

Health needs of people with pulmonary tuberculosis*

Necessidades de saúde das pessoas com tuberculose pulmonar

Necesidades de salud de las personas con tuberculosis pulmonar

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Abstract: Objective: to analyze the health needs of people undergoing treatment for tuberculosis assisted by health services. **Method:** a descriptive study with a qualitative approach, carried out with ten patients assisted by the Family Health Strategy teams and a reference service. The interviews were submitted to the thematic analysis technique and analyzed according to the Operational Taxonomy of Health Needs. **Results:** the patients reported needs for food and housing, were satisfied with the treatment, accessibility and cordiality of the health professionals, but dissatisfied with the investigation symptoms and evolution of the clinical picture. The bond with the nurse was positive. Orientations and search for information subsidized the autonomy and the way of living life. **Conclusion:** patients recognized the health needs related to access to technologies that improve and prolong life, but require precise diagnostic investigation, guidance for autonomy and ordering Primary Health Care.

Descriptors: Tuberculosis; Health Care; User Embrace; Personal Autonomy; Integrality in Health

Resumo: Objetivo: analisar as necessidades de saúde das pessoas em tratamento para a tuberculose assistidas pelos serviços de saúde. **Método:** estudo descritivo, com abordagem qualitativa, realizado com dez pacientes

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assistidos pelas equipes da Estratégia Saúde da Família e serviço de referência. As entrevistas foram submetidas à técnica de análise temática e analisadas conforme a Taxonomia Operacional de Necessidades de Saúde. **Resultados:** os pacientes relataram necessidades de alimentação e moradia, mostraram satisfeitos com o tratamento, acessibilidade e cordialidade dos profissionais de saúde, mas insatisfeitos com a investigação dos sintomas e evolução do quadro clínico. O vínculo com o enfermeiro foi positivo. Orientações e busca de informações subsidiaram a autonomia e o modo de andar a vida. **Conclusão:** os pacientes reconheceram as necessidades de saúde referentes ao acesso às tecnologias que melhoram e prolongam a vida, mas requererem investigação diagnóstica precisa, orientação para autonomia e ordenação da Atenção Primária à Saúde.

Descritores: Tuberculose; Atenção à Saúde; Acolhimento; Autonomia Pessoal; Integralidade em Saúde

Resumen: Objetivo: analizar las necesidades de salud de personas en tratamiento por tuberculosis asistidas por servicios de salud. **Método:** estudio descriptivo, cualitativo, realizado con diez pacientes asistidos por los equipos de Estrategia Salud de la Familia y servicio de referencia. Entrevistas sometidas a la técnica de análisis temático y analizadas según la Taxonomía Operativa de Necesidades de Salud. **Resultados:** los pacientes reportaron necesidades de alimentación y residencia, se mostraron satisfechos con el tratamiento, accesibilidad y cordialidad de los profesionales, pero insatisfechos con la investigación sobre los síntomas y evolución del cuadro clínico. El vínculo con el enfermero fue positivo. Orientaciones y búsqueda de información subvencionaban la autonomía y la forma de vivir. **Conclusión:** los pacientes reconocieron las necesidades de salud relacionadas con el acceso a tecnologías que mejoran y prolongan la vida, pero requieren una investigación diagnóstica precisa, orientación para la autonomía y ordenamiento de la Atención Primaria de Salud.

Descriptor: Tuberculosis; Atención a la Salud; Acogimiento; Autonomía Personal; Integralidad en Salud

Introduction

Tuberculosis (TB) still presents itself as a public health problem that requires investment in rapid actions for universal health coverage, which allows access to health care service, without financial burden, in primary care. In addition to social protection when considering the social determinants of sick people that have an impact on the disease.¹

The relationship between social inequalities and TB points to an articulation with the social dimension of the population, which involves age, income, unemployment, access to health services, living and working conditions. These factors enhance the production and social reproduction of the determinants of the disease that hinder its control and require the organization of society to expand coping strategies.² Thus, social inequalities present themselves as challenges for TB control when they reach populations less favored, especially

those without material conditions whose vulnerability to illness and hospitalization are marked in stories that point to the lack of protection of human rights.³ Such living conditions of people with TB will require greater efforts on the part of health professionals who must consider, listen to and meet their health needs.

In this sense, the Operational Taxonomy of Health Needs was adopted in the present study, whose theoretical conclusion is the social dimension of health phenomena with particular conditions. These needs are always historical, dynamic and changing, with a subjective and individual component. They point out as a perspective to rethink equity, comprehensiveness, re-organization and operational health practices.⁴

Taxonomy results from four elements. The first refers to the need for good living conditions that define health as a set of possibilities given in a certain society; of quality of life that aims to overcome the polarized view of medicine and the adoption of resources to guarantee comprehensive health care. While the disease is defined as a sign of private existence and expresses the difficulty in the life of a person with unfavorable conditions (access to housing conditions and personal habits).⁴

The second relates to the need to guarantee access to all technologies that improve and prolong life. It points out the individual and collective demand in the search for access to light, light-hard and hard technologies that health services must offer and translates society's aspirations for new standards of social rights (right to a healthy life, pain relief, active and pleasant old age).⁴

