The experience of Chinese undergraduates with pulmonary tuberculosis: a qualitative study

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Abstract

Background: Although undergraduates with pulmonary tuberculosis (TB) are a distinct social group, little is known about their experiences. This paper explores the experiences and psychological processes of Chinese undergraduates with pulmonary TB.

Method: A qualitative study was conducted among 17 undergraduates with pulmonary TB. Data were generated through in-depth interview. The data were read, analyzed, examined, classified, and extracted.

Result: Five themes emerged: complex feelings, an incorrect perception of TB, influence on daily life, poor social support, and positive influence of illness.

Conclusion: Chinese undergraduates with TB have a general lack of knowledge of TB; their mental and psychological burden is significant during the treatment; and there is serious conflict between treatment and study during their treatment and rehabilitation. Undergraduates with TB need systemic health education. Doctors, nurses, and TB control and prevention workers should provide psychological support for undergraduates with TB, and universities should implement the government’s policy on TB and provide
opportunities for the patients to continue their studies.

**Background**

In China, there is a high incidence of pulmonary tuberculosis (TB) among undergraduates, who are in a period of rapid growth and development and endocrine instability. It has been reported that the morbidity of pulmonary TB begins to rise at this age. Currently, there are more than 1900 universities and over 20 million undergraduates in China. In the past 10 years, the number of universities has almost doubled, and the number of undergraduates has increased sixfold. But the infrastructure for these universities has fallen behind. Six to 8 people live in one dormitory room; 60 to 200 attend lectures in one classroom; and 1000 to 2000 eat in one dining hall. A large number of universities and undergraduates, collective livelihood, and close interaction are salient features of the Chinese university system, which results in an obviously higher TB morbidity in undergraduates than the general population. The pulmonary TB prevalence rate in undergraduates is between 0.40% and 1.52%, and its attack rate can be as high as 2.975%–4.202% during a pulmonary TB outbreak. In recent years, reports on TB prevalence in Chinese universities are not rare.

The World Health Organization recommends the implementation of the Directly Observed Treatment Short Course (DOTS) strategy, which emphasizes quality diagnosis and treatment and use of standardized outcome definitions. The goal of the DOTS strategy is the success of biological therapy, but it does not address the patients’ social and psychological experiences. Thus, the psychological state of TB patients is largely unknown.

A study from Pakistan showed that pulmonary TB causes many problems for patients, including stigmatization, social isolation of them and their families, diminished marriage prospects for them and for their family members, and even divorce. Nearly all the patients are angry and distressed. Most Chinese undergraduates with pulmonary TB experience negative mood, including anxiety, moping, tension, pessimism,
etc. [11], but reports on the experiences of undergraduates with pulmonary TB are rare.

This study uses a qualitative approach to explore the feelings and psychological processes of undergraduates with TB and seeks to find unifying characteristics and the causes of their negative emotions. The results are of use to healthcare workers in making a comprehensive plan for biological therapy, social support, and self-adjustment for undergraduates with TB. It can also provide scientific evidence for the validity of making humanistic policy by universities and departments of TB control and prevention.

**Method**

The study design was qualitative, using an in-depth interview approach.

**Participants**

According to educational background, grade, and school, this study used the method of purposive sampling and chose 17 undergraduates with pulmonary TB. Seven were registered with the Center for Disease Control (CDC) of Shaanxi in China. Ten were hospitalized in Shaanxi provincial TB hospital.

**Training**

The interview was mainly conducted by a professor from the medical college and assisted by postgraduates. The postgraduates were trained to collect data for qualitative research before the interviews. In September 2008, to ensure the effectiveness of the data, the researcher selected two cases to make a pre-interview; the data were then transcribed into words, and the research team read and analyzed it together. The formal interviews were conducted from October to November 2008.

**Data collection**

This study was approved by the university Ethics Committee. The participants verbally agreed to be interviewed or signed informed consent. Patients who were hospitalized were interviewed separately in a private office; patients who were out of the hospital were interviewed separately in a place negotiated by the
researcher and the participant. In-depth interview was used to collect data. The interview was voluntary and adhered to the principles of nondisclosure and convenience. The participants were told of the aim and process of the study, the principle of nondisclosure, and the necessity of recording. There were two interviewers: one was mainly responsible for interviewing, and the other was primarily responsible for noting and audio-recording.

