

# Direct observation and adherence to tuberculosis treatment in Chongqing, China: a descriptive study

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**Introduction** China has an estimated 5 million people with tuberculosis (TB). Official policy is that treatment of all patients is directly observed by health workers; completion rates are reported to be in excess of 90%, and drugs should be supplied for free. However, some research suggests there is a gap between the official policies and practice.

**Methods** Survey of TB patients in four counties of one municipality; record assessment at one TB centre; patient and village doctor in-depth interviews.

**Results** Sixteen per cent (64/401) reported being directly observed every time they took treatment; less than 5% of TB patients (17/401) were observed by health staff. Overall, 12.5% (50/401) reported they had not taken any TB drugs in the previous week, but this varied between the four counties (range 6.2 to 21.7%). We used survival analysis with medical records at one centre: 74.1% of new patients collected their drugs for their sixth month of treatment, and 50.3% attended the final visit at 6 months. Qualitative research indicated direct observation is neither well understood nor thought to be necessary, and that patients reported being charged expensive fees for ancillary treatments, such as liver protection drugs.

**Conclusion** In China, direct observation is not well implemented and may not be a feasible policy option. Official completion rates are higher than we found in this study. The concept of free treatment has become blurred, with charges for additional tests and drugs, especially liver protection drugs. The government is already actively tackling these issues, and involvement of managers and others in this process will be helpful.

**Keywords** Tuberculosis, DOT, compliance, China

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**KEY MESSAGES**

- Direct observation of drug taking by a health worker is national policy for TB control in China. In the study area described, less than 5% of patients were directly observed, and health workers and patients did not consider the policy feasible or necessary.
- Records showed that less than 50% of new patients attended follow up at six months, and irregular treatment and failure to complete treatment was common under the direct observation policy. This will contribute to the risk of drug-resistant TB developing and to relapse.
- Anti-TB treatment is supposed to be free, but patients were charged high costs for additional tests and drugs, especially liver protection drugs. This may represent a considerable financial barrier for TB patients to adhere to treatment. Despite optimistic estimates from international agencies, current policies, their implementation, and actual TB cure and completion rates in various areas of China need to be reviewed.

**Introduction**

The government of China's 10-year tuberculosis Infectious and Endemic Disease Control (IEDC) Project introduced the World Health Organization (WHO) recommended DOTS strategy in 1991, financed by a loan from the World Bank. The policy includes directly observed treatment (DOT) (World Health Organization 2002; World Health Organization 2006), and China's national policy is committed exclusively to health workers directly observing all patients to help improve tuberculosis (TB) case management (Centre for Disease Control 2002).

However, performance data have been variable. A national TB epidemiological survey revealed that only 30–40% of detected TB patients were under case management by the TB dispensary, and only 27.3% of all TB patients were estimated to be taking anti-TB drugs regularly (National Technical Steering Group of the Epidemiological Sampling Survey for TB 2004). Later reports from WHO have been more optimistic regarding DOT coverage: in 2004 it reported that 78% of the Chinese population had been covered by DOTS by 2002 (World Health Organization 2004), and were being observed by health workers when taking their treatments. Performance data collected through the public health system report cure rates of more than 90% (Chen *et al.* 2002; Wang *et al.* 2007). These widely varying figures give cause for concern. In addition, there appear to be problems with implementing the policy of free or subsidized treatment that is part of the China National TB Programme (World Bank 1991).

Given the debates around effective policy implementation, this research was carried out at the instigation of a Municipal TB programme in collaboration with researchers, to identify ways that TB health service delivery could be improved. The research aimed to: a) measure the level of direct observation by health workers; b) estimate the completion rate from data within facilities; and c) explore patient and provider views on factors influencing adherence.

**Methods****Study sites**

The study municipality is Chongqing, in South West China, with a population of 30 million, living in a mountainous area,

with a socio-economic profile below average. The Health Bureau and the municipal TB dispensary implement the TB control programme. In each of the 40 counties, the programme is implemented by the county TB dispensary or the County Centre for Disease Control. In our study, we purposively selected four counties as representative of the whole of Chongqing, in terms of socio-economic development, geographic and transportation condition. This is illustrative of an urban area (JLP), a middle socio-economic area (RC and LB) and a poor rural area (XS) (see Table 1). All sites had TB information systems, appropriate health staff, and were willing to cooperate. Official statistics put completion rates at about 90% for new patients, in line with the national average. However, as this was inconsistent with other resources (National Technical Steering Group of the Epidemiological Sampling Survey for TB 2004), we therefore assessed adherence by a patient survey, and made an independent estimate from individual patient records at one County TB Dispensary where records were reasonably well kept and performance was likely to be optimal.

**Patient survey**

Smear-positive TB patients who started treatment within the preceding year (that is, currently on treatment or completed treatment recently) were the target population of this study. A sample size of 369 was calculated based on a required precision of  $\pm 5\%$  around the 95% confidence interval of adherence rate. The estimated adherence rate used in sample size calculation is 60%, according to a pilot estimation using medical records information. As there were approximately 800 patients meeting the criteria across the four counties, we sampled every other smear-positive TB patient registered in the preceding year at each of the county TB dispensaries.

