



Perceptions and experiences of health care seeking and access to TB care—a qualitative study in Rural Jiangsu Province, China

B. Xu^{a,b,*}, G. Fochsen^b, Y. Xiu^a, A. Thorson^b, J.R. Kemp^c, Q.W. Jiang^a

^a Department of Epidemiology, School of Public Health, Fudan University, Shanghai 200032, China

^b IHCAR, Karolinska Institute, Sweden

^c Equi-TB Knowledge Program, Liverpool School of Tropical Medicine, UK

Accepted 19 November 2003

Abstract

This study aims to obtain an in-depth understanding of factors that influence the health seeking behavior of TB patients, and access to tuberculosis (TB) care in counties with or without National TB Control Program (NTP) in rural China. Sixteen focus group discussions (FGDs) composed of TB patients and health care providers were held. Content analysis showed perceptions that financial difficulties influence health care-seeking behavior of TB patients in both program and non-program counties. Female and elderly patients were perceived to be more reluctant to seek health care and to seek care for cough from village health stations rather than general hospitals. Many TB patients said they could not afford the cost of TB care, even where services were subsidized. Fee-for-service incentives of health care providers and their ability to make a correct TB diagnosis were also perceived to influence patient access to TB care. Inappropriate treatment of cough patients was perceived to increase the risk of missing smear-positive diagnoses.

© 2004 Elsevier Ireland Ltd. All rights reserved.

Keywords: China; Tuberculosis; Focus group discussion; Socioeconomic status; Poverty; Gender

1. Background

Tuberculosis (TB) is a major public health problem in China. In 2000, the 4th National TB Survey reported that the infection rate of TB, based on PPD (tuberculin Purified Protein Derivative), was 44.5%, with a prevalence of smear- and/or culture-positive pulmonary TB of 160/10⁵, and a mortality rate of 8.8/10⁵. Among the 1278 identified TB cases in the survey, only 378 had been diagnosed as having TB

(29.6%), and 93 had been reported (7.3%) to the TB management system [1].

To address the threat of TB, the National TB Control Program (NTP) was initiated in the early 1990s, mainly with funding from a World Bank loan and the Ministry of Health (MoH), China. In NTP-covered areas, the directly observed treatment, short course (DOTS) strategy, recommended by the World Health Organization, is followed; based on passive case-finding and free or partly free TB health care for sputum smear-positive TB patients [2]. By the end of year 2000, 59% of the rural counties in China implemented the NTP strategy [3].

* Corresponding author. Tel.: +86-21-54237710;

fax: +86-21-63052506.

E-mail address: bxu@shmu.edu.cn (B. Xu).

Although TB treatment is provided free or partly free to smear-positive TB patients in the program area, there is no financial assistance for access to TB diagnosis facilities for TB suspects (i.e. patients with symptoms of prolonged cough, cough with sputum, bloody sputum and hemoptysis). In the NTP-covered area, the so-called ‘convergence management system’ has been set up. County and above TB dispensaries take the responsibility of TB diagnosis, therapy management and case registration. TB suspects should pay for the diagnosis and treatment. Before getting a smear-positive diagnosis in the county and above TB dispensaries, physicians in town and county general hospitals are encouraged to refer TB suspects to the county TB dispensary. They receive a RMB 20 (US\$ 2.5) incentive payment for each diagnosed smear-positive TB patient. This applies only to the counties in the World Bank project area. No incentive payment is made for referral in the MoH project area. In non-program areas, TB suspects and patients have to pay for both diagnosis and treatment and patients may have TB diagnosed in general hospitals or TB dispensaries.

Early passive case finding and treatment compliance based on access to appropriate TB care, are the cornerstones of effective TB control. Studies of the perceptions and experiences of access to TB care have shown that care-seeking behavior and access to TB care may be influenced by the costs of TB care, lack of knowledge of TB, and social rejection or stigma, especially among vulnerable groups [4–15]. Poverty is a key risk factor for TB and for reduced access to TB care [4]. Poor people are more likely to have TB, [5,6] and tend more often to be unable to access TB care due to the economic costs involved [7]. In Vietnam, gender differences in health care-seeking behavior have been reported. Among women, fear of social isolation, and inappropriate attitudes of health providers were found to delay health care seeking, whereas among men, health care seeking was negatively influenced by fear of the costs of TB treatment and neglect of symptoms [8]. In some African countries, there are reports that lack of knowledge and low levels of education among poor rural patients result in early symptoms of TB being missed or being confused with other illnesses such as malaria or the common cold [9–11]. Stigma has been considered as an important barrier to access to TB care among rural people, e.g. in Vietnam [12].

