberculosis can effectively be treated with DOTS (Directly Observed Treatment, Short-course) is not enough to control the disease. Patients have to find their way to DOTS first. To better understand the route to DOTS in rural Nepal we interviewed twenty-six patients enrolled in DOTS. In semi-structured interviews DOTS patients shared their disease history and health seeking behaviour. Patient routes often started in the medical shop and led via intricate routes with multiple providers to facilities with higher qualified and more competent staff where tuberculosis was diagnosed. Analysis showed several factors that influenced the route to DOTS. Besides known patients factors (such as severity of complaints, the ability to pay for services, availability of services and peer support for choosing a provider) we also identified specific health services factors. These included the perceived quality, costs and service level of a provider, and not being adequately referred by one provider to another. Self referral because of waned trust in the provider was very common. In contrast, once tuberculosis was considered a possible diagnosis, referral to diagnostic testing and DOTS treatment was prompt. Patient routes are likely to become shorter if providers of care are better capable of recognising tuberculosis and if providers are willing to refer patients in case of unsatisfactorily response to treatment, and if service level in facilities is improved. Whereas international initiatives rightfully address the disease management skills of providers, additional strategies are needed too. These should address the referral between providers in different levels of health care and the quality of services in primary care facilities.
Background

Tuberculosis causes a high burden of disease worldwide, especially in low and middle-income countries, despite the availability of efficacious treatment [1]. Tuberculosis treatment revolves around the DOTS strategy which has been proven to be effective [2]. An enduring challenge is how to ensure that tuberculosis patients find their way to DOTS. Lack of community awareness and patient knowledge about tuberculosis and its management have been mentioned by other researchers as obstructing factors [3;4]. Besides these patient factors, health service factors may be obstructing the road to tuberculosis treatment [5]. In this respect, insufficient human resources, lack of diagnostic facilities are some of the known barriers. As a consequence, patients may spend an unnecessary length of time before reaching DOTS, resulting in worse outcomes and an increased risk of disease transmission. Internationally, efforts have been made to improve the health services for patients with lung diseases, including tuberculosis. As patients ordinarily seek health care from multiple sources for different reasons, both in western and non-western societies [6-8] it is important to understand their routes through the system. Health care policymakers and program-designers need information about how patients use the health system and whether this confirms implicit assumptions about its functioning. With this in mind we assessed the patient’s narrative of their journey that eventually resulted in tuberculosis treatment. We aim to answer the following questions: “What is the route that these patients took through the health care system, from the moment of their first complaints until the start of DOTS treatment?”, “What were their reasons for taking this specific route?".

Methods

Setting

We conducted the study in the rural lowland district of Nawalparasi, in the Terai area of Nepal, bordering India. The Nepalese health care system faces multiple challenges such as lack of financial and human resources, difficult geographical and poor general infrastructure [9;10]. The health care system can be characterized as a national health system based on the principles of primary health care. In addition, there is a large private health care sector [11]. Nawalparasi has 601,000 inhabitants, for whom the following governmental health care facilities are available: 1 district hospital in its capitol Parasi, 5 primary health care centres, 8 health posts, 63 sub health posts, and a multitude of private health care facilities: hospitals, clinics, consulting medical officers, health workers and drug retail shops [12]. Much more and larger facilities can be found in the nearest big city, Butwal, approximately one hour by bus from Parasi. The sub-health posts are the smallest governmental health care facilities and provide basic health care. This includes mother and child health care, by a mother and child health worker, and general health care, by an auxiliary health worker who is also
the in-charge of the facility. Health posts have more, and higher educated staff. Primary health care centres are yet another, higher, level of facilities. The one district hospital has one medical doctor who is responsible for clinical care and the management of the hospital and who is also the head of the district health care as a whole. The regional hospital is the referral hospital for several districts and offers outpatient and inpatient services by many specialists. The tuberculosis control program in Nawalparasi is part of the national tuberculosis program. This previously ‘vertical’ program has been integrated at service provision level over the past decades. In Nawalparasi the facilities for tuberculosis management include 4 DOTS centres for diagnosis and treatment as well as 10 DOTS sub-centres where sputum smears can be prepared and patients receive their medication after a diagnosis at a DOTS centre [13]. Patients presenting in primary care health facilities, who are suspect of having tuberculosis, need to be referred to a DOTS centre for re-assessment, diagnosis and treatment. In Nawalparasi DOTS sub-centres are located in all health posts [14].