Patients were asked 'how often did anybody observe you taking anti-TB drugs?' and four choices were given: 'every time, most times (more than half), rare (less than half), and none'. The government national guidelines explicitly state that patients should be observed 'every time' (Centre for Disease Control 2002). Since TB patients were taking medicine every other day, 'Interruption of treatment' was defined as those who missed their last three doses; or had run out of medicine for more than a week. 'Interruption of treatment' among patients recently completing treatment was defined as those who stopped taking drugs 6 days before the end of the standard

**Table 1** Characteristics of study counties

County	Population	GNP per capita (Yuan)	Terrain	Sputum-positive TB patients registered 2004	TB programme status	Cure rate, 2004 routine statistics <sup>†</sup>	
						New	Re-treatment
JLP*	799 000	19 426	Urban, hilly	280	Additional Municipal dispensary TB control programme	91.6	76.7
RC	813 000	5 110	Rural, hilly	455	Country authorities have actively encouraged village doctors to contribute to TB control	97.1	95.2
LB	517 000	6 900	Rural, mountainous	572	Part of Global Fund TB Control Project 2004	94.2	90.0
XS	605 900	3 120	Remote, mountainous	391	Part of Global Fund TB Control Project 2004	95.0	90.0

\*County where we analysed records for actual completion rates in 2004.

<sup>†</sup>Data Source: Routine statistics from Municipal TB Dispensary.

course, or who had run out of medicine for more than a week before the end of the standard course. This method provides a measure, at one point in time, of a patient's self-reported recent drug-taking history.

We trained and carefully supervised four postgraduate students to interview patients. Patients on treatment or recently completed were identified at each TB dispensary from the registration book. Most interviews with TB patients were conducted in their homes; for those patients living far away, notice was sent out and they were interviewed at the nearest township health centre. Community health workers and local health staff were not present during the interview. When a patient could not be found, we tried to identify and interview another patient in the village meeting the same criteria. Each evening, research supervisors checked the completed questionnaires and interviewed the interviewers to make sure all the items in the questionnaire were correctly understood and filled in. The data were double entered by two postgraduate students using Epi Data 2.1. After validation, the data were analysed using SAS 8.2. Two key indicators (direct observation and interruption of treatment) were defined and analysed. Univariate analysis was applied to find out the influencing factors.

### Records analysis at JLP

Monthly summaries of attendance and completion were recognized as being inaccurate. Therefore, we went to the original patient records and monitored completion over an 8 month period (January to August of 2004) at the county TB dispensary, which included both patients who had completed their treatment and those currently on treatment. We collected medical records of both new and re-treatment patients. New patients were defined as patients who had never had treatment for TB, or who had taken anti-TB drugs for less than 1 month. Re-treatment patients were those previously treated for TB whose treatment failed, who defaulted, or who relapsed. The collection and recording of these data was supervised by the principal investigator.

We applied survival analysis (Kaplan-Meier method) to estimate the completion rate. In the analysis, 'event' was defined as patients who withdrew from the standardized short course chemotherapy because of death, treatment failure,

default or transferring out. 'Survival time' was the time interval from the start of treatment to the 'event' of withdrawal. The unit of 'survival time' was by month, as patients were expected to attend clinics monthly. Patients attending the clinic on the fifth month, where they would collect their drugs for their last month of treatment, were considered as 'treatment completed'. We also calculated the percentage attending for the final visit at 6 months when cure would normally be assessed.

### In-depth interviews

We interviewed TB patients (33) and village doctors (11) from all four counties. In each county, we purposefully selected patients from the county TB register to capture a range of experiences and views, considering age, gender and including both new and re-treatment patients.

All participants who were asked to participate agreed to be interviewed. Village doctors (eight male, three female) were recruited and interviewed. Standard topic guides were used to ensure relevant areas were covered during interviews, including patient and doctor's opinions about: DOT implementation, adherence to treatment, cost of TB treatment and patient management. Interviews were conducted in Chinese Mandarin, lasted between 30–50 minutes and were tape-recorded with participants' informed consent. Interviews were conducted in participant's homes or at the nearest township health centre.

The Framework approach was applied to analyse qualitative data from in-depth interviews (Richie and Lewis 2003), and MAXqda software was employed to manage, code and retrieve data. Tape recordings were transcribed verbatim in Chinese characters. Two bilingual (Mandarin/English speaking) team members read through the transcriptions and listed recurring viewpoints relevant to the areas of questioning and common themes emerging from the data; this formed the basis of the thematic framework. Transcriptions were imported into MAXqda (in Chinese characters) and a coding system set up based on the thematic framework. Code labels were in English as MAXqda does not support Chinese labelling. One author applied the coding system to all interviews.