Patients’ care-seeking behavior and access to TB care may also be affected by the motivation, quality and capacity of TB care services [13].

Very few studies have been conducted in China on the perceptions and experiences of accessing health care, particularly of rural people. The 4th National TB Survey showed that the TB-related mortality in poor rural areas was nearly three times as high as in the economically developed urban areas. The difference could be attributed to poor living conditions, the underlying health and nutritional status, costs of health care, inadequate access to health services, and lack of knowledge of TB [1]. Although China is experiencing rapid economic development, most rural people still live in poverty [14]. Over 85% of the rural population have no medical insurance [15]. For the poorest quintile of rural population, only 4.7% was covered in any kind of medical insurance in 1998. To make matters worse, the price of health services has been increasing subsequent to the health systems reforms since mid-1980s [16]. A study of care-seeking behavior among 246 cluster-sampled rural families in Shanxi Province, showed that the main barriers to care seeking were poverty and absence of medical insurance. In year 2001, the average household expenditure for health care was RMB 385 (US\$ 45), including RMB 97 for transportation, for the families needing medical services, while the average household income was only RMB 850 [17]. Another study, conducted by Dong et al. [18] in central China, found that insured patients had more access to expensive drugs, were more often referred to specialized health care facilities, and had a higher cure rate (according to the doctor’s opinion) for TB compared to uninsured patients. Yip et al.’s [19] study on determinants of patient choice of medical provider reported that poverty might be the most important factor that causes health seeking delay and poor access to TB care.

The Chinese Government has committed to reach 70% case-detection rate and 85% cure rate of smear-positive TB cases in 2005 [20]. For early detection and timely treatment of TB cases in China, it is imperative to understand how the poor perceive and experience access to TB care. The objectives of this study are to obtain an in-depth understanding of factors that influence TB patients’ care-seeking behavior, and access to TB care in rural China.

2. Subjects and methods

2.1. Study setting

Two counties in north Jiangsu Province in East China were purposely selected as the study sites to cover areas with and without the National TB Control Program. In Jiangsu, like the rest of China, there is a three-tier health care system from the village health station, to the township hospital to the county hospital and the county-level TB dispensary. In the village health station, village health workers (VHWs) provide primary health care services; most of them have less than 2 years of medical training, and they only have a basic knowledge of medicine and primary health care.

The first county selected was Jianhu County (JH County), which has implemented the NTP strategy since 1997. The second county selected was Funing County (FN County), which does not have a specific TB control program. The reported average annual income for rural residents was similar in both areas: 3356 Yuan per capita in JH County and 3144 Yuan in FN County. The registration rate of new TB and sputum smear-positive TB in JH County were 25.5 and 17.8/10⁵, respectively, in 2000; compared to 40.1 and 14.1/10⁵, respectively, for FN County.

In JH County, only doctors in TB dispensaries are officially responsible for making a TB diagnosis. TB suspects can visit the TB dispensary directly or can be referred by physicians from the general hospitals. The NTP provides subsidized TB health care for smear-positive TB patients. Smear-positive TB patients pay 140 Yuan for the 6 months treatment course, which includes the expenses for sputum smear tests and a chest X-ray. Direct observation of treatment is carried out by the VHWs. In FN County, TB diagnosis and treatment are available in general hospitals and the county TB dispensary. Smear-positive TB patients pay for the TB diagnosis and 6–9 months' treatment at a cost of 600–900 Yuan. Patients are encouraged to complete the treatment course, and re-visit the hospitals based on the advice of their doctors.

2.2. Focus group participants

Focus group discussions (FGDs) were conducted among pulmonary TB patients and health providers from village health stations, township hospitals and

county TB dispensaries. In total, 16 FGDs (eight in each county) were organized, consisting of groups of TB patients (five groups), village health workers (VHWs, five groups), health providers from the township hospital (five groups), and from the county TB dispensary (one group).

The five patient groups comprised nine women and 21 men in different treatment stages. The participants' ages varied from 25 to 78 years old, with a mean of 45 years. Over 85% of the participants were farmers.

Twenty-eight VHWs attended the five FGDs. Since most VHWs working with disease prevention in the selected counties are men, the groups included only three women. The participants were between 35 and 50 years old.

Fifteen female and 15 male health providers from township hospitals and the TB dispensary were recruited for the groups of hospital providers.

2.3. Data collection

The research team consisted of one Chinese epidemiologist, one doctoral student and three master students. Each group had five to six participants and lasted for approximately 1.5 h. FGDs were conducted in a private and comfortable space.

