The health needs and vulnerabilities of tuberculosis patients according to the accessibility, attachment and adherence dimensions*

ORIGINAL ARTICLE

AS NECESSIDADES DE SAÚDE E VULNERABILIDADES DE PESSOAS COM TUBERCULOSE SEGUNDO AS DIMENSÕES ACESSO, VÍNCULO E ADESÃO

LAS NECESIDADES DE SALUD Y VULNERABILIDAD DE PERSONAS CON TUBERCULOSIS SEGÚN LAS DIMENSIONES DE ACCESO, VÍNCULO Y ADHESIÓN

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ABSTRACT

The objective was to know the experience of people with tuberculosis, identify their health needs and vulnerability in face of the disease, and in terms of their accessibility to treatment, their attachment to the health team, and adherence to the treatment. This qualitative study was performed at family health care units. Interviews were performed with patients following treatment, using the criterion of information saturation. The statements were analyzed using Alceste software. The late diagnosis reflects the lack of knowledge about the disease and come professionals' lack of preparation. The support consists a determinant aspect in patient follow up, who, by feeling welcomed, were encouraged to follow the therapeutic scheme. The health needs were related to the good life conditions, such as the right to food, work, housing, education, leisure, and taking on healthy life habits. The authors emphasize on the valorization of the experience of people following treatment to support the health care practice of professionals centered on the health needs and vulnerabilities of the population.

DESCRIPTORS

Tuberculosis
Health Services needs and demand
Health Services accessibility
Public health nursing

RESUMO

Os objetivos foram conhecer a vivência das pessoas com tuberculose e identificar necessidades de saúde e vulnerabilidade frente ao adoecimento, no que diz respeito ao acesso ao tratamento, ao vínculo com a equipe de saúde e à adesão ao tratamento. Trata-se de um estudo qualitativo, desenvolvido em unidades de saúde da família. Entrevistaram-se pessoas em tratamento, utilizando-se o critério de saturação das informações. Na análise dos depoimentos utilizou-se o software Alceste. O diagnóstico tardio reflete a falta de conhecimento sobre a doença e o despreparo de alguns profissionais. O apoio constituiu um determinante no seguimento das pessoas que, sentindo-se acolhidas, foram incentivadas a seguir o esquema terapêutico. As necessidades de saúde relacionaram-se às boas condições de vida, como direito à alimentação, trabalho, moradia, educação, lazer e adoção de hábitos de vida saudáveis. Ressalta-se a valorização da vivência das pessoas em tratamento para apoiar a prática assistencial dos profissionais focada nas necessidades de saúde e vulnerabilidades da população.

DESCRITORES

Tuberculose
Necessidades e demandas de Serviços de Saúde
Acesso aos Serviços de Saúde
Enfermagem em saúde pública

RESUMEN

Se objetivó conocer la experiencia de personas con tuberculosis, identificar necesidades de salud y vulnerabilidad al padecimiento, en perspectiva del acceso al tratamiento, del vínculo con el equipo de salud y de adhesión al tratamiento. Estudio cualitativo, desarrollado en unidades de salud familiar. Se entrevistaron personas en tratamiento, utilizándose el criterio de saturación de información. Se analizaron los testimonios mediante software Alceste. El diagnóstico tardío refleja falta de conocimiento sobre la enfermedad y baja calificación de algunos profesionales. El apoyo constituyó un determinante en el seguimiento de personas que, sintiéndose acogidas, incentivaron su interés en seguir el esquema terapéutico. Las necesidades de salud se relacionaron con las buenas condiciones de vida, como derecho a la alimentación, trabajo, domicilio, educación, placer y adopción de hábitos saludables. Se resalta la valorización de la experiencia de personas en tratamiento para apoyar la práctica asistencial del profesional, enfocada en necesidades sanitarias y vulnerabilidad poblacional.

DESCRIPTORES

Tuberculosis
Necesidades y demandas de Servicios de Salud
Accesibilidad a los Servicios de Salud
Enfermería en salud pública

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INTRODUCTION

The occurrence of tuberculosis (TB) – a disease that is still neglected in Brazil – requires the knowledge of the context of the life conditions and geo-social space in which people suffering from TB live[1]. The TB problem reflects the stage of social development within a country. The country, on the other hand, determines the poverty status of the patients, which, when associated with a health system, still fragile in its organization and with deficits in the administration of health services, leads to the maintenance of diseases like this, determined by the social context.