A bilingual and a non-Mandarin speaking researcher examined the frequency of coded segments, and combined codes into

**Table 2** Patients reporting on direct observation for TB treatment

	<i>n</i>	%
Directly observed every time*	64	16.0
Directly observed sometimes	48	11.9
Never directly observed	289	72.1
Total	401	100.0

\*Ministry of Health policy at the time of survey.

larger categories, to form six main themes. Coded segments relevant to each theme were translated into English and summarized in a chart. This enabled English and bilingual researchers to look across the data of all cases and explore differences between sub-groups (patients and doctors, male and female, new and re-treatment patients, and across counties). The dimensions of each main theme and differences between subgroups are described in the results section; illustrative verbatim quotes for each theme appear in Boxes 1 to 6 in the Appendix in both Chinese mandarin and English. Of the patients interviewed, 19 were men, 14 were women of a wide variety of ages; 23 were new patients; 10 were re-treatment patients; 8 lived in the city, 11 in a rural hilly area, 6 in a rural mountainous area, and 8 in a very remote area.

### Ethics and funding

Ethical approval was obtained from Chongqing Medical University. The study was funded by the Ministry of Health and the Department for International Development UK. The funding bodies had no involvement with the study design, analysis or interpretation of the results.

## Results

### Patient survey

Four hundred and five patients were interviewed (four excluded because of starting treatment more than 1 year ago). One-third of new patients were treated for longer than the standard treatment of 6 months. One-fifth of re-treatment patients (19/90) were treated for longer than the standard of 8 months (Table A1 in Appendix). In younger age groups, there were similar numbers of men and women, but men predominated in the older groups (Table A2).

Only 16% (64/401) of patients reported that they were directly observed every time they took their drugs (95% CI: 12.4% to 19.6%); 72% reported that they had never been observed (Table 2). Less than 5% (17/401) were directly observed by a health worker, and 15 of these patients were from one particular county where authorities had actively encouraged village doctors to contribute to TB control (RC county). The remaining 11% were observed by family members. Analysis by gender, age group and basic knowledge about TB showed no association.

At the time of interview, 12.5% (95% CI: 9.2% to 15.7%) of patients reported 'interrupted treatment' by our definition (missed last three doses, or run out of medicines for more

**Table 3** Self-reported interrupted adherence and potential influencing factors

Possible factors	Interrupted adherence* % (n/N)	$\chi^2$	P value
<b>Study site</b>			
JLP	6.2% (7/113)	12.14	0.01
RC	13.8% (13/94)		
LB	9.8% (10/102)		
XS	21.7% (20/92)		
<b>Direct observation</b>			
Observed every time	12.5% (8/64)	0.00	0.99
Observed sometimes or never	12.5% (42/337)		
<b>Gender</b>			
Male	15.1% (41/271)	5.42	0.02
Female	6.9% (9/130)		
<b>Belief: can TB drugs be stopped after TB symptoms have gone?</b>			
Yes	29.3% (34/116)	42.42	<0.01
No	5.6% (16/285)		

\*Missed drugs for >1 week (last three doses) or ran out of drugs for more than a week.

**Table 4** Adherence for smear-positive TB patients in one County TB Dispensary (*n* = 151) derived from Kaplan Meier analysis

	<i>n</i>	Patient attendance at follow up					
		At 1 mo	At 2 mo	At 3 mo	At 4 mo	At 5 mo	At 6 mo
New cases	131	95.6	85.5	82.7	79.1	74.1	50.3
Re-treatment cases	20	84.2	73.7	73.7	64.5	64.5	42.9

than a week). This varied considerably by county from 6.2% at JLP to over 20% in XS (Table 3).

Interruption of treatment was similar in patients who reported being directly observed and those who did not report being observed. Interruption was more common in men, and in people who stated they believed that TB drugs could be stopped after TB symptoms disappeared (Table 3).

### Completion

Table 4 gives the results from the Kaplan Meier analysis from study site JLP. Of the 151 patients, 1 died (after 1 month), 2 transferred out (missed 2 month appointment), and 2 were identified as treatment failure (at 3 and 4 months). In this group, the most optimistic completion estimate is those attending the clinic 5 months into the treatment, when, for new patients, their last 1 month of drugs is dispensed. For new patients, this was 74.1% with 50.3% attending at 6 months, when a sputum check was normal practice. There were fewer patients classed as re-treatment, where standard treatment is meant to be 8 months of treatment: 64.5% attended the 5 month visit, and 42.9% attended at 6 months.

## Qualitative findings

Six main themes arose through the analysis using the Framework approach. They represent factors that may influence DOT implementation and adherence.

### *1) Most TB patients are responsible themselves for taking their drugs*

Most TB patients said that they took drugs on their own at home and knew nothing about the records of drug taking (see Box 1 in Appendix). Some reported that they lived very close to the village doctor but did not have any supervision of drug taking. Some even felt surprised when hearing the term 'direct observation'. None of the village doctors interviewed mentioned that they directly observed each dose taken by TB patients. Most of them said that they provided intermittent home visits and/or telephone calls to remind patients of taking drugs. Some also acknowledged that they never manage TB patients in the way of DOT. Village doctors in XS County said that they had neither heard about it before nor were they required to conduct it (Box 1).