Each FGD had a moderator and a note-taker who understood the local language. The FGDs were also tape-recorded. The tapes and notes of the FGDs were transcribed into mandarin Chinese, and then translated into English by the research team members. Later, the transcribed materials were checked by university students who are familiar with the local language by comparing the recorded tapes to the transcriptions.

A semi-thematized guide, covering general as well as specific questions, was utilized in the session. The questions focused on perceptions and experiences of TB care seeking and access to TB care, such as knowledge and stigma of TB, perceived difficulties in care seeking, and experiences on obtaining and providing TB care.

2.4. Data analysis

Qualitative content analysis with an inductive approach was used in the data analysis [18]. The transcribed materials were coded line-by-line or paragraph-by-paragraph by the first author of this paper and the

team members. The codes were clustered together to create tentative categories and sub-categories, and two main themes emerged based on the patterns and relationship between the categories.

2.5. Ethical considerations

Ethical approval was issued by the Ethics Committee of Fudan University. Informed consent was sought from all participants of the group discussions. Drinking water and Chinese tea were available during the FGDs. No gifts or stipends were provided.

3. Findings

3.1. Factors influencing patients' care-seeking behavior

3.1.1. Gender and age

One of the main topics of the focus group discussions was whether the care-seeking behavior in terms of delay and health facility selection varies among different sub-groups of the population. With regard to gender, initially group respondents did not think there were any gender differences in health seeking for cough. Many participants mentioned that socialism demanded 'men and women the same'. A common view was that for any really serious disease, both men and women would go to see a doctor. However, further discussion revealed that some women hesitate to seek health care, especially when the economic status of the family is poor. There was general agreement that women cared less for their own health than for the health of their husbands and children.

Because women manage the family they know how hard it is to get money so they want to save money ... but they will want to pay money for their husband and child so Chinese women are great. (Female provider)

Another aspect of women's reluctance to seek health care was related to the status of men and women in the family. Many participants agreed with laughter that 'men and women the same' is a slogan rather than a reality. Respondents said that in rural Jiangsu, men do heavy physical work on the

lands, or work in the construction or transportation industry away from their hometown. All the participants agreed that men were primarily responsible for supporting the family, and hence greater importance was attached to their health.

Since the man is the key person in the family, if he gets sick he has to be treated urgently. But if the woman gets TB, since it's not fatal, she'll probably not see a doctor. (Physician)

Men are the backbone of the family. Without men, the families will be crushed ... (VHW)

Groups were probed as to why women cared less for their own health. None of the participants explicitly stated that women were less important than men. However, both patient and provider groups listed some factors, which subtly expressed their opinions that women's work at home was less valued and that women's contributions to the family were not the same as those of men.

Women stay at home, play Mahjong (Chinese game) and cards, knit woolen sweaters, cook, wash, and take care of children. They have no income. (Patient)

For those women who did seek care for cough, it was generally reported that most of them visited the village health station first. Both patient and provider participants agreed that women chose to go there because of its closeness and convenience, because of having minor symptoms and for the cheaper medicine.

The care-seeking behavior of old people was also elaborated on in the FGDs. Elderly people were perceived to seek health care much later than young people and they would normally opt for the village health station for treatment.

Participants described that when elderly people are ill, most of them will try to treat themselves by drinking water and resting until their illness becomes more serious. According to some of the health providers, delays in seeking care among elderly patients resulted in them presenting symptoms of late stage TB: cavities on the lungs and hemoptysis.

The reasons for delay were mainly related to poverty and lack of cash income. Although it was reported that the children of elderly people would pay

for their parents' medical expenses, if these expenses were large, this would be unaffordable. Meanwhile, even if the children could afford the expenses for their parents' TB care, elderly people would not like to use their children's money because they reasoned that their children were not rich, and the money should be used for issues perceived to be more important such as the grandchildren's education.

I had three children, some are not poor. But my cough is minor. They have their own families. I shouldn't make trouble for them. (Old patient)

3.1.2. Socio-economic status and its interaction with gender, age and education

Although care-seeking behavior is perceived to vary according to gender and age, all the participants agreed that the key factor influencing care seeking was the socio-economic status. The respondents said that the very poor (men or women, young or old), would not seek health care for cough, unless they had cash in hand.

Though the annual average income per capita in these two counties was around RMB 3300 in 2000, many farmer families lived on an income of RMB 1000–2000 or less per year. The participants listed several attributes, such as farming, doing heavy physical work, old age, having a chronic disease and economic dependency to define the poor.

There were also reported interactions between socio-economic status and gender, age, and education. Old people, women and people from poor families have the least education. If the family was poor, girls were usually asked to give up their education and let their brothers go to school instead. With a lower level of education, most women are unable to get a stable employment or income.