Study design, data collection, and study period
In semi-structured interviews, respondents were invited to tell their story of how they first perceived their complaints, sought treatment, and how they eventually ended up in the DOTS treatment program. We asked respondents about their route through the health care system and the reasons for this route. Respondent’s characteristics were collected with a questionnaire. Interviewers (MB, AtA) used one interpreter to communicate with respondents in local languages (Nepali and Bojphuri). Interviews were recorded on tape and summaries of the interviews were written in English by the interpreter and reviewed by the interviewers. To assess the validity of the summaries we transcribed the recordings of five interviews. Independent translators translated these transcription from local languages into English. We compared these transcriptions to the written summaries. We found the summaries to correctly reflect the fully transcribed interviews with respect to the routes and reasons for these routes. Details about locations of providers and types of treatment were omitted in the summaries, as were courtesy introductions.

The quotes presented in the results section are phrased in third person, reflecting the translations by the interpreter. Text in [rectangular brackets] indicates additional information by the researchers about facilities or providers.

Data for this study were collected between November 2002 and April 2003. During the time of the interviews the exchange rate for Nepalese Rupees was 78 to 1 US Dollar, 81 to 1 Euro [15]. The estimated gross domestic product per capita (purchasing power parity basis) was $ 1400 [16].

Measures
A topic list was used to semi-structure the interviews. After brief introductions the respondent was asked to share the story of his/her illness: What were the initial complaints when he/she first fell ill? Did he/she get any help or advice? From whom/where did he/she get help or advice? Why did he/she choose this person/provider? What happened next? These
questions were repeated until the story of how he/she got enrolled in DOTS was completed. The interview ended with registering respondents characteristics age, gender, profession, position in household, marital status, town or village of residence.

**Study population and recruitment of respondents**

Eligible patients were all tuberculosis patients who collected their daily or weekly doses of tuberculosis treatment at one of five selected DOTS (sub-)centres in Nawalparasi. The centres were selected on geographical accessibility and facility level (DOTS sub-centres and DOTS centres). Each facility was visited on several occasions. There were 12 interview days. Patients were invited to participate in the study upon arrival at the DOTS facility. To avoid interference with and from health workers, the consenting patients were interviewed in a separate room, or outside the DOTS facility building but mostly on the facilities’ premises.

**Ethical considerations**

We conducted this study within the framework of the Practical Approach to Lung Health initiative, which was implemented and evaluated under supervision of the Nepal Health Research Council. Respondents gave informed consent. Anonymity was assured and we explained respondents that participation would not have effect on their treatment. None of the invited DOTS patients declined participation.

**Analysis**

The analysis of the summaries of the interviews identified the different providers that were visited by patients, and in which order, and the arguments stated for the patients’ specific choices. For the analysis of these routes we categorised the mentioned providers and facilities into three groups, according to the anticipated level of competence of the attending staff. The first group (A) consists of the medical shop, where drugs can be purchased and where no formal consultation is necessary. The second group (B) consists of private health workers (not known to be medical doctors), sub health posts, health posts and primary health care centres where trained health workers provide disease management. The last group (C) consists of medical doctors in private practices, and hospitals where medical doctors are available for patient care. In all groups we indicate the number of private and governmental providers and facilities. The general description of the routes also includes the providers that diagnosed tuberculosis or ordered the test that led to diagnosis of tuberculosis. We grouped the reasons for their route in the following order: Firstly, what were the initial complaints and which provider was visited to address these complaints first. Secondly, if patients changed providers what were the grounds for this change and how did they chose a new provider. In our analysis we also looked at the importance of referrals as these could provide a clue whether the system is able to guide patients to higher levels of care when needed. This is particularly relevant for programs as the PAL initiative that aim to improve the adequacy of the referrals of suspected tuberculosis cases. Arguments for not going to a certain provider were also included in the analysis.
Results

We interviewed 26 tuberculosis patients, 12 women aged between 7 and 48 years (mean 29) and 14 men aged between 15 and 74 years of age (average 42). The 7 year old girl was accompanied by her father who responded to the questions by the interviewer. Respondents’ characteristics are shown in table 1.

