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Factors associated with early and late diagnosis of tuberculosis: a descriptive study

Mara Cristina Ribeiro Furlan¹, Regina Lúcia Dalla Torre Silva²,
Sonia Silva Marcon²

¹ Federal University of Mato Grosso do Sul

² State University of Maringá

ABSTRACT

Aim: To identify the factors related to the early and late diagnosis of tuberculosis (TB) and the feelings and experiences of people infected with the disease. **Method:** This is a descriptive study of a qualitative nature performed with 23 subjects in TB treatment in Maringá-PR, Brazil. Data collection occurred in April 2012, through semi-structured interviews. Content analysis was used for data treatment. **Results:** Three categories were evidenced: Knowing the path: factors related to early and late TB diagnosis; Pain Relief: unveiling the feelings of sufferers following a diagnosis of TB and; changes resulting from the diagnosis of TB. **Discussion:** Prompt diagnosis and early treatment are seen as essential factors for disease control. **Conclusion:** Factors such as providing subsidies to a potential TB sufferer for undertaking diagnostic tests and the availability of results in a timely manner are crucial for early treatment.

Descriptors: Tuberculosis; Diagnosis; Health Policy; Nursing.

INTRODUCTION

Tuberculosis (TB) in Brazil, as well as worldwide, can have a far-reaching effect. This was evidenced in the late nineteenth and early twentieth centuries when half of affected individuals died⁽¹⁾. Currently, although there are already technological resources capable of promoting the control of TB, there is still no prospect of achieving, in the near future, its elimination as a public health problem. In Brazil there are approximately 85,000 new cases of the disease each year and five thousand deaths in the same period. Moreover, TB is the main cause of death in AIDS patients⁽²⁾.

One of the most disturbing factors in the fight against TB is late diagnosis, which can result in a more severe presentation of the disease with a larger number of long-term recurrences, increased mortality and perpetuation of the chain of transmission⁽³⁾. Early diagnosis and prompt initiation of drug treatment are critical for the effective control of the disease⁽³⁾.

Besides the importance of early diagnosis, it is essential to ensure successful treatment. Consequently, it is necessary for healthcare professionals to understand the experiences of TB sufferers during the treatment period and what changes may arise thereafter. This will enable healthcare professionals to strategize and develop guidelines in order to help users get through this phase in a less painful way and alleviate any concerns they may have about the disease as any doubts may impact negatively during the treatment. Thus, the aim of the study was to identify factors related to early and late diagnosis of tuberculosis and identify the feelings and experiences of TB sufferers after falling ill with the disease.

METHOD

This is a descriptive study of a qualitative nature carried out with 23 subjects in TB treatment in Maringá, Brazil, which is located in the northwestern region of the state of Paraná, with a total area of 488 km² and population of 357,077 inhabitants⁽⁴⁾. In relation to the health services networks, the city is the headquarters of the 15th Regional Department of Health of Paraná, which is made up of 30 counties and includes 10 hospitals and 1,280 inpatient beds, 32 Basic Health Units (BHU) and two Polyclinics. The diagnosis of TB can be performed in any healthcare service, whether public or private, but the treatment is decentralized for the BHU and the 67 teams of the Family Health Strategy (FHS). The reference service for the cases of difficult diagnosis, multidrug resistant infection, among others, is the Intermunicipal Consortium of Public Health of Northern Paraná (CISAMUSEP), with its headquarters in the city of the study.

Information relating to the socio-demographic and clinical profile of potential participants along with the telephone numbers of the subjects was obtained from the Diseases of Notification Information System (SINAN, in Portuguese) with the cooperation of TB of the 15th RS Paraná. All study participants were over 18 years of age with the cognitive ability to answer the research questions and were not being held within the prison system.

Data collection was carried out in April 2012. First, we surveyed the list of subjects and, subsequently, we contacted them by telephone. During these calls the objectives of the study were explained and the subjects were asked whether they were willing to participate in the study. Where subjects agreed to participate, a home visit was scheduled. The search for new participants continued until the data became repetitive and the study's objectives had been

achieved. Data collection occurred through the following question: Tell me how your TB diagnosis occurred and what your feelings were when you discovered you were infected with TB? The interviews were recorded to ensure the reliability of the records and to prevent the loss of evidence relevant to the study. The interviews were then transcribed and subjected to the process of content analysis⁽⁵⁾.