Fielding & Fielding's Triangle correction was used in the interview. Nonverbal information, such as tones, facial expressions, and gestures, were observed during the interview. An interview schedule was used to collect data (see Table 1), and the interviewer guided the participants in expressing their feelings, psychological processes, and thoughts during the illness. Each case was interviewed for 50–70 minutes. To accomplish this task, the interviewer set aside, as much as possible, any preconceived notions, expectations, or frameworks about the phenomenon and opened themselves fully to the process. All of this can enhance the accuracy of the study.

Data analysis

Colaizzi's method and Sandelowski's tactics were used in the process of data analysis; the researcher attempted to blend into the experiences of the participants. The researcher used Beck’s criterion to evaluate whether the results were credible and could be understood.

The first step of the analysis was to transcribe the audio-record word-by-word on the computer. The researcher repeatedly listened to the audio-record and read the transcript and noted observations. Meaningful phrases were written on a memorandum, classified, and put forward as the primary tentative idea. The meaningful contents were coded and categorized based on the tentative idea. Cases of disagreement were discussed among the research team to reach a final consensus. Based on former works, these categories were organized into themes. The principal researcher revisited the main points of the findings with the participants.
and asked whether they were consistent with their experiences.

**Result**

The 17 participants’ demographic characteristics are summarized in Table 2.

Five main themes were generated after analysis as follows:

**Complex feelings**

Undergraduates with TB described various emotions during their illness. They constantly mentioned fear, being upset, anxiety, being afraid, helplessness, sadness, guilt, boredom, and expectancy.

**Fear**

In their mind, TB is a very serious disease that would badly harm them. Some of them believe TB cannot be cured; some even fear that they may die from TB.

"Hearing I was diagnosed with TB, I was badly afraid...When I was a child, I often heard that if one suffers from it...he will die."

The types of isolation measures in the TB hospitals indicated to them that TB is a strongly infectious disease, which deepened their feelings of fear.

"I notice that many people here wear big surgical masks; feels strange; I was badly afraid at first."

Before they were hospitalized, they regarded TB hospitals as not the same as common hospitals. They thought the management in TB hospitals was stricter than the common hospital and that there would be more measures to restrict them.

"I imagine that the TB hospital is circled by an iron fence. All the patients wear white gowns and bask in the sun. Someone who visits a patient can only pass things through the fence to the patient—just like a jail."

**Anxiety**

Most of the patients reported they felt anxious and upset before they were diagnosed. They repeatedly
received heteropathy, but there was no effect. They began to confuse what was wrong with them, and they were upset and anxious.

"I suddenly caught a cold; then I saw a doctor, took pills, and got injected. But I caught a cold again and again—at least three times. Oh, why do I constantly catch a cold?"

"I have a fever. I told myself that I just caught a cold and I will be OK. However, it could not be cured for a long time. I began to feel upset—more and more upset."

At the beginning of hospitalization, some of the patients did not want to accept the fact that they suffered from TB. Although some of the patients accepted it, the psychological burden was still there, and they could not put their hearts into receiving treatment.

"I have no symptoms. At first, I always thought that if I do not have TB, and then I get infected, what shall I do? Those thoughts cram my mind, and then the food is not delicious to me. I cannot sleep well."

"During the first week of hospitalization, my burden was heavy. I went to bed early, but I did not sleep deeply. It was easy to wake me up."

Agony

After nearly one month of treatment, testing occurs again. The patients expect that the treatment will be effective, but they also fear it is not. It is agonizing for them.

"I really expected to be checked again; however, when the day came, I was afraid. If there was any problem, I would have to stay here for a longer time. I was extremely afraid. This feeling lasted to the time I was tested again."

"It was time to be tested again. I was panicky; it cannot be expressed in words. I was afraid of the results; whether it is effective or not?"