Table 1  Respondents characteristics

<table>
<thead>
<tr>
<th>Age in years</th>
<th>Women (n=12)</th>
<th>Men (n=14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minimum – Maximum</td>
<td>7 – 48</td>
<td>15 – 74</td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>28.7 (11.7)</td>
<td>41.6 (16.0)</td>
</tr>
<tr>
<td>Occupation (n)</td>
<td>Housewife (7)</td>
<td>Farmer (3)</td>
</tr>
<tr>
<td></td>
<td>Housewife and laborer (4)</td>
<td>Farmer and laborer (3)</td>
</tr>
<tr>
<td></td>
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<td>Driver (2)</td>
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<td></td>
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<td>Laborer (1)</td>
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<tr>
<td></td>
<td></td>
<td>Carpenter (1)</td>
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<tr>
<td></td>
<td></td>
<td>Mechanic (1)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Retired from army (1)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Student (1)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Hotel employee (1)</td>
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Years of schooling per age group:

<table>
<thead>
<tr>
<th>Age 7-18</th>
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</tr>
<tr>
<td>7</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Missing</td>
<td>1</td>
<td>0</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Age &gt;18</th>
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</tr>
</thead>
<tbody>
<tr>
<td>0 years schooling</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>4</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>5</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>8</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Missing</td>
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<td>0</td>
</tr>
</tbody>
</table>

Number of providers approached before treatment start

<table>
<thead>
<tr>
<th></th>
<th>Women</th>
<th>Men</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3</td>
<td>1</td>
<td>5</td>
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<tr>
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<tr>
<td>8</td>
<td>1</td>
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</table>

Kind of provider first approached

<table>
<thead>
<tr>
<th></th>
<th>Women</th>
<th>Men</th>
</tr>
</thead>
<tbody>
<tr>
<td>Private providers</td>
<td>10</td>
<td>11</td>
</tr>
<tr>
<td>Public providers</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
General description of routes

The most common starting point for the patient’s route was the medical shop, not the governmental sub health post or health post. (Table 2) At medical shops drugs were purchased, with or without consultation from a health worker. As complaints persisted or even worsened, the routes of our DOTS patients led to health workers or medical doctors who held formal consultations. Drug retail was no longer the foremost important characteristic. Subsequently, facilities with a good reputation for competence and or diagnostic facilities were consulted at increased financial costs. Eventually the patients arrived higher up in the organizational hierarchy of the health care system.

When explaining their road to lung health, 21 patients reported that they first went to a private health facility, 5 consulted a governmental primary health care facility at the start of their pathway. After a minimum of one (1) and a maximum of eight (8) different providers in all possible combinations and orders (data not shown) the patients had reached a provider (11 of category B and 15 of category C) who diagnosed tuberculosis and were subsequently enrolled in DOTS. The last health care facility before enrolment was for 15 patients a government health care facility (i.e. hospital, primary health care facility, or Health Post), and for 11 patient the last stop was at a private health care facility. (Table 2)

Table 2 First and last providers visited on the journey to tuberculosis treatment

<table>
<thead>
<tr>
<th>First providers visited after initial complaints (n=26)</th>
<th>Last providers visited before enrollment in DOTS (n=26)</th>
</tr>
</thead>
<tbody>
<tr>
<td>(A)</td>
<td></td>
</tr>
<tr>
<td>(10) Medical Shop (p)</td>
<td>(0) Medical Shop (p)</td>
</tr>
<tr>
<td>(B)</td>
<td></td>
</tr>
<tr>
<td>(3) Health Post (g)</td>
<td>(2) Health Post (g)</td>
</tr>
<tr>
<td>(8) Priv. Practitioner (p)</td>
<td>(3) Priv. Practitioner (p)</td>
</tr>
<tr>
<td>(8) Priv. Practitioner (p)</td>
<td>(3) Priv. Practitioner (p)</td>
</tr>
<tr>
<td>(C)</td>
<td></td>
</tr>
<tr>
<td>(2) Hospital (g)</td>
<td>(8) Hospital (g)</td>
</tr>
<tr>
<td>(2) Medical doctor (p)</td>
<td>(3) Medical doctor (p)</td>
</tr>
<tr>
<td>(1) Hospital (p)</td>
<td>(5) Hospital (p)</td>
</tr>
</tbody>
</table>