### *2) Patients and village doctors regard direct observation as unnecessary*

Many patients reported it was unnecessary to be directly observed by a doctor. They felt they were able to remember to take the medicine by themselves; some said they were motivated to take their drugs because they wanted to be cured and recover. A few patients regarded supervision as a 'bother' to the doctors and a waste of their time. During interviews, most village doctors said that, with constraints of limited time, long distance and lack of incentives, it was unrealistic and unnecessary for them to conduct DOT (Box 2).

### *3) Most new patients comply with treatment*

The majority of new patients interviewed said that they never forgot to take drugs during the treatment (see Box 3). Village doctors believed that most TB patients could keep taking drugs, because they wanted to be cured as early as possible. However, a minority of doctors gave us examples of patients who had stopped treatment for various reasons, such as drug side-effects and financial difficulty.

### *4) Most patients report they are charged expensive fees for treatment*

Most patients said that they had to pay for TB treatment. Among them, only a few could differentiate free (anti-TB drugs) and charged drugs (liver protection drugs) (see Box 4). Patients complained that it cost them tens to hundreds of Yuan to buy 'additional' drugs and examinations relating to their treatment; many reported having to borrow money to afford treatment. The cost of treatment varied between the counties; patients in RC county described a higher cost for drugs, on average 200–300 Yuan per month (£13–£20 per month). The high cost of treatment was also one of the main reasons mentioned by patients who interrupted drug taking. Village doctors reported that patients complained to them about the high cost of treatment, and that they cannot afford examinations and additional drugs.

### *5) Stigma exists in communities*

Many patients described being treated differently by people in their immediate communities after getting TB. They suggested neighbours or friends did not like to talk with them, or kept a certain distance while talking with them for fear of infection (see Box 5). TB patients tended to conceal their disease from others for fear of being isolated. Some described being treated differently by family members. Village doctors also reported that community residents did not like to get close to TB patients, because they were afraid of being infected.

### *6) Village doctors report incentives are less important than responsibility*

Village doctors are supposed to receive 60 Yuan (£4) through the World Bank/DFID-assisted TB programme for managing one TB patient for 6 months, but the level of financial support and implementation of incentive payments varies by county; one village doctor from RC county said he had never heard about the incentive payment. Most village doctors interviewed suggested that even without this money, it was their responsibility to manage TB patients (see Box 6). Some village doctors also expressed that fixed financial support would help them to manage patients effectively, since they currently do not receive any salary from the government, and have to earn their own living through fees for service.

## Discussion

The study results show that health worker direct observation of TB treatment was low. At county level, between 6.2 to 21.7% of patients had run out of drugs, or not taken any in the previous week; and actual completion rates in one county studied were lower than reported in national statistics.

We paid careful attention to quality. In the questionnaire, we minimized respondent bias by using carefully trained independent interviewers; in the medical record data for survival analysis, the principal investigator monitored data collection; and for the qualitative interviews, we paid careful attention to content and analysis by applying the Framework approach rigorously to the Chinese narrative. The main constraint of this study relates to the extent to which it reflects adherence in other areas of China, as it was carried out in a limited number of counties. However, there is no reason to believe the study site has any worse performance than other provinces in China, and there is a need for more extensive careful recording of true adherence. In the patient survey, our replacement strategy would tend to make adherence seem better than it actually was; nevertheless, it was still low.

The national guideline is that all smear-positive TB patients should be directly observed for treatment by community health providers or family members. WHO reported high levels of direct observation (World Health Organization 2004) and others have reported good completion rates (Chen *et al.* 2002; Wang *et al.* 2007). Our study showed only 16% of TB patients were directly observed when taking anti-TB drugs. Whilst the China reporting system does not actually record whether patients are directly observed during treatment, nevertheless the stated national policy is for direct observation.

We decided to be cautious in our interpretation of the question about direct observation by family members. The reason for this is that we were not clear whether respondents simply meant that family members happened to be in the room when they were taking treatment. The concept of direct observation by another person, including family members, was really quite unfamiliar, and we did not check whether 'observation' actually also included active participation of the family member in the whole process. If they are to take on more of a monitoring role, it is likely that training and instructions will be required. Health staff did not view the policy as practical or feasible.

Most village doctors are now private practitioners, have no government salary and make a living through fees for services. Implementing direct observation is a time-consuming job. Though the World Bank/DFID-assisted TB control programme provides 60 Yuan to a village doctor for managing one TB patient, this money is not always available; if it were available, 60 Yuan is simply not enough payment for the inputs that are required. This is probably the explanation for some village doctors reporting that incentives were less important than responsibility.

The official completion rate in the county we studied was 91.6%, yet our analysis of records, which was in part prospective, indicated the most optimistic completion rate proxy for new cases was 74.1% (percentage of new patients starting treatment who visit on month 5 for their last month's treatment), with only 50.3% attending the final visit at 6 months. These completion data are from the best performing centre (JLP) among the four centres, since JLP is one urban district of Chongqing city and its TB control programme is managed by a provincial-level facility, while the other three are all in rural areas and managed by county-level TB dispensaries. Performance at other centres is likely to be worse, and certainly self-reported adherence rates at the other centres were much lower. Thus it is probable that true adherence is considerably lower at the other centres, and these patients are important as they are at risk of relapse.