Boredom
TB patients only need an intravenous infusion for a short time and take pills on a regular schedule every day. There was too much spare time for them, and they became bored.

"Every morning, the nurse began to infuse me at 8 o'clock; it ended at 10. Then I have nothing to do the whole day. I was panicky."

"I have nothing to do at home—one month, another month. It is so boring. After all, I am a young man."

**Expectancy**

Some patients reported that the thing they were concerned the most about was the effect of the treatment. They expected that they could be discharged from the hospital as soon as possible.

"The doctor said that the treatment is effective. I can leave here after 50 days. Once I am cured thoroughly, I will not be anxious."

"I just hope I can be cured thoroughly and can have a full recovery, and then I can set my mind at rest."

"I do not know when I can leave the hospital. I just wait. I wait to leave every day."

**Incorrect perception of TB**

This category emerged from the subcategory of lacking knowledge of TB and the policies of centralized management.

**Lacking knowledge of TB**

Undergraduates with TB know little about the symptoms of TB, and the knowledge they known is limited to their own symptoms.

"The way I was infected? Oh...maybe I ate something that is not clean."

"Some may have no symptoms. Generally, weight loss, loss of one's appetite, then cough and night sweats."

"At the beginning, I knew nothing about it. Although, I've stayed here for a period of time, I still only know a little."
Unclear about policy of centralized management

Most of the undergraduates had never heard of centralized management: only two knew of it.

"Policy of free charge for TB? I do not know. I have never heard of it."

"I only know that when I am diagnosed with TB, I should go to the CDC to receive treatment, and I can get free drugs from there. Any other things? I do not know."

"In my mind, free means I need not pay any expense. Other students also ask why it costs so much."

"I have heard of that policy, but it costs too much for me. I am unable to speak clearly about it."

Influence on daily life

This category emerged from the following subcategory: discontinuation of study, interpersonal relationships being limited, increased financial burden, worry about relapse and employment.

Discontinuation of study

Receiving treatment disturbs undergraduates’ normal life, especially their studies, and it is the biggest problem caused by TB. All 17 undergraduates expressed their strong desire to study during the treatment. Most of them were unwilling to suspend their schooling because of treatment.

"My classmates, who want to be a postgraduate or to go abroad, began to take action. At the same time, it is difficult to find a job now. No one wants to fall behind, but I cannot do anything—just worry."

"I really want to take exams. If I do not take exams this year, I will have to suspend my schooling. It will delay my education by one year."

1Centralized management refers to the suspected or confirmed pulmonary TB patient’s ability to go to the CDC that is located in the district he or she lives in to receive TB management and treatment. In this case only, the policy of “free charge” is available.
"If suspending one's schooling is a policy in my school, I can accept it, rationally. However, in my bosom, if my condition complies with the standards of leaving the hospital, I prefer to go back to school."

Interpersonal relationships being limited

Undergraduates with TB are unwilling to tell others they suffered from TB because they are afraid of being discriminated against. The undergraduates said that their classmates keep them away intentionally or unintentionally because they do not want to be infected.

"I was in a bad mood at the beginning of recuperating at home. I did not want to see anyone. After supper, I sat in the yard for a while and then went to bed. My mother told others I was suffering from pleurisy. We did not tell them the truth. Most of the villagers like to gossip."

"Attitudes of my closest classmates changed; they were estranged from me, a little...but I can understand it (smile). If a classmate of mine suffered from TB, maybe I would also do this."

"I was self-abased after I was ill. Others may be disgusted with me. Although I am no longer a source of infection, I still keep away from others."

Increased financial burden

Most of the students come from rural areas, and long-term treatment costs them too much. Supplementary drugs used to reduce the side effects of TB drugs are expensive, and adding nourishment also requires money. Therefore, although there is a free policy, it still brings financial burden to some of them.

"I come from a remote rural area. Of course, my biggest problem is how to deal with the costs."

"There are 4 children in my family: 2 are in high school, and 2 are in universities. My parents rely on farming and a part-time job to support us. Now, they have to pay so much for me."