Content analysis involved carrying out a pre-analysis, exploration of the material and treatment of the results with inference and interpretation of meaningful categories. The thematic unit is the unit of meaning that is naturally released from a text analyzed according to criteria relating to the theory, which works as a guide to reading and consists of discovering the meaningful units that make up communication and whose presence or frequency of appearance can mean something for the analytical objectives of the study⁽⁵⁾.

This study is part of a research project entitled "Evaluation of the primary care services in tuberculosis control in the 15th Regional Department of Health of Paraná". The study was conducted in accordance with the guidelines established by Resolution 196/96 of the National Health Council and approved by the Permanent Committee on Ethics in Research with Human Beings of the Health Department of the State of Paraná (Opinion 423/2011).

We explained to the prospective participants, both by phone and in person, the procedures that would be adopted in the study, the type of participation required, that they had free choice in whether to participate or not, that there would be no harm to the care of patients, and the probable duration of the interview. All participants signed a consent form and, as a guarantee of their anonymity, they were identified by the letter "E" followed by ordinal numbers, gender, month of treatment and clinical form of TB.

RESULTS

The subjects

In most cases, the study participants had the pulmonary form of TB (82.6%), 52.2% were male and 52.1% lived with a partner. 13% were aged between 18 and 19 years old; 60.9% were aged between 30 and 49 years and; 26.1% were 50 years or older. Family income results showed 26.2% of respondents earned less than one minimum wage; 47.8% earned between one and three minimum wages whereas 13% earned five minimum wages or more with a further 13% not earning any kind of income. The educational levels of participants showed 60.9% had an incomplete elementary education; 17.4% had completed high school and; 8.7% had completed higher education. 60.9% of respondents lived with one or two people, while 39.1% lived with four or more people.

Analysis of participants' testimonials allowed us to capture users' perceptions on the issue in the form of three categories, which are presented and discussed below.

Knowing the path: factors related to early and late diagnosis of TB

Some factors were identified by the subjects as facilitators of diagnosis, among them the availability of transportation for undertaking tests and home visits for the delivery of the results, as seen in the following testimony:

They took me in an ambulance to get screened. The exams didn't take long to get ready [...] the nurse would come here to bring me the results and scheduled the consultations (E16, F, 2nd month of treatment, pulmonary TB).

Another factor that facilitates the diagnosis of TB is the investigation of the communicants:

My husband was affected first. Then the nurse asked me for an X-ray, which I did on the same day and then I went to see the doctor and he said that there was some alteration in my exam. In the same week I did that examination for collecting sputum samples, and the result showed that I was affected with TB (E2, F, 3rd month of treatment, pulmonary TB).

However, despite the fact that the investigation of the respiratory contacts is one of the structural axes of TB control, it is not always performed in all the necessary contacts preventively, as can be seen in the following report:

I went to the clinic and told them about my problem (cough and fever). As my husband already had it (pulmonary TB) I was diagnosed fast. They did not order the tests before. They just did it after I scheduled a consultation, because I had a high fever, coughed and lost too much weight. At this point I already suspected it (E4, F, 3rd month of treatment, pulmonary TB).

In addition, late diagnosis may be related to the lack of ability of health professionals. Some testimonials show that even in the presence of certain symptoms, patients need to undergo several medical tests and even make use of many medicines for other diagnoses.

It took too long to make the diagnosis. Health professionals from both the public and private sectors don't know

this disease. Only I know what I went through, I've been in this struggle for a long time (E23, M, 4th month of treatment, pulmonary TB).

It took them 45 days to diagnose me. I spent money, lots of money on medicines for cough and fever and they were not for TB (E7, F, 4th month of treatment, pulmonary TB).

If, in many cases pulmonary TB is diagnosed late, even when people have symptoms characteristic of the disease, including fever and nocturnal cough for more than three weeks, people with extra-pulmonary TB tend to suffer more with the anguish of not knowing the origin of their symptoms and illness, since this form is less common and it is not the first choice investigation of health professionals:

It took almost a year for me to discover it was TB. I went through several specialists, until an infectologist discovered it was TB. After that, my knuckles began to fade, despite having some still. But I could not stand going to so many doctors and taking medicine and they would only increase the quantity of medicine. (E18, F, 3rd month of treatment, lymph node TB).