Whether these management issues we identified around routine statistics are common in other counties in the country was not the brief of our study, but certainly the findings indicate some very careful audit and checking is required before being confident about the apparent high level of performance of the national TB programme. We would argue that there is a need for accurate information at all levels in order for staff to take remedial action: in the county, to follow up individual patients; in the province, to identify poorly performing counties; nationally, to help poorly performing provinces; and overall, to identify areas that are doing well to explore reasons for best practice.

In addition, the survey of reported patient adherence suggested irregular treatment was common, with patients frequently missing doses. This will contribute to the risk of drug-resistant TB developing.

The interviews with patients and health staff indicated that far from being free, patients were charged high costs for the diagnosis and treatment. This appears to be for additional tests and drugs, especially liver protection drugs, which are widely recommended by the doctors and appear to be a way of generating income from patients. These findings are consistent

with other research around charging (Garner and Ziganshina 2005; Xu *et al.* 2006), and suggest that there may be considerable financial barriers to starting and continuing treatment.

These problems are mainly rooted within the malfunctioning health system. Along with the market-oriented economic reform, government funds for public health facilities are limited. Now these services rely heavily on service charges, encouraging public health facilities to supply revenue-generating services. This is probably why patients always receive liver protection drugs and prolonged treatment (Meng *et al.* 2004). In such circumstances, village doctors, most of whom receive no salary from government, have no incentive to take responsibility for DOT.

With the collapse of the programme of rural health insurance (Feng *et al.* 1997), it costs the rural poor a lot of money for health care, even if the health services are supposed to be 'free' (Meng *et al.* 2004). This will contribute extensively to TB patients' interruptions and non-adherence to treatment.

The next step is to verify whether the situation found in these selected counties is similar elsewhere in the country. Strategic options include both specific approaches to detect and promptly respond to defaulters (Garner and Ziganshina 2005), or to involve families (Newell *et al.* 2006). If family members are to play the role of direct observation, they need more appropriate training and supervision. However, the gains with these approaches are likely to be minimal as there is a broader, underlying problem. To tackle the systems issues, key measures need to be taken to improve the whole health system performance. It could benefit from further investment from government subsidy to assist health facilities and health staff at county, township and village levels in delivering treatments that have significant externalities. Improving and expanding the pilot rural health insurance schemes will also provide more financial protection to the poor rural population in seeking appropriate TB health services.

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## Appendix

**Table A1** The length of treatment patients had already received at the time of interview

Month	Type of patients		Total <i>n</i> (%)
	New <i>n</i> (%)	Re-treatment <i>n</i> (%)	
1-6	251 (64.6)	51 (56.6)	302 (62.8)
7-8	83 (26.7)	20 (22.2)	103 (25.7)
9-10	24 (7.7)	17 (18.9)	41 (10.2)
11-12	3 (1.0)	2 (2.2)	5 (1.2)
Total	311 (100.0)	90 (100.0)	401 (100.0)

**Table A2** Age and gender of TB patients

Age (years)	Gender		Total
	Male <i>n</i> (%)	Female <i>n</i> (%)	
0-34	57 (49.1)	59 (50.9)	116
35-54	111 (69.4)	49 (30.6)	160
55+	103 (82.4)	22 (17.6)	125
Total	271 (67.6)	130 (32.4)	401

**Box 1** Mostly TB patients are responsible themselves for taking their drugs**(11) Female, new patient, XS county:**

Q: Did anybody supervise you while you were taking drugs?

A: No, I always took drugs myself. Because I am an adult, not a child.

Q: 你吃药的时候有没有人监督到你吃?

A: 没有, 都是个人吃, 因为我是大人, 不是小孩了。

**(19) Male, retreated patient, JLP county:**

Q: Did any doctor supervise you while you were taking drugs?

A: No doctor witnessed me, I take it myself.

Q: Did you take every dose?

A: Yes, the doctor gave me a table, there is a cross and after I take the drugs I marked it on the table.

Q: Even in the hospital, no doctor supervised you?

A: The patient should have self-awareness to take the drug; otherwise he cannot be cured.

Q: 你吃药的时候有没有医生看着你?

A: 没有, 这个个人吃嘛。

Q: 你每次都把药吃了没?

A: 都吃了的。发了一个表的, 上面打起叉叉, 吃了就划个圈圈

Q: 在医院里面吃都没人看吗?

A: 没有, 这个要个人自觉嘛, 有病自己要吃药嘛, 不吃不行的。

**(28) Male, new patient, LB county:**

Q: Did any doctor in county TB centre visit you during your course of treatment?

A: No, no doctor witnessed me.

Q: Did they tell you that you should be witnessed by a doctor when you are taking drugs?

A: No, who is concerned about you?