"Drugs for protecting our liver and promoting our appetite are not free; they are charged."
Worry about relapse and employment

"My TB will relapse if the pressure on my studies or work is too heavy in the future. This problem bothers me a lot," said a student who will rehabilitate soon.

The seniors will graduate soon; therefore, they are scared of their graduation and TB’s impact on employment.

"It will be inconvenient if I am not cured. Maybe the employers will not accept me. So I just hope I can be cured thoroughly, and then I can set my mind at rest."

"I hope I'm fine next year; otherwise it will have an influence on finding a job."

Poor social support

This category emerged from the subcategory of poor psychological support and poor health education.

Poor psychological support

Most of the undergraduates with TB reported that they were in a bad mood because of the illness. If their family members or friends provide psychological support for them, it goes well.

"This is the first time I am hospitalized. My parents and family are far away from me. I am so lonely and helpless when I face the hospital and the ward."

"Just like I was hurt. When there was someone to console me and talk with me, I felt better. At least, there was someone at my side."

Poor health education

The patients reported undergraduates badly needed information and knowledge about TB.

"In my opinion, the school not only needs to offer lots of information about TB for us, but it also needs to
take measures to prevent it, for example, vaccinating. It should be done rather than said."

Information on infectious diseases should be propagated frequently. And it needs various patterns. Then it gives everyone an awareness of it."

**Positive influence of illness**

After facing the negative impact on their physiology and psychology and their social life, they reflected a lot. They realized the importance of a healthy lifestyle and a strengthened physique. They especially became mature after struggling psychologically. It strengthened their courage to deal with difficulties in the future.

"I do not go to the internet bar now (smile). I exercise every day, and I eat on time. My lifestyle has become regular. Every morning I remember that I need to have breakfast."

"I've grown up mentally. It is an experience of my life. Although there were so many negative effects for me, it is a growth step. Whatever difficulties I encounter in the future, I believe I can manage it."

**Discussion**

This is the first reported qualitative study in mainland China exploring the experience of undergraduates with TB. The target population was patients inside and outside the TB hospitals. The use of in-depth interviews elicited rich and comprehensive information on the experience of undergraduates with TB: they lack knowledge of TB; their psychological burden is significant; and their study is interrupted because of the treatment.

Although these undergraduates have a high level of education and some of the participants had even been hospitalized, they lacked knowledge of TB, which was surprising to the researchers. Most of the patients knew that pulmonary TB is transmitted through the respiratory passage, but they could not explain how it is transmitted exactly, and they did not know whether the pathogen is bacterial or viral. Some of the patients believe the pathogen is caught from catching a cold or from eating dirty foods. This information deserves
There are subjective and objective reasons for this lack of knowledge. As stated by the undergraduates themselves, although information and knowledge of TB have been propagated by the health and education department, most of the students believe it is far away from them and has nothing to do with them. On World Tuberculosis Day, the folders or other materials distributed by health workers are often thrown out by the students without a glance. Few students take lectures given by health professors. Thus, the education and materials have little effect. From an educational perspective, Chinese undergraduates receive exam-oriented education. To enter a higher school or university, they must pass strict exams, and only less than a quarter of the students who take exams can enter university. As a result, the majority of the junior and senior schools neglect health education because of fierce competition. A health curriculum, which is mandated by the Education Ministry, has not been carried out by the schools\textsuperscript{[18]}. When they become undergraduates, their universities rarely have curriculum on infectious disease, and they only obtain knowledge of TB from TV, broadcasts, internet, or other media. But the information is fragmented, one-sided, and unsystematic. In addition, the undergraduates said that the healthcare workers, including doctors in the hospital of the university as well as doctors and nurses in the TB hospitals, only told them orally information on diagnosis and treatment or answered only their specific questions during the process of diagnosis and receiving treatment in the hospital. They had not gotten any systematic information on TB. In China, healthcare work is concerned more with acute and serious diseases, and the rehabilitation of TB is often neglected. Therefore, it is essential to do research on prevention and control of infectious disease in universities and to develop different patterns of health education for undergraduates.