Pain and relief: unveiling sufferers' feelings following a diagnosis of TB

Even with all the technology developed over the years, which enables more effective antibiotics to be employed in the treatment of TB, thus making it curable, its diagnosis is still a generator of fear and anxiety. This is not only due to the fear of death, but especially the stigma that accompanies the disease:

Two things I never wanted to have were TB and cancer. I have never imagined I would have it [...] I was never used to going out to dance, drink. Do not know why I was affected by this disease (weeping). (E1, F, 2nd month of treatment, pulmonary TB).

In other cases the stigma and even prejudice can be observed in the community:

I have no prejudice. When I got home from the hospital, the neighbors wanted to see me and I asked my wife to tell them that I had TB and it was not good for them to see me, because I still had the bacillus active in my body [...] But I'm upset, because even after four months, there are some neighbors who don't pass in front of my house still today (E23, M, 4th month of treatment, pulmonary TB).

When I was diagnosed it was my family who had prejudice. They wanted to take my daughters away from me during the treatment but I didn't let them. I took all of them to the clinic and asked the doctor and the nurse to explain to them about TB and the treatment. Then they stopped annoying me (E16, F, 2nd month of treatment, pulmonary TB).

On the other hand, TB diagnosis does not raise only painful feelings, once there are cases in which people are better informed and understand that it is curable. Added to this fact, the delay in reaching the diagnosis, and the suspicion of other diseases that are difficult to treat, generate a feeling of relief when one finds out that he is affected with TB.

I was hospitalized for 21 days without knowing what I had and was getting worse and worse. Then, one day my wife and my son came to visit me and the nursing assistant asked: where are the apron and mask? You cannot stay here without the apron and the mask. Then my wife asked: But why? I want to know what is happening! And the assistant said: I can't speak. My wife said: Then bring me someone who can speak. She called the nurse who said I was suspected of having TB, but it had not yet been confirmed [...] When they confirmed it I was relieved, because now I knew what I had, and would get cured (E20, M, 6 month treatment, pulmonary TB).

I was suspected of having lung cancer. When I received the diagnosis of TB I was relieved. (E13, F, 4th month of treatment, pulmonary TB).

Changes arising from the diagnosis of TB

TB is an infectious disease that affects, in the majority of cases, the lung. It causes individuals to have breathing problems, especially fatigue, leading many people to stop working for a long time. Others, because of financial need, continue to work despite it not being recommended:

I had to stop working because it makes me feel really short of breath. It is quite difficult because I'm self-employment. I'm the one who supports my family. I've already tried to receive sickness assistance, but they say that this disease does not grant me the right to receive it. Then I don't know what else to do. I tried to work, but I can't even stand

working half a day. (E14, M, 4th month of treatment, pulmonary TB).

During treatment I continued working. The doctor asked me to stay home for a few months, but I couldn't stop working. I work on my own, I manage constructions. I continued working normally and taking the medicine because I needed the money (E22, M, 6th month of treatment, pulmonary TB).

DISCUSSION

The characterization of patients according to the clinical form, showed predominance of pulmonary tuberculosis not differing from the distribution found in other studies^(6,7). However, this form of the disease is the one that deserves greater attention concerning the activities of TB control, since it is the transmissible form of the disease⁽⁶⁾. Thus there is the need for early diagnosis and treatment as soon as possible. The higher frequency of patients aged between 30 and 49 years also confirms the results of studies conducted in the southeast and northern regions of the country, which showed that the average age affected by the disease is 20-49 years^(8,9). With regards to gender, the proportion of men at 52.2% was slightly higher than that of women, which differs from findings in other studies that show the difference above 60%^(6,8).

Despite the relative ease and efficacy of the treatment, tuberculosis continues to be a public health problem worldwide⁽³⁾, and the speed in which a diagnosis is reached is one of the main challenges of the National Program for Combating Tuberculosis (NPCT). This is because early diagnosis decreases the chances of a greater number of people being infected due to the shorter period of the bacillus in the community.