Q: How about the village doctor, did he visit you?

A: Never.

Q: How far is it from his house to your house?

A: Not very far, just several paces, at most 2 minutes.

Q: 你看病的过程中县结防所的医生有没有来看过你?

A: 没有。

Q: 那他们有没有给你说你吃药的时候要请医生看着你吃?

A: 没有。哪个管你嘛。

Q: 村医)来看过你吃药吗?

A: 从来没有,

Q: 他家到你家有好远?

A: 没有好远, 几十步就到了。最多两分钟。

**(23) Male, new patient, RC county:**

Q: Did anybody supervise you while you are taking drugs?

A: No, no doctor supervised me. There is a table on the drug box; I just follow that instruction.

Q: Did you have a record for drug taking? [interviewer explained the table for recording drug taking]

A: No.

Q: Did you know about this record?

A: No.

Q: 那你吃药的时候有没有谁看着你吃吗?

A: 没有。药盒子上有个表, 我都按照那个在吃

Q: 你有没有服药记录卡?

就是吃药以后在上面作记录的卡片?

A: 没有。

Q: 你知不知道有这样的卡片?

A: 不知道。

**(15) Male, new patient, JLP county:**

Q: Did anybody supervise you while you were taking drugs?

A: Whom do I need to witness me? My family knows, they saw me take drugs.

Q: 你吃这个药有没有哪个看着你吃?

A: 这个要哪个看嘛, 家里面人晓得嘛。

Continued.



## Box 1 Continued

**(8) Village doctor, older male, LB county:**

Q: How do you manage TB patients?

A: Generally I ask him to live separately, (tell him) how to take drugs, suggest he sterilizes utensils such as bowls, chopsticks, beddings, etc

Q: Did you ever witness him to take drugs?

A: In terms of taking drugs, tell you the truth, I seldom, or I never witness him. I just explained it to him that the drug must be taken in the morning, before breakfast - because he lives far away.

Q: 你是怎么管理病人的？

A: 一般叫他单独生活，如何服药，给他建议碗筷，睡的被子枕头，帕子消毒，都要给他说

A: 那你去不去看着他吃药？

A: 吃药这个，明说，看的时候少，或者说纯粹没有去看过，只是给他解释过，早上空腹吃药，还有吃药的规律要给他说一下，因为他也不是这附近的，隔得很远

**(1) Village doctor, younger male, XS county:**

Q: Have you ever heard of patients being directly managed by village doctors?

A: I have never heard about that.

Generally speaking, patients take drugs on their own; sometimes township doctor visits them. If they can't find patients, I will help them. It's the township doctor's responsibility, we never do that.

Q: How long will it take you to visit patients?

A: It takes me about 10 minutes and another is 30 minutes respectively to access my patients.

Q: 你有没有听说由村医生直接管理病人？

A: 从来没有听说过。

一般都是他们自己吃。有时乡镇医生去看他们。我们就是配合。就是等乡镇医生找不到时，就让我们帮他们。（管理病人）那是乡镇的医生做的。我们一般不用这样做。

Q: 去看病人你要走好久？

A: 10多分钟。另外一个要半个小时。

\*Number in brackets is the unique identifier for each interview.

## Qualitative data

### Box 2 Patients and village doctors regard direct observation as unnecessary

**(33) Female, retreated patient, XS county:**

Q: Do you think it's necessary for the barefoot doctor [village doctor] to supervise you when you take drugs?

A: It's not necessary for the doctor to supervise me, I am strong-minded, no matter how hard it is, I will keep on taking drugs.

Q: 你觉得有没有必要请周围的赤脚医生在你吃药的这一天来看着你把药吃下去？

A: 没有必要，我自己有那么坚强，药再难吃我自己也会坚持吃下去。

**(23) Male, new patient, RC county:**

Q: Do you want anyone to supervise you to take drugs?

A: No, I don't want anyone.

Q: Why?

A: Because there are instructions on the drug box, I can supervise myself. I don't think it is necessary.

Q: 你不想有个人来看着你吃药？

A: 我不想

Q: 为什么？

A: 因为盒子上明明写得有，我自己会监督自己。我觉得那是多余，没有必要

**(6) Female, new patient, RC county:**

It's not necessary. I have self-consciousness; I don't want to waste their time, they are so busy. I should be responsible to myself, because I want to recover.

我觉得我没了这个必要的。我自己能够自觉，没的必要耽搁他们的时间，他们也很忙。

因为自己要为自己负责。自己也想医好。

**(32) Male, retreated patient, RC county:**

Q: Do you think it's necessary for the village doctor to supervise you to take drugs?

Q: 你觉得有没有必要让村医生监督你吃药？

Continued.

## Box 2 Continued

A: I don't think it's necessary to be supervised by the doctor while taking drugs. Because of my poor economic situation, I really want to be cured as soon as possible, so I remember to take every dose. Even if I forget to take drugs before breakfast I will take it after that. No matter how many pills, I can take them.