The mental and psychological burden is significant among undergraduates with TB and is related to the lack of knowledge of TB, traditional views, and their growth environment.
First, fear often springs from ignorance. One important reason for their heavy psychological burden is the lack of knowledge of TB: they do not know the pathogen; they have no idea about the process of diagnosis and treatment; they do not know the effects and side effects of the drugs; they do not know how diagnosis is made and the prognosis of TB; and they also do not know the content of the policy of free charge. Second, traditional views also affect them. The TB diagnosis generally causes distress among the members of a patient's family. In China, the older generation believes that disease and disaster are determined by fate and any associated suffering is valued because it repays the debts of previous lives\textsuperscript{[19]}. It is said that nine in ten patients who suffer from TB will die. Family members’ traditional, one-sided, and incorrect perception of TB misleads undergraduates with TB. Third, their growth environment also has an influence on them. Because of the implementation of the Family Planning Program in China, most undergraduates are the only child in their family. Their parents and family members dote on them, which results in most of them being unable to live independently. At the same time, most of the Chinese undergraduates go to universities that are far away from their hometown. For most of them, it is the first time they have left their parents, and they face the exam of independent living. As a result, when they are suddenly diagnosed with TB, they have to live in the hospital to receive long-term treatment, and they do not know how to deal with it. A coping crisis occurs.

It is a common desire of undergraduates with TB to study during treatment and rehabilitation.

The Chinese government states clearly that if a patient’s sputum microscopy is positive after regular treatment for 2–3 weeks and there is no infectiousness, the patient can take part in normal work, study, and social activities\textsuperscript{[20]}. However, most universities state that patients who are freshman found to have TB during the physical examination for entering university must go back to their hometown to receive treatment. If the patients have already studied at the university, they must receive treatment at home or in the hospital. They must not go back to school until they are cured thoroughly. Although those rules ensure other students will not
be infected and cater to most healthy students' opinion that they are unwilling to live together with TB patients who still take pills, it brings a heavy burden and stress to undergraduates with TB. In China, lessons and exams must be taken on a specific time table according to the student's grade. All the participants expressed their strong feeling of being unwilling to delay their studies and postpone graduation. But the rules limited them, and there is significant psychological conflict. Research has pointed out that undergraduates with TB hardly pay attention to their studies, and it affects their feelings, sleep, diet, etc. \cite{21,22,23,24}, especially for the seniors who have to find a job, which leaves them significantly anxious and depressed\cite{25}. To keep studying, some of them rent a room outside the school after they are discharged, and some of them go home to receive the subsequent treatment until they are cured thoroughly. This creates inconvenience for them concerning their studies and daily life and also makes them feel that they are separated from their classmates and out of favor with others.

**Conclusion**

This study explored the experiences of undergraduates with TB before the onset of the illness and during the treatment and rehabilitation period, which has value for developing more realistic and humanistic policy. Undergraduates with TB have a general lack of knowledge of TB; their mental and psychological burden is significant during the treatment; and there is serious conflict between treatment and study during their treatment and rehabilitation. Undergraduates with TB need systemic health education. Doctors and nurses at the university and in TB hospitals, as well as TB control and prevention workers, should provide psychological support for undergraduates with TB. Universities should implement governmental policy on TB and provide opportunities for the patient to continue their studies.

**Authors’ contributions**

ZS, YH and ZT conceived of the study, participated in design and coordination. ZS, LX and ZJ performed the data collection, data analysis and draft the manuscript. ZS made critical revision to the paper. YH and ZT
supervised the study. All authors read and approved the final manuscript.

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**Competing interests**

The authors declare that they have no competing interests.

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**Table 1**  Interview schedule

1. How are you getting on since your illness?

2. What factors do you think caused your illness? (When and where were you infected possibly?)

3. In which way were you diagnosed?(Seeing a doctor or medical examination?)

4. Would you please describe your feelings since your diagnose with TB?

5. What problems has your illness brought to you?

6. Do you prefer to stay at home or schoolduring the treatment period?

7. What are you concerned about the most?

8. Do you have any knowledge of TB?What is the knowledge?
9. Do you know the government's policy on TB? Do you have any suggestions on it?

Table 2  Demographic characteristics of the patients

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Reference