(A) = medical shop, drugs can be purchased without prescription and formal consultation is necessary  (B) = private health workers (not known to be qualified medical doctors), sub health posts, health posts and primary health care centers with trained health workers  (C) = qualified medical doctors in private practices, and hospitals where medical doctors are available for patient care

(p) = private health care facility (g) = governmental health care facility

Overall, patients visited facilities with higher qualified staff at the end of their routes. The routes differed considerably both in length as in providers visited, with an occasional U-turn to a lower level of care:

"you are suffering from fever for a long time, so it has changed to typhoid", the doctor said and gave medication for typhoid. She took this medicine from the district hospital for one week. Someone from her neighborhood had told her about video X-ray, she
knew that she could go to the regional hospital for this, but she had not enough money. Because she still thought it might be malaria she went to a health post to get a malaria test. At this health post the malaria test was performed and malaria medication was given, but they also advised her to do a sputum test”. (Interview summary 5).

Once a provider suspected tuberculosis, sputum tests were ordered.

“After a week of taking medication she went back to the government health post. This time she did tell about her husband’s tuberculosis. The health worker examined her, she was given plastic containers and asked to bring sputum to health post the next day. Slides were prepared and these confirmed that she had tuberculosis.” (Interview summary 25).

After the diagnosis of tuberculosis a referral to the DOTS programme followed:

“The first time he went to this health worker he told him he had loss of appetite. The private health worker listened to his lungs and prescribed syrups and pills costing Rs 900. The second time the same thing happened. The third time he was advised to get a sputum test, he did not turn in enough sputum and tuberculosis was suspected, but not confirmed. The private health worker again prescribed medication. The fourth time his sputum was successfully tested and tuberculosis confirmed and he was prescribed medication and referred to the DOTS centre at the district hospital by this private health worker.” (Interview summary 6).

Providers also informed diagnosed patients that tuberculosis treatment was available for free:

“The medical shopkeepers told him that he could buy it from them, but that he could also get this tuberculosis medication for free at the district hospital” (Interview summary 9).

“It was confirmed that he had tuberculosis and the doctor told him so. He informed him that he should take medicine for 6 month and that he could buy medicine at medicine shops, or get it for free at a government health facility” (Interview summary 2).

Although an exception was also reported:

“She went for an X-ray at a private shop as advised by someone in her community who said that she could know exactly what was wrong. The X-ray cost her Rs 320. The person who did the X-ray told her that she had tuberculosis, but no other advise or treatment was given” (Interview summary 23).

Reasons for the followed route
Initial complaints, care seeking actions and first providers visited

Respondents’ stories started with a variety of complaints, such as fever, cough, headache, blood in sputum, abdominal pain, and loose stools. Most respondents mentioned the complaints to their family members or to others who were close to them. Also the health care
options were discussed with them. The first health care seeking actions, following the onset of the initial complaints, were related to the **perceived seriousness of illness** and **anticipated level of competence** needed from a provider:

When respondents thought that the complaints were due to a not-severe and not chronic illness they were hopeful that they could manage on their own and bought medication at a medical shop.

“He first thought he had the common cold and stayed at home for 2 to 3 days. After 2 to 3 days his nephew bought one tablet for the fever from a medical shop that he took.” (Interview summary 17).

“Because she thought she was suffering from a simple illness, she did not think it necessary to go to a health post, which in her opinion is for more severe diseases. She first went to a medical shop and got medication for her fever and her headaches” (Interview summary 3).

“At first the gland in the neck was very small ….. I did not know what this could be and bought pain medication from medical shops.” (Interview transcript 7).

One respondent said that her **peers recognized the complaints** and she sought help from a **specific provider known to be competent** in treating such complaints:

“Someone from her neighbourhood, who had dropped in on the family to watch television, told her mother that her daughter might have tuberculosis because she had been coughing for a long time, and advised to take her to Semari [the nearest Primary Health Care Centre]. He had taken his wife there when she had been coughing, and she had been diagnosed with tuberculosis.” (Interview summary 24).

Also **economic factors** influenced the choice of a provider:

“He did not consult any other medical practitioners in these four years because he did not have enough money. He had blood in his sputum during this time.”(Interview summary 1).

“They could not afford to send him to Parasi hospital until six or seven months later” (Interview summary 4).