Respondents said that most poor people do not have medical insurance and would have to pay out of pocket for their health care.

All respondent groups said that village health stations were the facility level visited most often by poor patients. There, patients can obtain antibiotics, such as penicillin, streptomycin and Cefradine for their cough. Furthermore, there is no registration fee, or expenses for special examinations or laboratory tests. The price of drugs in the village health station is usually cheaper than in the hospitals.

3.1.3. Knowledge and perceptions of TB

Many patient participants reported that if they had known they had TB, they would have sought medical care much earlier. They stated that before being diagnosed they only had very limited knowledge of TB. When their early symptoms of cough started, they perceived them as minor ailments and did not find it necessary to seek care at a hospital. When the cough lasted for weeks or months or they had hemoptysis, they perceived their illness as being serious.

The social consequences of TB were discussed in the FGDs. All the provider groups denied that TB was stigmatized. From their perspectives, patients should not feel ashamed of their TB when seeking care, although they acknowledged that there were some TB patients, especially young patients and women patients who asked the doctor to keep their disease confidential.

Most of the patients reported not feeling ashamed of having TB, though some of them reported that they had been excluded from the community. Most groups stated that in general, people did not like a TB patient to visit their home, to contact their children, or to share a meal. They also reported that parents would not let their son or daughter marry a TB patient, not even an ex-TB patient. The patient participants said that discrimination by neighbours and relatives, particularly by teachers and educated people, did not influence their care seeking for TB, because without getting treatment, they could not get rid of the disease, and the discrimination as well. Some of them asked the doctors to conceal their TB. All of them agreed that for young, unmarried people it could be necessary to keep the disease a secret. The underlying reasons for not marrying a TB patient was that they could not produce a healthy baby in the future; TB patients were unclean, and incurable TB would impoverish the family.

3.2. Factors influencing access to TB health care

3.2.1. Availability of subsidized TB care and patient's expenditure on TB care

Subsidized TB care was considered to be an important factor in improving access to TB care by all the participants. Participants from JH County stated that TB suspects were informed that only RMB 140 should be paid if they were diagnosed with smear-positive TB in the county TB dispensary. Most participants from

JH County agreed that patients could deal with this expenditure for one visit to the dispensary, although some of them expressed concern about the payment. It was further argued by both patients and providers that smear-positive patients could complete the treatment course even if they had to borrow money from relatives and neighbors to cover the RMB 140. No other charges were expected, but patients would need to pay for their transportation for three visits to the TB dispensary, for repeated smear tests, a chest X-ray and renewing their prescriptions.

The program is very good for poor people. But (RMB) 140 Yuan is not a small amount. (Old patient)

In FN County, it was stated that TB diagnosis and treatment cost several hundreds or thousands. As described by participants, money was required for chest X-rays, tests for liver function, blood, urine and sputum were asked for repeatedly, before and during the treatment. All examinations and medicines were charged for. The health provider groups complained that patients did not like to take most of the tests. Only chest X-rays were accepted by patients. All groups agreed that treatment interruption occurred frequently due to shortage of money, particularly after the first 2 months of treatment.

In total, I spent more than (RMB) 3000 Yuan in the first two months. After I felt better, I stopped taking medicine. (Patient)

I have been treated for 3 months ... I have no money. I don't want to continue ... Farming the land, feeding some pigs, I make about (RMB) 1000 Yuan a year. For this TB, I have spent around three hundred. I have chronic stomach disease. I'm old, so old, I'm not afraid of death. Just die! (Patient)

3.2.2. Quality of TB diagnosis

Groups mentioned that access to TB care might also be influenced by poor quality of TB diagnosis. They exemplified that this might be due to the failure of doctors to recognize TB symptoms, that no smear tests were conducted or that the quality of smear tests was poor. The providers from township hospitals in JH County described that the examination used most often for chronic cough is fluoroscopy and chest X-ray.

Unless a 'typical' TB image was recognized on the film, they would not refer patients to the county TB dispensary, due to the additional costs and inconvenience for the patients. Moreover, patients will not be subsidized if they obtain a smear-negative TB diagnosis. Although the providers have been trained to identify TB, some of them admitted that they were not very alert to TB-related symptoms, and chronic cough was usually considered to be a sign of chronic bronchitis.

In the non-program FN County, both health providers and patient participants reported that smear tests frequently were not provided to chronic cough patients.