The third element deals with the need to have a bond with a professional of the team (subject in relationship), with the construction of favorable spaces for affective bonding, sick/family bonding and bonding as an essential aspect of clinical practice, with the patient being able to enhance changes in this practice.⁴

Finally, the need for autonomy and self-care in choosing the “way of walking life” (the construction of the subject) requires demonstrating that passivity is an obstacle to healing, prevention and health promotion. Therefore, the patient must expand his ability to understand his own body, illness, his relationship with the social and survival environment, life and quality of life. In addition to incorporating ideas from critical thinking in Health Education, which are part of the process of building each person's autonomy.⁴

Thus, the Primary Health Care nurse has used personal and environmental factors linked to the use of health technologies, which are related to welcoming, communication and bonding during the treatment, used as tools to develop structured care with necessary actions to the success of TB treatment and the reduction of weaknesses through preventive actions.⁵ In addition, they must use user-centered practices, such as directly observed treatment.⁶ It is emphasized that, for this, health professionals need to consider the scenario socio-cultural and psychosocial illness of the person with TB, which allows understanding how they build their daily lives and have autonomy to modify it by articulating protective knowledge and practices.³

In general, people with TB are negatively affected both in the home and in the social environment; needing psychosocial adjustment to the disease and support in the face of the risk of adapting poorly to illness.⁷ This situation affects self-care and decision-making regarding the search for better living conditions.

In this context, the development of this study is justified by the health needs common to people with TB, which can be identified in access to technologies, in the link with the team in health information for their autonomy and self-care. These dimensions determine the relevance of the theme in the face of health inequalities and the possibility of building comprehensive care by health professionals. This research aimed to analyze the health needs of people undergoing treatment for TB assisted by health services.

Method

This is an exploratory study, with a qualitative approach, based on the elements of the Operational Taxonomy of Health Needs, which comprises the need for good living conditions; the need to guarantee access to all technologies that improve and prolong life; need to have a bond with a team professional; need for autonomy and self-care in choosing the “way of walking life”.

The municipality, located in the southern region of the state of Ceará, had a total of 40 teams from the Family Health Strategy (FHS) and a specialty center. The latter had an infectious disease physician, nurse and physiotherapist to guarantee assistance to patients with infectious diseases. TB patients had access to this service through referral or spontaneous demand.

In these health services, 25 cases of people with pulmonary TB were identified. Ten participants were elected, eight of whom were attended by the FHS team (urban and rural areas) and two patients from the specialty center who met the inclusion criteria.

Inclusion criteria were: being at least 18 years old; diagnosis of pulmonary TB; be accompanied by the FHS team/specialty center; and being in the treatment maintenance phase. This period is justified by the belief that the time elapsed from the treatment is important for the individual to feel some health need. A patient was excluded after a change in diagnosis during the data collection period. There were two refusals to participate in the research, four abandoned treatment, five were discharged and three were excluded because they did not meet the inclusion criteria.

For data collection, carried out from March to June 2015, a semi-structured interview was used, which included questions guided by health needs that sought to identify meanings about health and being sick with TB and its health needs; as for the health services that had access, tests and resources that contributed to the treatment; the relationship established between health professionals and the choice of the treatment location; the guidelines received during illness/treatment; and access to information and participation in a health education group.

Face-to-face contact was made and the interviews took place at the health unit or home, being recorded, with an average duration of 35 minutes, and later transcribed in full.

For empirical material, the thematic analysis technique was used, which is based on the discovery of the nuclei of meaning that are present and frequent in the meanings of the object of study. The technique is performed in stages of pre-analysis, with floating reading and apprehension of the central ideas transmitted in the data; constitution of the corpus representative of the material; and the reformulation of analytical objectives by exhaustive rereading and coded composition of the context and records; then, the exploration of the material, with the understanding of the text by the formulations of the thematic categories. Finally, the treatment of the results obtained and interpretation based on the literature.⁸ The results were descriptive and presented in tables. The analytical categories were based on the elements of the Operational Taxonomy of Health Need.⁴

The research project was assessed and approved on March 5, 2015 by the Research Ethics Committee (REC) of the Universidade Regional do Cariri, Brazil under opinion 974.841 (CAAE: 42118915.4.0000.5055), and complied with the Guidelines and Regulatory Norms for Research Involving Human Beings (CNS Resolution 466/12). The study participants were given a Free and Informed Consent Form, which was signed in two copies (one for the participant and one for the researcher), authorizing voluntary participation. To guarantee anonymity, the participants were named E1, E2 and so on, according to the sequence of the interviews.

Results

In this investigation, people with TB were adults, aged between 20 and 65 years (average 40 years old), declared themselves to be brown, with low-income level (1 minimum wage: R \$ 788.00) and education. Half of the participants were outside the formal labor market and two

families received government benefits (Bolsa Família), sharing their income with two to eight people in precarious housing due to the accumulation of garbage and the lack of basic sanitation.