“Someone from her neighbourhood had told her about video X-ray, she knew that she could go to Butwal for this, but she had not enough money. Because she still thought it might be malaria she went to the nearest health post to get a malaria test” (Interview summary 5).

The **reputation of a provider** was mentioned by respondents. Either a reputation known by the patient before the complaints started, or a reputation that the patient came to know while discussing the complaints with others.
“he started a fever, with headache and whole body ache. During the first ten to twelve days of his illness he stayed at home without any medication. After this he went to a certain private clinic because his friends suggested he (should) go there and he had heard about this place before.” (Interview summary 8).

The **perceived quality and service level at sub health posts**, seem to be an obstacle for patients to use these facilities. None of the respondents had visited the sub-health posts during their route to the DOTS program. Patients reported aspects of these facilities such as drug availability, competence of staff, waiting times, and minimal opening hours, to prevent them from going there.

“You have to queue at sub health posts and health posts”, “and you have to pay five rupees to make a ticket and you can not buy on credit”, “he had to buy medication anyway, he could just as well go to a private health worker immediately”, and “these sub-health posts do not have all the medicines”, are arguments that made respondents reluctant to go there. (Interview summaries 7, 15, 9).

**Social dependence** was mentioned by yet another respondent. He could not go to the provider of his preference because

“at the time there was nobody willing to accompany him there” (Interview summary I).

**Changing providers, referral.**

All respondents reported to have consulted more than one provider. The main reason was that after the initial treatment the complaints persisted or returned after initial relief. The trust in the provider had waned.

“The first and second time he was prescribed medicine for simple cough and fever. He took these for seven days both times. It gave him some relief for some days but it did not cure his cough and after the second time he became angry and said to the medical doctor: if you can cure me then do, if not please tell me so. (…) The third time he was told it was typhoid and was given ayurvedic medicine. This also did not help. The fourth time the same doctor prescribed two medicines for typhoid. He took one that cost Rs 45 per day, it made his muscles shrink and his condition worse. After this the doctor wanted to check his urine and stool but he decided to go to a private nursing home in Butwal” (Interview summary 2).

**To consult a different provider was mostly an initiative from the patient** or his/her peers, not from the current provider.

“He did not get better and his family members and people from his neighbourhood advised him to go to …” (Interview summary 17).

The actual choice for another provider was **more complex when the complaints became more serious** and needed a **more competent provider**, that often lived further away.
“It seemed in the beginning that her problem of diarrhoea was controlled when she took medicines. Afterwards, when she got seriously ill, then everybody suggested to take her to Butwal.” and “there –in the medical shop- was also a doctor who was a quack. They treated but nothing improved. When the baby got weaker, than I hastened to Butwal “ (Interview transcript nr 9, father answering for the 7 year old patient).

“. when blood started to appear in his sputum he became afraid (...) and someone in his neighborhood suggested that he was not getting better and advised him to go to ...” (Interview summary 1).

Such consultations would therefore **cost more money**, both for consultation and travelling:

“She first contacted a private health worker at Tadi [small village] near her home. He told her she had typhoid and prescribed medication. While taking this medication she felt better for 8 days but after it was the same as before. Sometimes the medicine would be undigested, it would appear in her faeces. After this health worker she went to another private health worker who also diagnosed typhoid and gave medicine twice. Many people advised her to go to a good doctor in Parasi or in Butwal or to go to Harnata [location of a famous doctor in India]. The transportation by train and accommodation costs to India were Rs 400. Because she had no money she did not follow up on this advice.” (Interview summary 5).

One respondent mentioned that it was actually the **provider that advised her to go to a different provider** who had higher qualifications:

“... blood in her sputum for four times came. Initially she took medicine from the medical shop near her home. However, she did not get better and her condition became more severe. Then the medical shopkeeper told her that “I cannot control it” and advised her to go to AMDA [a certain private not-for-profit clinic] in Butwal” (Interview summary 26).

**Discussion**

Our analysis of twenty-six interviews with diagnosed tuberculosis patients under DOTS treatment in rural Nepal shows a route that led via multiple providers, in private and public health care facilities, to tuberculosis treatment. The reasons for seeking health care and for their choice of a specific provider were a heterogeneous mix of arguments. These arguments included both patient specific and provider specific arguments. The former included perceived seriousness of the disease by the patient or his peers, the ability to pay for services, and peer support for choosing and visiting a provider. These findings confirm findings of other studies in different contexts in developing as well as developed countries [17-20]. Provider specific aspects were also explicitly mentioned by the respondents. These included
the perceived quality, costs and service of a provider and being adequately referred by one provider to another.