In JH County, the lab of the TB dispensary was equipped according to the guidelines of MoH. But in FN County, smear tests were conducted both in the township and county hospitals and in the TB dispensary. A provider from a township hospital complained:

Our lab is very poor. The ultra-violet lamp was borrowed from another hospital. The agents for tests were given by another hospital. And the patients used some antibiotics before coming to our hospital. So the sputum smear-positive rate is very low ... The self protection funding is "Zero". No ventilation tunnel, poor equipment. I'm afraid of being infected. So I do it as quickly as possible. Of course, many mistakes are made. (Provider)

Many patient participants from FN County described how they were diagnosed as having TB without a smear test. One of the TB patients blamed the hospitals very much. She said it took her 10 months to get a smear test although she visited the prefectural hospital and the county hospital repeatedly. She was diagnosed with smear-positive TB following hemoptysis after she had been coughing for 10 months.

The providers from FN County concluded that due to the low smear-positive rate, and the low smear test rate, there were many patients who were treated for TB, but who never received the confirmation of TB diagnosis.

3.2.3. Influence from "fee-for-service" payment mechanism

On the pathway to TB diagnosis and treatment, patients can visit different levels of the health care system. Some physicians from township hospitals in

both counties complained that patients were kept in the villages and treated with antibiotics. After being treated with antibiotics for several days, patients with a cough usually felt better. They would go back to the village health station when they got another cough episode, and stay there for several weeks, or even several months. They would not visit any hospitals until the disease deteriorated. Several physicians even reproached the VHWs for using Cortisone to inhibit inflammation and make the patient feel better, thereby keeping them at the village health station. A reason for this was that the VHW's income comes from the payments of patients alone.

But this issue was so sensitive that all the VHWs in both counties denied it. They said Cortisone and similar medicines are not allowed to be used in their small clinics. They emphasized that patients would go to the hospital themselves anyway.

Patients come to us because they live close to our clinics, the price is cheap . . . Visiting us only requires (RMB) 30–40 Yuan, but visiting a hospital requires one to pay more than one hundred. (VHW)

As the physicians in hospitals criticized the VHWs' intention to keep patients, the VHWs criticized the "fee-for-service" incentives in the hospitals. They said that the high charge for medical care in hospitals is unaffordable for most poor patients. Patient participants did not reproach the health providers directly in the FGDs. However, some patients, most of them from FN County, were suspicious of the examinations and treatments they had received in different health facilities causing delay of TB diagnosis, high cost and poor effects of the treatment, together with severe side effects of the medicine. They reported being suspicious of the quality and price of drugs, and the doctor's motivation.

The attitude of doctors is good. But doctors should consider their economic benefits. They will lose their jobs if they can't earn much money from patients. The hospital needs as many patient visits as possible. One more visit, one more chance of getting money. If patients visit hospitals more, of course doctors get better incomes. (Patient)

For this "fee-for-service" incentive, patient participants from FN County made a conclusion about all the health providers:

The doctor is a "business" doctor. If patients are cured, doctors will lose the source of their income. (Others agreed with this.) (Patient)

4. Discussion

4.1. Methodological considerations

Focus groups discussions are considered to be an appropriate method for identifying and exploring beliefs, attitudes and behaviors [21]. The explorative nature of this study generates data useful for questionnaire design and variable definition for further quantitative research on access to TB care and its risk factors in rural China.

Literature on the use of FGDs in the Chinese population is scarce, but a study among Hong Kong Chinese women found that the use of FGD provided an effective method for collecting qualitative data in Chinese populations [22]. This method is extremely meaningful in the context, because so very little in-depth research on the perceptions and attitudes of TB patients and providers in China has been published. The 4th National TB Survey revealed that case detection and referral rates remain disappointingly low and that the prevalence reduction targets of the NTP 1991–2000 have not been achieved. Our study in the Chinese rural population—the high risk population to TB—give an insight into why TB cases are being missed, even in the NTP areas.

The findings from FGDs are assessed according to the criteria of trustworthiness. The trustworthiness of the findings can be achieved by gathering data from participants with various experiences to shed light on the research question from a variety of aspects [23]. In this study, patient participants with different occupations and socio-economic status were invited, including farmers only working in the field, farmers with alternative production, employees of township enterprises, government employees, teachers, etc. Patients were in different TB care stages (treatment completed, treatment ongoing, and treatment interrupted) with their own specific experiences and perceptions on the access to TB care. Health provider participants came from different levels of health facilities, including village health workers, physicians and nurses in internal medicine, lab technicians of township

hospitals and TB program staff. Village health stations and township hospitals are the basic units of the three-tier health care system in whole China. Participants from these health facilities had the most direct experiences of health care provision to patients with TB symptoms. The findings from this study can to some extent be expected to reflect the influencing factors on access to TB care in other counties and provinces of rural China, given the variety of the participants' backgrounds and experiences and the similarity of the health care system and the demographic and socio-economic distributions in rural China. Findings from this study provides rich information for the development of quantitative studies on the access to TB care in rural China, such as how to define and rank people's socio-economic status, and how to define and collect data on explanatory variables influencing rural people's access to TB care.