A: 没的必要的, 因为我家里面经济条件很差, 欠那么多债, 我还是一心想早点吃好, 每天都要记到吃药; 如果吃饭前搞忘了, 吃了饭之后都要吃。再多的药, 现在开的辅助药, 一顿就要吃几十颗药, 我一把就吃了。

**(9) Female, new patient, LB county:**

I don't think it's necessary. I want to be cured as early as possible, so I always take drugs on time.

我觉得没有必要, 因为我想早点好, 肯定要按时吃药的嘛。

**(5) Village doctor, older male, JLP county:**

Q: Do you think it's necessary for village doctor to witness patients taking drugs?

A: I think it's unnecessary. They are patients, they must take drugs. As long as the doctors explain clearly to them, they will take drugs without any supervision. Nowadays rural people also value their lives, and always follow doctors' suggestions. As long as we explain clearly, he will take drugs even if doctors don't visit him.

Q: 你觉得有没有必要请医生看着病人把药吃下去?

A: 种我想其实没有什么必要, 本来他就是那种病人, 必须要吃的, 只要你给他讲解, 做耐心细致的工作, 你不去督导他也要吃。现在的农民生命都还是比较宝贵的, 医生的话是最听的, 你只要给他讲清楚了, 你不去他都要吃。

**(8) Village doctor, older male, LB county:**

According to the national level TB control guideline I should supervise patients. However, I cannot meet it because of time and distance constraints.

A: 按照结防的规律来说应该必要去看他, 但是这个时间地点条件达不到。

**(10) Village doctor, younger male, LB county:**

Q: Have you every heard that TB patients should take drugs with doctor's witnessing?

A: Yes.

Q: Do you think it's feasible or not?

A: I think It's not feasible.

Q: Why?

A: Because it's impossible for us to spend all the time on one patient, we just often visit him. It is impossible for us to take care of one patient all the time.

Q: 你听说过肺结核病人吃药要在医生的面视下吃

A: 辟谣说法吗?

Q: 那你觉得这种做法可行不?

A: 我觉得不可行。

Q: 为什么?

A: 因为我们毕竟不可能整天或者全部时间都花在他身上, 只能说是经常去看他, 不可能随时都照看他。

## Box 3 Most new patients comply with treatment

**(26) Male, new patient, RC county:**

I want to be cured, how can I forget to take drugs? No, I won't.

自己要想病好怎么会忘记(吃药)呢, 不会的。

**(5) Female, new patient, RC county:**

Q: If the doctor doesn't come to supervise you will you take drugs?

A: Yes, I will take drugs because it's good for my health.

Q: 如果医生不来监督你, 你晓不晓得吃药?

A: 我还是要吃的, 为了自己的病好。

**(27) Male, new patient, LB county:**

I never stop taking drugs.

Now I have finished the 6-month treatment, however, I think if I take drugs for 1-2 more months, the treatment outcome will be better.

没有断过药, 但我觉得6个月到了呀, 还应该加固一、二个月, 很可能那个效果要好一些;

**(17) Male, new patient, LB county:**

Now I feel better, but I won't stop treatment unless the doctor asks me to stop.

(吃了几个月的药)要好些了。医生叫我停我才停,

## Box 3 Continued

**(31) Male, retreated patient, XS county:**

Q: Will you continue your treatment?

A: I have no money. If my daughter sends money back [daughter is a migrant worker], I will continue to take drugs; otherwise I won't take it any more.

Q: 你不继续吃下去吗?

A: 没钱了。要娃儿和女儿带钱回来。女不带钱来就不吃了。带钱来又去拿(药)。

**(10) Female, retreated patient, LB county:**

I took drugs for 2 months and stopped for another 2 months, and then I started the treatment again. If I have money I will take drugs, if not I will delay going to buy drugs until I can't bear it anymore.

After the symptoms disappear, I will stop treatment.

先是吃了两个月,然后又停了两个月,停了两个月又才(开始吃药),  
有钱就吃,实在是挨不住了,拖不住了,就去买药吃;吃了松活了之后,又不吃了,就是那样子  
的。

**(8) Village doctor, older male, LB county:**

The patient wants to be cured, so he would like to take drugs, it's not necessary for us to worry about them.

病人他还是希望自己好,还是晓得吃,用不着我们格外去操多少心,

**(3) Village doctor, younger female, RC county:**

After I told him how to take the drugs, he also paid attention to drug taking and wants to be cured.

我交代他怎么吃啊,他自己还是比较重视吃药,就希望病治好嘛。

## Box 4 Most patients report they are charged expensive fees for treatment

**(1) Male, new patient, XS county:**

Totally I spent 205 Yuan for 2 months' treatment, among which, 28 Yuan for transportation, and the rest is for drugs.

I don't know some drugs, but I know I paid for Jiuweipian [vitamin supplements].

两个月的药花了205块。有28块的车费,除了28,就都是药钱。  
有些药我都认不到。有九维片我晓得。

**(24) Male new patient, RC county:**

It's very difficult. I have to pay 200-300 Yuan each month for Jiehewan [TB drugs], liver drugs, and drugs to protect stomach.