The conditions that favor the perpetuation of TB in our country include, among others, the impoverishment of families, the difficulty in accessing health services, the aging of the population, the growth of socially marginalized groups and the increase of internal and external migrations[2]. In addition, there is also the association of TB with AIDS and the development of multidrug resistance (TBMDR), recent challenges that complicate its control.

The present study aimed at learning, according to the perception of people with TB, the experience of living with the disease and identifying their health needs and vulnerability to becoming ill with TB, considering access to treatment, bonding with the health team and compliance with treatment.

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METHODS

This is a qualitative study, developed in the family health units of Capão Redondo, an administrative district located in the south region of the municipality of São Paulo. The authors interviewed 19 people with TB, using the criteria of data saturation. Inclusion criteria were: being diagnosed with TB in 2010, undergoing treatment for at least a month, not belonging to the prison system, being 18 years old or over and not presenting cognition limits. The interviews were performed by the authors between October 2010 and February 2011 during the wait for medical appointments or attendance to perform observed ingestion of medications. The interviews took place in a reserved room at each health service, with each lasting an average of 30 minutes. Interviews were recorded and then transcribed at a later date.

Data were collected via an instrument, with questions regarding sociodemographic data and a guiding question regarding the experience of living with TB in order to identify the health needs and vulnerabilities related to access to services, bonding with healthcare teams and compliance with treatment. A field journal was created to register situations and impressions regarding conversations with health professionals, observations of the care provided to people with TB and notes taken during the interviews. The analysis of the statements was performed with ALCESTE (*Analyse Lexicale par Contexte d'un Ensemble de Segments de Texte*), software created for textual data analysis or textual statistics. This software groups words that appear together in sentences and are expressed by the highest number of subjects. The obtainment of significant results requires material in sufficient quantity so that the statistical element is considered in the analysis. Initially, it is necessary to format the analysis corpus, which consists of units of initial contexts (UIC). Each class is made up of units of elementary contexts (UEC), which are segments of the text dimensioned by the software due to the size of the *corpus* and according to a classification of vocabulary distribution, having similarities among themselves and being different from the other classes[3].

The subjects were invited to participate voluntarily in the study, as described in the Term of Free and Clarified Consent. The study complied with the rules of Resolution no. 196/96, being submitted to and approved by the Committees of Ethics in Research of the USP School of Nursing and the Municipal Department of Health of São Paulo (protocol number 783/2006/CEP/EEUSP).

RESULTS

Characterization of the subjects

This study had the participation of 19 people with TB, with the following characteristics: 12 were male, predominantly aged between 18 and 29 years (n = 12); 11 were single, six were married and two divorced; and all of them were educated (one had completed elementary school, eight had attended but not completed elementary school, seven had completed high school and three had attended but not completed their high school education). Regarding their living conditions, all of them lived in brick houses, 13 in their own homes and six in rented houses. As for the number of people living in their houses, three of them lived with one or two people, eight lived with 2 or 3 people and eight lived with more than four people. Among the interviewees, one was retired and 18 stated they were working before receiving their TB diagnosis; after diagnosis, only eight remained employed. Most of them had a family income between 1 and 3 minimum wages (n = 14); two had an income between 3 to 5 minimum wages, one did not have any income, one mentioned an income under one minimum wage and only one subject stated receiving an income the equivalent of more than 5 minimum wages. The prevalent TB case type was newly diagnosed (n = 18), with only one case of recurrence. Regarding the clinical form of TB, the pulmonary form was observed in 16 cases, the pleural form in 2 cases and only one subject had osseous TB. At the time of data collection, 14 were between the first and third month of treatment, four were between

the third and the sixth month and one of them had been in treatment for over six months. All subjects were undergoing supervised treatment (ST), most of them at the Family Health Unit (n = 17), and only two at home.

The analysis *corpus* contained 19 UICs, referring to the statements of the people with TB. The discursive material was divided by ALCESTE into six classes, made up of 631 UEC.

Class 1 of ALCESTE gathered statements that referred to the impact of the TB diagnosis on people's life. The knowledge of the diagnosis had repercussions, both positive and negative, on the lives of the patients, and feelings of fear, anxiety and nonconformism were the most frequent.

The statements showed that the fear of prejudice and discrimination was considered to be a negative consequence of the disease, generating anxiety and suffering. Some of the study subjects reported that the disease affected their family relationships, mainly with closer relatives, who stopped visiting their houses as soon as they were aware of the diagnosis. On the other hand, some people received support from their families, which was considered an encouragement to complete the treatment.