One problem, identified in this study, was that male health providers talked more than female providers in the group discussions. This was partly because most health providers in the TB control area—especially physicians and program managers—are male. Women worked mainly in nursing, laboratories and data management. From our observations, it was clear that all the physicians, both male and female (though they were few) participated actively in the discussion. Female providers in lower-ranked positions talked actively whenever the topics were related to their own area or to general perceptions on TB. For the issue of female care-seeking behavior, both male and female participants described the reluctance to seeking health care of women and discussed the reasons of the gender differences actively. In the FGDs with patients there were no obvious hierarchical pattern in the discussion among the participants, despite the heterogeneity of the groups with respect to sex. All participants seemed to be relaxed and discussed lively the topics that were introduced by the moderator. On the tapes and notes, more than 50% of the interventions were made by female participants. However, the women's voices were not heard separately in this study. Given the experience of the group dynamics in this study, it would be valuable to do separate groups for women as well as in-depth interviews with women in further studies.

Another problem in the FGDs with health providers was that they seemed anxious to answer in a 'correct' way, especially in the group composed of staff from the

county TB dispensary. However, as the results show, by organizing more FGDs in township hospitals rather than the county TB dispensary, and by adding more specific questions about social roles and their own experiences of providing health services, providers more openly revealed beliefs and experiences.

In the data analysis, the data was approached inductively without any predetermined theories in order to be as unbiased as possible. However, we are still influenced by previous knowledge in the research area of access to TB health care and its influencing factors. This has been defined as "sensitizing concepts" in qualitative research, which indicates that the researcher is guided by previous experiences and theories, although no specific hypotheses are used [24].

4.2. Impacts and interactions of socioeconomic factors on access to TB health care

An important finding in these focus group discussions was the statement made by the participants that the socio-economic status of the patients including family income, occupation and medical insurance were the main factors influencing the care-seeking behavior and access to TB health care.

The global TB re-emergence has become a threat to the health of the poor rural population in China. The 4th National TB Survey found that among the 1278 identified TB cases, 78% had an annual average income lower than the local average level, and 92% of them had no medical insurance of any kind [1].

Economic barriers, such as treatment fees, transportation costs and loss of income, have been highlighted, in different study settings, as negatively influences on patients' possibilities to seek health care and adhere to treatment [25–27].

In China, financial difficulties have been reported to be the most important reason for not seeking health care for people with a low income. Being a farmer has especially been associated with an increased risk of delay in health care seeking because of payment difficulties [28]. This draws attention to how financial aspects of TB programs affect people in rural areas living under poor economic conditions.

In JH County, the cost for a sputum smear test was only RMB 5, yet, some patients admitted having difficulties to afford it. Although partially free TB care was provided in JH County, only patients who

had a smear-positive TB diagnosis could benefit. Until having smear tests, patients have to cope with the costs of diagnostic examinations and tests, and transportation to and from the county TB dispensary. With a smear-negative TB diagnosis, patients have to pay out-of-pocket for TB care charges. In FN County, TB diagnosis and treatment are even more costly, since fewer sputum smear tests are provided, more diagnostic examinations are often conducted, and unpredictable costs for treatment can be charged.

Data from the focus groups showed that poor patients initially went to the village health station to seek health care. Due to the health care reforms in China during the last two decades, the village health stations have received an increasingly smaller share of the public funding and have to rely mainly on fee-for-service [29]. In our study sites, there were no funding for village health stations from public funds. Village health stations function like a commercial company, with 85% of the investment coming from the VHWs, and 15% from the village organization. The village health stations' dependence on fee-for-service revenue contributes to supplier-induced demand. As reported both by the providers and patients in the FGDs, there was a tendency in the village health stations to provide treatment for symptoms diagnosed as common cold. There were perceived to be financial incentives for the village health workers to keep TB suspects for treatment, instead of referring them to the township or county hospitals for further diagnosis.

The same incentives were perceived to exist in the hospitals. Patients stay in village health stations and general hospitals for long periods delaying their pathway to appropriate TB care. In fact, it was perceived that some patients were kept intentionally by the health providers. The 'moral hazard' afflicting the health providers under the influence of the fee-for-service system, was perceived to cause delays in TB diagnosis at any kind of health facilities, and thus contribute to the further transmission of the illness [28].

Issues concerning inappropriate treatments, selling of various antibiotics to cough patients, both at village health stations and hospitals were recounted in the FGDs. This implies an increased risk that smear-positive TB cases are missed, resulting in loss of subsidies for patients, otherwise eligible.