困难啊,拿一个月的药都要二三百块钱,有结核丸,其他的就是一点护肝的和养胃的,

**(16) Male, retreated patient, JLP county:**

Although the anti-TB drug is free, I have paid much money for other things. For example, I paid about 180 Yuan for Hupanpian [liver drugs] in the first month.

吃点药不花钱嘛,但是那些花钱就多了。  
第一回开的护肝片,就是一百八十几。

**(20) Male, retreated patient, JLP county:**

I collect free drugs these months, however I still spent more than 400 Yuan. 150 Yuan for 2 examinations, I paid more than 400 Yuan for 'free treatment'.

这几个月拿的是免费药,还是要四百多块钱,检查两样,一样就是七十八块,两样就是一百五十几,免费药还是四百几。

**(6) Female, new patient, RC county:**

Among the drugs for which I paid 380 Yuan, TB drugs only account for very small part.

I can't afford those bandit drugs, for which I paid 500-600 Yuan every time.

380多块钱的药,真正(治)肺结核的(药),只  
我晓得不要,他都晕这晕那的,次都要五六百。

**(28) Male new patient, LB county:**

In the propaganda material it [TB drugs] is said to be free, so I think Jiganpian [liver drugs] should also be free.

布告上写的是一分钱不要。肌苷药也应该免费

## Box 5 Stigma exists in communities

**(26) Male, new patient, RC county:**

Now when I meet neighbours, we just say hello to each other, then they go away.

Before I got TB, we always sit down and chat for a while.

现在(邻居)看到就招呼一下就走了。(得病)

以前的话大家遇到了要坐一会儿,耍一会儿,说一会儿。

**(22) Male, new patient, RC county:**

From their words, now I think everybody has a poor impression of me. They are afraid of being infected by me.

每个人的讲话好像都对我有个不好的印象。他就

怕这个有那个细菌传播的。他就怕自己也传播了

**(14) Female, new patient, XS county:**

My neighbours knew that I had a disease, but they didn't know it was TB.

After knowing my disease and that I can't do any agriculture work any more, who want to visit me?

(邻居)他们晓得我有病,但是不知道是结核病。

知道我有病,还来找我做什么嘛,做事又做不得,哪个来找我嘛。

**(2) Female, new patient, JLP county:**

After they (friends and relatives) knew my disease, they always keep a certain distance while talking with me.

亲戚朋友晓得我有这个病了,说话都要隔我远一点。

**(25) Male, new patient, RC county:**

To me, my friends and neighbours still treat me same as before.

我觉得,作为朋友来讲,那些左邻右舍对待我没什么变化。

**(16) Male, retreated patient, JLP county:**

Q: What influence does TB have on your life or work?

Q: 你觉得得了结核病对你的工作、生活有没有什么影响?

A: I didn't tell anyone about my disease.

A: 那个我谈都没有谈,到现在我都没有谈(指对周围的人讲)。

Q: You think it will impact on you?

Q: 你觉得还是有点影响?

A: Definitely, there must be some influences. For example, if I ask them to play cards nobody will come. Who would like to come? After all, it's an infectious disease.

A: 这有时候不是钱的问题,你搞到这个工作了,如果不给钱,我们同样也要把这个工作做起,所以钱是次要的,做了这行还是要尽到应有的责任。

**Box 6** Village doctors report incentives are less important than responsibility**(10) Village doctor, younger male, LB county:**

*It's not the business of money. I am a village doctor, even if no money [management fee], I still need to do it [manage TB patients]. Money is not the most important issue; the village doctor should have his/her responsibility.*

这有时候不是钱的问题，你搞到这个工作了，如果不给钱，我们同样也要把这个工作做起，所以钱是次要的，做了这行还是要尽到应有的责任。

**(7) Village doctor, male, RC county:**

*Even if no money [management fee], I still have to do that job.*

*It's not a big loss without the money (60 Yuan), nor a big help with it. It's my responsibility, I should do it. To be a village doctor you must sacrifice something.*

就是没有钱嘛，我们还是要去看的。  
(六十块钱)对我们也没有好大的损失，也没好大的帮助。因为那个是我们分内的工作，反正是该干，因为做这行，你必须有付出。

**(5) Village doctor, older male, JLP county:**

*Even without money, I still need to do. Just like in the SARS pandemic or cholera pandemic, we didn't get even a coin.*

没有钱我们还不是做，像非典的时候，霍乱疫情的时候，我们同样没要一分钱。

**(4) Village doctor, younger female, RC county:**

*I know I can get money for managing patients. I should manage him no matter whether I can get money, since we live close to each other; we live in the same village.*

我晓得有(病人管理费)，但是有有我都觉得还是应该管理。因为他病人挨得我们那么近，反正都是一个村里面的。

**(9) Village doctor, younger male, LB county:**

*If we have certain economic resources we can concentrate on the job. However, now we have to make money for a living.*

有一定的经济来源，生活保障之后，就可以一心一意的，工作上，方方面面都要抓的。现在实际上还是主要靠自己找钱。