The initial fear of transmitting the disease to other people contributed with the adoption of behaviors of social isolation. In the statements of the subjects, the decision to hide the diagnosis from families and co-workers was frequent, as expressed in this sentence:

> ...I am undergoing a treatment for pneumonia, ...bronchitis (Subject 3).

Class 2 gathered statements regarding the manifestation of TB; in other words, the development of signs and symptoms of the disease, such as cough, fatigue, chest pain, dyspnea, anorexia and weight loss, among others. This class also included the relationship between the beginning of the treatment and the improvement of symptoms mentioned by the subjects, in addition to complaints related to the adverse effects of the drugs prescribed to treat TB, which were mainly present in the first two months.

Class 3 discussed the wait for the TB diagnosis, evidencing the transition through several health services until the correct diagnosis was provided.

Through the statements it was perceived that, in addition to ignoring the signs and symptoms of the TB, some health professionals were unprepared to recognize the disease. There was a frequent report of the subjects going to different health services without having the possibility of TB suggested, which delayed the correct diagnosis and the institution of treatment, contributing to the maintenance of the chain of transmission of the disease which was often identified only after the subject had been hospitalized.

The past experience that some of them had with a family member with TB helped the diagnosis and the investigation of other cases among the communicant subjects, as may be observed in the following sentence:

> I have done the sputum xamination, I explained that in my family my brother and a niece had TB, and one passed it to the other (Subject 15).

Class 4 gathered statements related to the knowledge, beliefs and perceptions regarding TB. Regarding the latter, three elements were identified: some interviewees referred to TB as a completely new experience to them, others considered it a disease they were already familiar with and others related it to a disease from the past. Most of them had no knowledge or insufficient knowledge regarding TB, although they were in treatment and had received education from the health professionals. The following sentence illustrated the type of knowledge they had regarding TB:

> The disease comes from sharing a cup you used from someone else; I do not know what the disease is or how you get it (Subject 6).

In the study group there were people who voiced doubts regarding the transmission of the disease, others who ignored the source of infection and some who associated transmission with low immunity or to the habit of being in crowded places.

The contents grouped in Class 5 concerned the importance of the support received during treatment. The understanding and support of family, friends, co-workers and healthcare service providers were important in determining the compliance of these people with the TB treatment; once they accepted their condition they were encouraged to follow the therapeutic plan. The creation of a bond between people with TB and the health professionals is favored by daily contact, as may be observed in the following sentence:

> I arrive at the Unit, talk to the people, they treat me very well and I want to get better so that I can see my family well (Subject 18).

The desire to obtain a cure for TB and to recover their health motivated the adherence to the treatment and the self-care, leading to the adoption of healthy life habits, such as sleeping and eating well, not using illicit drugs and avoiding drinking alcoholic beverages. On the other hand, prejudiced behaviors may also complicate compliance:

> My wife and my daughter used to buy packages of masks for me, and that was the worst thing for me, I wondered why I could not die already (Subject 10).

The last class, Class 6, comprehended the health needs of people with TB and the conditions that facilitated or complicated their coping with the disease. For the interviewed people, their health needs included: adequate

living conditions – which comprised access to appropriate nutrition, work, housing, education and leisure – and the adoption of healthy life habits – such as the practice of physical exercise and not using illicit drugs (alcoholic drinks and smoking). In a disease such as TB, which is often socially determined, financial difficulties defined the lack of minimum conditions for coping with the disease. The following statement evidenced the difficulty in complying with treatment due to not being able to eat well:

> They say I have to eat well, but I am poor, sometimes I do not have any food. I should eat more often, because when I go to the doctor there is no provement. Only taking the medicine sometimes is not enough to kill the bacteria (Subject 8).

The conditions of completing the treatment and obtaining a cure were also mentioned as health needs. For some interviewees, however, health needs were reduced to biomedical aspects, and their satisfaction depended on the medical care provided. Speeding up the scheduling of activities, such as the collection of material for exams, appointments and execution of exams, was identified as another need.

The ability to cope with the disease was strengthened when there was: quality care, bonding with the health professionals, acceptance by the professionals, proximity of the health service to their homes and incentives received to complete the treatment, such as a monthly basic food basket and a daily meal. The determinants that complicated the execution of the treatment were: lack of appropriate nutrition, adverse effects of the tuberculostatic drugs and, for some subjects, the need to be at the health service everyday for the ST.

DISCUSSION

The statements allowed the authors to better understand the reality of people who live with TB, their experience with the disease, the recognition of their health needs, and the conditions that facilitate or complicate their ability to cope with the disease.