Another important issue discussed in the focus groups was how the economic situation of the fam-

ily seemed to influence the gender differences in care-seeking behavior. Poor women seemed particularly reluctant to seek health care. A quantitative study in Vietnam reported that women with prolonged cough tend to spend less money on health care compared to men, [30] and women were shown to have a lower case detection rate than men [31]. In this study, from the participants' viewpoint, the delayed health care seeking of women was ascribed to the real economic status of family, rather than gender differences. But the findings actually revealed important perceptions of gender roles and status in rural society. Men were considered to be the main supporters of the family. Chinese parents have higher expectations of their sons than of their daughters, thus boys get more opportunities to obtain a longer education than girls do. This finding suggests that in rural China, patriarchal family structures, in which men are considered more important than women, still exist. Women in rural Jiangsu Province were still to a large extent confined to unpaid work in the household making them dependent on their husbands' income. Women's status accompanied by their economic dependency was perceived to constrain their decision-making power regarding their own health and health care seeking.

Similar difficulties in access to TB care exist for elderly people. In rural Jiangsu, old people usually live separately from their children, although they often help to care for the grandchildren, when their children work away from hometown. They support themselves through very limited income from farming. Their dependence on the children for health care constrains their health seeking. In their roles as care-takers of their grandchildren, they are very important risk factors for TB transmission.

5. Conclusion

The findings in this study illuminate some important aspects of TB care in rural China. However, findings from qualitative studies must be interpreted with regard to the specific context of the study setting.

Financial difficulties of TB patients influenced their health care-seeking behavior. Elderly patients and female patients were more reluctant to seek health care and tend to seek care from the village health stations for cough, particularly when their economic situation

are not secure. Many TB patients cannot afford the expenditure of TB care, even where services were subsidized.

Although the TB control program has improved access to TB care for identified smear-positive TB cases, particularly for the poor in JH County, costs are still incurred for diagnosis, transport to and from the county dispensary, and for treatment of smear-negative TB. These factors may explain some of the under-notification of TB cases even within NTP areas, as revealed in the 4th National TB Survey.

The Chinese Government is committed to expand DOTS coverage to 90% of the rural counties by 2005 and to 95% by 2010. It is clearly extremely important to resolve the inherent conflict between the publicly funded NTP and the privately financed health facilities, which are dependent on fee-for-service revenue, in order to be able to improve the case detection rates and improve the case management. The views and perceptions expressed by both patients and providers point to the need to involve all health care facilities in the TB control program. It is obvious that the RMB 20 incentive payment is totally inadequate to compensate for the revenue loss for referring doctors. We suggest that access to TB care can be further promoted by raising the income levels of the rural population, by reconstructing the rural medical insurance system, as well as by improving the availability of the TB control program, expanding NTP subsidies also to smear-negative TB patients, reorganizing the NTP to cover both the vertical public system and the general health facilities, strengthening the training in recognition of TB, creating a realistic incentive for referral of TB suspects and raising the awareness of the general population as to the signs and symptoms and correct diagnostic procedures for TB, with special focus on the gender and age aspects.

Acknowledgements

This investigation received financial support from the UNDP/World Bank/WHO Special Program for Research and Training in Tropical Diseases (TDR). We are grateful for the valuable advice and comments provided by Prof. Vinod K Diwan and Dr. Lennart Bogg.