Therefore, it is of great importance that health professionals develop strategies for an early diagnosis, such as the availability of transportation for carrying out exams and home visits for the delivery of results.

Another strategy that should be adopted is the investigation of respiratory communicants. However, worryingly, some study subjects were not aware that the infection could be passed on to others. In this context, the NPCT recommends that all the contacts of TB patients, especially the lung positive ones, should be investigated to ensure they had not acquired the infection⁽²⁾, because often the source of infection is an individual with the pulmonary form of the disease, spreading bacilli to the outside world, according to the patient's bacteriological status or condition. It is estimated that in a community over the period of a year, a source of TB infection can infect on average ten to fifteen people who have been in contact with it⁽¹⁰⁾.

In order to monitor the assistance provided by healthcare services, and the quality of services, in preventing the spread of TB, it is important to pay attention to the contacts of TB sufferers. It is necessary for services to incorporate epidemiological surveillance, that is, to identify the contacts of TB sufferers, ensure they take the necessary tests and to continually monitor them. The risk of becoming ill for a person whose spouse is affected with tuberculosis is two to 40 times higher than the general population, which indicates that the proximity of the contact is one of the important aspects to be considered in the transmission of the bacillus⁽¹⁰⁾.

The lack of investigation into the contacts of TB sufferers can be explained by the overload on the healthcare service and the lack of investment in an organized public healthcare policy, as well as incorrect information provided by patients regarding the risk of transmission and the need for investigation of the respiratory

communicants⁽¹¹⁾. However, if a TB sufferer's contacts wait for the onset of symptoms before seeking assistance, this is indicative of a failure in the epidemiological investigation of the household's contacts. Thus, the shortage of trained human resources for the diagnosis still represents a major difficulty for control of the disease^(12, 13).

Sometimes, a late diagnosis may be related to the inability of health professionals to correctly diagnose the disease, even in the case of respiratory symptoms. Thus, even if patients seek help from healthcare services, it may not solve their problem⁽¹⁴⁾.

It is noted that the study subjects looked for healthcare services familiar with symptoms of TB, but the health professionals redirected them to other services for diagnosis. Therefore, there seems to be a vicious cycle of repeated visits to health services without obtaining the correct diagnosis, which results in non-specific treatments, which generates costs for the system and also for the patient⁽¹⁵⁾.

The delay in diagnosing TB may mean a worsening of the patient's condition as well as a potential increased spread of the disease in the community, since, once the symptoms are noticeable, the patient is already in a more advanced stage of the disease and has already been in contact with several people⁽¹⁸⁾. In a study conducted in São Paulo-SP, with 11 patients who underwent TB treatment and 12 healthcare professionals, it was found that the time between the first consultation in a healthcare facility and the diagnosis was too long, namely, on average two weeks and, in 25% of cases it would take around eight weeks for the commencement of the treatment⁽¹¹⁾.

Prompt diagnosis and early treatment are seen as essential factors for disease control, since the interruption of the transmission chain depends almost exclusively on the treatment

of infected individuals⁽¹⁵⁾. We suggest that the delay in diagnosis, after the patient's entry into the healthcare system is related to problems in the infrastructure of the system and lack of knowledge about the disease, its signs and symptoms by healthcare professionals⁽¹⁵⁾.

Another factor related to the delay in diagnosis is the possibility of being infected by the disease in its extra-pulmonary form. This can be explained by the difficulty of access to most of the lesions for analysis and correct diagnosis and the fact that, usually, the lesions are paucibacillary, a situation in which the bacilloscopy is usually negative⁽¹⁶⁾ in a way that the bacteriological confirmation of the diagnosis occurs in only a quarter of cases.

It is clear that, in some cases, the patient feels responsible for the TB infection, as if the disease is some form of punishment for a behavior that excludes him from the normal standards of society⁽¹⁵⁾.

Moreover, the experience of the diagnosis of TB can generate feelings of anxiety, as patients still suffer from the stigma and prejudice of society. These feelings were also identified in another study, which revealed that the diagnosis of TB creates an emotional impact because of negative representations about the disease that still persist today⁽¹¹⁾. As much as this is an ancient disease, its mode of transmission and treatment are unknown to many people, which may cause fear in friends and family when dealing with patients during treatment, preventing them from providing support during this difficult phase⁽¹⁴⁾.