The late diagnosis of TB, as a result of the people's delay in going to a health service at the onset of the initial signs and symptoms of the disease, associated with the low availability of these services in comparison to the demands of the people, contributed to increasing their level of debilitation[4]. The lack of knowledge regarding the disease, including erroneous and mistaken concepts regarding the transmission of TB, strengthened the individual dimension of the vulnerability of these people to the process of becoming ill with TB.

Supervised treatment (ST) is not only a guarantee of the regular ingestion of medications; this strategy also allows the establishment of bonding between the health professional and the person with TB, given their daily contact. This close relationship with the health professional, as well as the support from the family, contributes to effective coping with the disease and is considered fundamental to the success of the treatment by allowing the person to share the difficulties stemming from living with TB[5].

The establishment of a bond between patient and healthcare professional is related to the care practice, translated in an attitude of concern, interest and affection towards the other. The manner in which these people are embraced by the professionals at the health services influences their compliance with the treatment. The knowledge of the social context in which they live, such as the conditions of life, employment and family relationships, may strengthen the relationship of commitment and bonding with these professionals; in other words, the subject is the protagonist in the process of health production.

The execution of the ST in the context of the family health strategy deserves to be highlighted, since its purpose is the health professional's knowledge regarding the patients' families and life contexts, facilitating the establishment of bonding, the sharing of commitment and the emancipation of the subjects, making them feel equally responsible for their treatment[6].

In the statements, the embracing and bonding with the health professionals were identified as light technologies developed by the health professionals, regarded as fundamental in optimizing the necessary care. These practices help the subjects recover their autonomy, through the establishment of an open dialogue and qualified listening, changing the focus from the production of procedures to the supplying of care[7].

Although TB is a curable disease, it still represents a remarkable event in the person's life, especially since stigma and prejudice still follow the disease[8].

A study developed with people living with TB in treatment at a health center in Fortaleza evidenced the impact of the disease on the family, which experienced embarrassment and the weakening of the patient's self-esteem; despite the family's efforts to protect themselves from social discrimination, having the disease meant changes in their social relationships[9].

Despite the encouragement that people with TB receive from health professionals to cope with the transitory difficulties brought about by the drug treatment, it is observed that these difficulties are adversities in the lives of these people and leave permanent marks in their lives[5].

The life contexts in which TB is manifested are the probable cause of the relationship that the affected subjects established between health needs and adequate living conditions, including the adoption of healthy life habits, conditions which are needed to complete the treatment and achieve a cure.

The care offered by Family Health Strategy professionals must be marked by qualified listening, appreciation of patient complaints and identification of their needs, so that, together with the person in treatment and his/her family, strategies and actions may be defined and executed, in a process of co-responsibility between the professional and the patient[10]. Listening to the patients is believed to be essential, because that is the only possible way to identify their true needs, which often may be different than those recognized by the health professionals. Therefore, health practices must be centered on the person instead of the disease, concentrated on the dialogue and in the bonding, to fulfill the population's needs[11].

The health needs identified by the study resulting from the subjects' experiences with TB were present in the six classes composed by the UEC, and were identified by the interviewees as: the period that preceded the diagnosis, the impact of the diagnosis, the development of signs and symptoms, the delay in obtaining the correct diagnosis and the knowledge, beliefs and attitudes regarding TB.

People's vulnerability to become ill with TB was also evident in several classes, and in some of them it occurred more intensely, as evidenced by the late diagnosis, the lack of knowledge, the beliefs and concepts regarding the disease and the lack of recognition of the disease by the professionals. In other classes, the vulnerability to illness was minimized; for instance, regarding the programmatic dimension, when there was access to the correct diagnosis, support during the treatment and familiarization with the disease.

CONCLUSION

The study showed that compliance with treatment has multiple determinants and made clear that access to diagnosis and medications is not enough to ensure effective compliance. The study also demonstrated the importance of understanding the health-disease process as a social phenomenon and contemplating the health needs emerging throughout the entire process of coping with TB so that vulnerability to becoming ill with TB is modified.

In light of the TB situation in Brazil, there is a need for more emphasis on qualitative studies focused on the improvement of the care of the person with TB, as well as on the qualification of health professionals, so that the health practices aimed at the control of this disease will become more effective, bringing more quality to the care process. Therefore, the authors hope the results of the present study will guide actions to promote quality, resolved and humanized care, thus contributing to the reorganization of the health services that provide care to people who live with TB in our area, through the knowledge of their needs and vulnerabilities.

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