A potential problem in our analysis was misclassification of the provider and health care facilities. Whether or not a shop keeper was also a health worker was often unknown to the patient. Likewise, a private health worker was sometimes known to be a health worker or a medical doctor but not always. Although much attention was given to verify the level of providers this might have led to misclassification. As both health workers and medical doctors are mentioned in all phases of the journey we believe that mis-classification has not led to distortion of our overall findings. Misclassification of health care facilities is much less likely as this could be verified on the basis of the reported location.

One of the limitations of our study is of course that we only interviewed patients that actually found their way to the DOTS programme. We have no information therefore about the extent to which tuberculosis patients do not find their way into the programme. Our findings would benefit from a comparison with data from patients that were actually followed during their journey towards treatment.

Self-referral because of lack of treatment results and waned trust was very important in the patients’ routes. Patients reported that the decision to change provider was usually taken by the patient themselves, supported by suggestions of their peers. Referral by providers was not based on the provider’s perception of his own competence, the symptoms presented by the patient, or the lack of treatment results. In contrast, however, provider initiated referral after a tuberculosis diagnosis seemed to be unproblematic. Once a provider had thought of tuberculosis, and sputum tests had confirmed the presence of *M. tuberculosis*, referral to the tuberculosis programme seemed a logical and prompt next step. Providers did inform the patient about the fact that tuberculosis drugs are free and that treatment is available near home. Referral to the DOTS programme seems to be perceived by the provider as a successful and acceptable end of the consultation and diagnostic process.

Probably the lack of medical knowledge is one of the reasons for what seems to be a trial and error case-management. There might be other interpretations too. Firstly, managing a case in spite of inadequate knowledge may indicate that it is difficult for providers to acknowledge that someone else might be more competent to deal with the health problem presented.

Secondly, once a provider refers a patient he/she is no longer the provider’s customer. This is on short term a direct and negative economical consequence of an in potential professionally sound decision. This economical argument (for non-referral) seems obvious for health workers in private facilities but it could also be applicable to health workers in public facilities. Health professionals in the public facilities commonly also have a private practice from where they sell drugs that are not available at the government facility or where they conduct follow-up consultations outside clinic hours [21]. Their public activities could be seen as an entry point for clientele into their private enterprises. As a consequence, patients might undergo inappropriate treatment and waste valuable time and money with an incompetent provider. These negative effects became more evident as the symptoms worsened and the choice for yet another provider became more complex.
Initiatives that aim to strengthen the capacity of primary care facilities, such as WHO’s Practical Approach to Lung Health (PAL) [21-23] can benefit from these findings. If, for example, sub health posts are expected to become a major tool in passive case-finding of tuberculosis then the perceived low service quality of sub health posts needs to be addressed. To improve health care in general—and passive case finding for tuberculosis in particular—the issue of referral needs explicit attention. Socio-economical factors as mentioned above seem to be important for not referring the patient. To improve referral in general, a reward for adequate referrals may be considered. As financial benefits might turn out to be perverse incentives such measures need careful consideration. Another suggestion – albeit a challenging one - could be to build social networks of lung health care providers (public and private) at different levels of care who share resources and knowledge, allowing for referral of patients to known colleagues. As members of the same social network a referral might not be considered as failure but as a joint effort for the better of the patients’ health.

Conclusion

Tuberculosis patients in rural Nepal have followed intricate routes before reaching DOTS. Self-referral, because of lack of treatment results and waned trust, was the most common reason for changing providers. This not only indicates that providers often fail to treat the patient satisfactorily, but also do not guide the patient on his/her route to better treatment. To address these health system factors we need to develop complementary strategies that strengthen the service performance of health facilities and improve the collaboration between providers at different levels of care. This can contribute to strengthening passive case-finding initiatives and eventually smoothen the road to tuberculosis treatment.

Acknowledgements

We are indebted to the respondents, the staff of the regional health office, and the staff of the tuberculosis treatment centres for their kind cooperation. We thank J Schuster, JF Wendte, NS Klazinga and C Gunneberg for valuable comments on earlier drafts of this paper.

Reference List