A study conducted in Ribeirão Preto, São Paulo, showed that the family had an important role to play in protecting the patient from social discrimination, supporting him during the diagnosis and encouraging him during treatment. However, the impact of the disease still causes constraints and a lowering of the patient's self-esteem⁽¹⁴⁾.

Literature relating to the diagnosis of TB in relation to lung cancer indicates that the preference for acquiring TB rather than cancer may be related to a better prognosis of the first, with a lower percentage of mortality and only oral drug treatment, while cancer, in most cases, requires chemotherapy, which causes major toxic and side effects. Furthermore, lung cancer, in many cases, requires surgery and presents greater lethality.

It is essential that all patients understand that TB is curable, as long as the treatment is followed properly. This fact makes the moment of diagnosis easier, with fewer distressing feelings for the patient and may provide greater adherence to treatment.

There can be a number of changes arising following the diagnosis of TB, for example, many people stop working for a long time due to the symptoms of the disease. As the disease mostly affects people who are socially vulnerable and young adults, that is, adults of working age, the absence from work is a factor that can aggravate their socioeconomic status.

Moreover, the debilitating symptoms arising from TB can have a negative effect in terms of his/her contribution to the labor market and the patient perceives himself as unproductive, not being able to remain active or to support his/her family. This situation represents a loss of self-efficacy and social dignity, imposed by a society that values the person for what he/she is able to produce with his/her work⁽⁸⁾.

Consequently, treatment should exceed the approach that reduces the problems to clinical and biological aspects⁽¹⁴⁾. It is necessary to establish links between healthcare professionals and patients, so that the professionals understand the situations of their patients and develop connections with other social assistance sectors so that the TB patient can receive assistance at this time. Otherwise, the patient may abandon

the treatment and continue to have contact with a large number of individuals thereby potentially spreading the bacillus.

CONCLUSION

The results of this study show aspects that facilitate the early diagnosis of TB, including the availability of transport for examinations, home visits for delivery of the results of these exams and the investigation of the contacts of persons who are already infected with the disease. On the other hand, the findings showed that several aspects can delay diagnosis, such as: the inability of health professionals to identify the disease, even in cases of patients with respiratory symptoms; healthcare services with no solutions for the problems; the presence of extra-pulmonary TB and the non-integral and non-humanized performance of healthcare professionals.

Among the feelings resulting from the diagnosis of TB, it is possible to perceive fear, apprehension and anguish regarding prejudice and a stigma presented by the community and family. Another factor arising with the disease is the need to be absent from work but not everyone stopped working as they needed to support their families.

In view of this, it is up to healthcare professionals, especially nurses, to use a different approach with patients with TB, as delayed diagnosis increases the risk of the general population acquiring the disease and unnecessary costs to users, among other problems. Factors such as providing subsidies to the user to undertake tests and the availability of results are essential in providing early treatment. Another important factor is the completion of the investigation of all the contacts of TB sufferers, given the fact that this population is more propitious to infection. Efficient organization of the healthcare service

is essential for this to occur. All people on TB treatment should have in their medical records data concerning their contacts and information about whether an investigation of the disease was carried out or not. If it was not carried out, it is necessary to perform an active search.

It is noteworthy that, in most cases, the nurse is the team manager responsible for the diagnosis and treatment of TB, either in reference hospitals or in the Family Health Strategy. It is, therefore, up to this professional to organize the working process of the team, given the constraints highlighted by this study for the diagnosis of TB.

In addition, managers should provide continuous education so that the professionals working in the Tuberculosis Control Program are alert to the symptoms of the disease and may provide adequate care. This includes guidelines for the user and his family about the mode of transmission, treatment, the side effects of any medication, among others, in order to minimize the negative feelings towards the illness.

Finally, new strategies between sectors are needed, aimed at promoting health and the improvement of life quality of certain population groups, since the prevention and control of TB should be guided by a vision that goes beyond the clinical perspective and should include the living conditions of these patients

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