References

- [1] MOH, China, Report on Nationwide Random Survey for the Epidemiology of Tuberculosis in 2000. Journal of Chinese Anti-Tuberculosis Association 2002;24(2):65–107.
- [2] Department of disease control, MOH. National workbook of TB control. Beijing: Ministry of Health; 1999.
- [3] Duanmu HJ. Potential of TB control and research in 21 century. Chinese Journal of Tuberculosis and Respiratory Disease 2000;23(1):6–8.
- [4] Waaler HT. Tuberculosis and poverty. International Journal of Tuberculosis and Lung Disease 2002;6(9):745–6.
- [5] Barr RG, Diez-Roux AV, Knirsch CA, Pablos-Mendez A. Neighborhood poverty and the resurgence of tuberculosis in New York City, 1984–1992. American Journal of Public Health 2001;91(9):1487–93.
- [6] Tupasi TE, Radhakrishna S, Quelapio MI, Villa ML, Pascual ML, Rivera AB, et al. Tuberculosis in the urban poor settlements in the Philippines. International Journal of Tuberculosis and Lung Disease 2000;4(1):4–11.
- [7] Needham DM, Godfrey-Faussett P, Foster SD. Barriers to tuberculosis control in urban Zambia: the economic impact and burden on patients prior to diagnosis. International Journal of Tuberculosis and Lung Disease 1998;2(10):811–7.
- [8] Johansson E, Long NH, Diwan VK, Winkvist A. Gender and tuberculosis control perspectives on health seeking behavior among men and women in Vietnam. Health policy 2000;52:35–51.
- [9] Gelaw M, Genebo T, Dejene A, Lemma E, Eyob G. Attitude and social consequences of tuberculosis in Addis Ababa, Ethiopia. East African Medical Journal 2001;78(7):382–8.
- [10] Liefoghe R, Baliddawa JB, Kipruto EM, Vermeire C, De Munynck AO. From their own perspective. A Kenyan community's perception of tuberculosis. Tropical Medicine & International Health 1997;2(8):809–21.
- [11] Salaniponi FML, Harries AD, Banda HT, Kang'ombe C, Mphasa N, Mwale A, et al. Care seeking behavior and diagnostic processes in patients with smear-positive pulmonary tuberculosis in Malawi. International Journal of Tuberculosis and Lung Disease 2000;4(4):327–32.
- [12] Johansson E. Emerging perspectives on tuberculosis and gender in Vietnam, PhD thesis. Stockholm: Department of Public Health Sciences, Karolinska Institute; 2000.
- [13] Prasad R, Nautiyal RG, Mukherji PK, Jain A, Singh K, Ahuja RC. Diagnostic evaluation of pulmonary tuberculosis: what do doctors of modern medicine do in India? International Journal of Tuberculosis and Lung Disease 2003;7(1):52–7.
- [14] 2001 local statistics report, vol. 3. National Bureau of Statistics of China; 2002.
- [15] Dong HJ. Health financing systems and drug use in rural China, Doctoral thesis. Stockholm: Department of Public Health Sciences, Karolinska Institute; 2000.

- [16] Gao J, Qian J, Tang S, Eriksson B, Blas E. Health equity in transition from planned to market economy in China. *Health Policy and Planning* 2002;17(Suppl 1):20–9.
- [17] Liu LP, Li QL, Yang HY. Health seeking behaviours and its influencing factors among rural people. *Chinese Primary Health Management* 2002;22(5):23–4.
- [18] Dong HJ, Bogg L, Rehnberg C, Diwan V. Health financing policies—providers' opinions and prescribing behavior in rural China. *International Journal of Technology Assessment in Health Care* 1999;15(4):686–98.
- [19] Yip WC, Wang H, Liu Y. Determinants of patient choice of medical provider: a case study in rural China. *Health policy and planning* 1998;13(3):311–22.
- [20] Department of disease control, MOH. Operational guideline of national tuberculosis control program. Beijing: Ministry of Health; 1999.
- [21] Berg B. *Qualitative research methods for the social sciences*, 3rd ed. Needham Hights, MA, USA: Allyn & Bacon; 1998.
- [22] Twinn S. An analysis of the effectiveness of focus groups as a method of qualitative data collection with Chinese populations in nursing research. *Journal of Advanced Nursing* 1998;28(3):654–61.
- [23] Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today* 2004;24: 105–12.
- [24] Sandelowski M. Writing a good read: strategies for re-presenting qualitative data. *Research in nursing and health* 1998;21:375–82.
- [25] Kahn A, Walley J, Newell J, Imdad N. Tuberculosis in Pakistan: socio-cultural constraints and opportunities in treatment. *Soc Sci Med* 2000;50(2):247–54.
- [26] Nair DM, George A, Chacko KT. Tuberculosis in Bombay: new insights from poor urban patients. *Health policy and planning* 1997;12(1):77–85.
- [27] Needham DM, Godfrey-Fausett P, Foster SD. Barriers to tuberculosis control in urban Zambia: the economic impact and burden on patients prior to diagnosis. *International Journal of Tuberculosis and Lung Disease* 1998;2(10):811–7.
- [28] Bogg L. Health care financing in China: equity in transition, PhD thesis. Stockholm: Department of Public Health Sciences, Karolinska Institutet; 2000.
- [29] Bogg L, Dong H, Wang K, Wenwei C, Diwan V. The cost of coverage: rural health insurance in China. *Health Policy and planning* 1996;11(3):238–52.
- [30] Thorson A, Noa NP, Long NH. Health seeking behavior of individuals with a cough for more than 3 weeks. *Lancet* 2000;25356(9244):1823–4.
- [31] Thorson A. Equity and equality-case detection of tuberculosis among women and men in Vietnam, PhD thesis. Stockholm: Department of Public Health Sciences, Karolinska Institutet, 2003.