Needs for good living conditions

The TB health-disease process was understood with divergent conceptions. Health represented quality of life, independence, happiness and faith; disease corresponded to deterioration, denial, dependence and sadness related to the disease. TB transmission was associated with the environmental conditions in which they live in relation to polluted air, cold weather, dust and landfill, in addition to the use of alcohol, smoking and flu processes. Health needs were identified as better living conditions, food, work, financial resources, changes in habits and self-care in the face of the illness process.

Chart 1 - Perception of patients with tuberculosis undergoing treatment regarding the needs for good living conditions. Crato, CE, Brazil, 2015

Health	<i>It is better to have your health; to have your strength [...] it is better for us to have nothing, to have the power of God and to be healthy that we won any battle. (E4)</i> <i>With health the person is everything, and without health the person is nothing. (E3)</i>
Disease	<i>I felt dead. I didn't sleep at night crying with disgust. I was in the mood to send my husband to buy poison, because I was unwilling to live! (E3)</i> <i>The worst thing in the world is that we are sick. Not being able to do anything, not being able to walk. The person who is sick has no joy. (E4)</i>
Cause of transmission	<i>I say that this was from here [refers to the garbage dump], cachaça and cigarettes, taking this dust. (E2)</i> <i>Cigarettes cause tuberculosis, the flu, there is no way for a person to escape. (E8)</i>
Health need	<i>Follow this treatment to improve. (E8)</i> <i>People's living conditions are also poor, they don't have adequate food, they need fruit. (E9)</i> <i>Return to normal life, without any problem and no longer have those excess drinks, binge. (E6)</i> <i>My food takes care of me, preserves me from many things. (E4)</i>

Need to guarantee access to all technologies that improve and prolong life

Patients sought the health service with cough, hemoptysis, fever, tiredness and weight loss. The diagnosis occurred in the specialized unit, with a time of less than 1 month and more than 1 year. Both primary and secondary services were the gateway, which provided the hard technologies, such as X-rays and smear microscopy. Complementary exams were requested and, because they are carried out in private services, cost the patient.

The treatment of most of the participants took place in family health units close to the place of residence, being carried out by some in the specialty center due to the bond or living in an open area of the FHS. They were satisfied with the treatment, accessibility and cordiality of the health professionals, but dissatisfied with the lack of investigation of the symptoms and because they did not have a clinical evolution. Many wanted to include other types of problem solving services and access to other technologies.

Chart 2 - Need to guarantee access to all technologies that improve and prolong life. Crato, CE, Brazil, 2015

<p>Respiratory symptoms and available technologies</p>	<p><i>He was coughing blood [...] they asked for sputum exams, X-rays, and the one from here [shows the left arm-Tuberculin test], [...] the one from the nose [bronchoscopy], where he gave the bacteria. (E4)</i></p> <p><i>About 15 days to 20 days he started with a very strong cough. I looked for the post [FHS] [...] I did the X-ray, sputum exam and started the treatment. (E8)</i></p> <p><i>It's been three years [...], I never had a fever and little cough. The doctor at the clinic asked for an X-ray of the chest, [...] said: it's just a thing of the past [...]. The doctor [rheumatologist] ordered a tomography [...] gave an extensive injury and tuberculosis. I had to do a biopsy [...]. When I received it, it was tuberculosis. (E9)</i></p>
<p>Gateway</p>	<p><i>I went to the hospital, the doctor asked for a plate [X-ray] [...] ordered to go to the health center, show the exam. (E3)</i></p> <p><i>I went to the hospital with cough and tiredness and there I was admitted. [...]. The doctor [pulmonologist] asked me for the exams [...] he told me to get the medication right here [FHS]. (E10)</i></p>
<p>Satisfaction with the offer and resources available in health services</p>	<p><i>I consider [satisfied]. Because you're doing my treatment right. (E5)</i></p> <p><i>If it weren't for this post here, I was dead. (E7)</i></p> <p><i>No. I was the one alone [...]. I really wanted a place that would solve all my problems. (E9)</i></p> <p><i>I am not satisfied, I am in the same way as the beginning of the disease, [...] I should change my medication. (E2)</i></p>

Need to have a bond with a team professional

The participants pointed out satisfaction and bond with the nurse during the consultation and home visit. All professionals were concerned with the treatment and gave advice regarding self-care. Almost all respondents underwent referrals and guidance from health professionals. Only one participant chose the treatment site due to the bond and trust in the specialist doctor.

Chart 3 - Need to have a bond with a team professional. Crato, CE, Brazil, 2015

Relationship with the nurse	<i>She [nurse] treats me very well, she is always smiling. She conducts home visits. (E7)</i> <i>My relationship with her is good; she always worries about bringing the medication, every month. (E9)</i> <i>Always very attentive, but she does not visit. (E6)</i>
Satisfaction with other professionals	<i>The Health Agent lives nearby, always comes here and talks to me a lot about this disease. (E5)</i> <i>The doctor [pulmonologist] [...] always received me very well. (E4)</i>
Protagonism in the choice of treatment site	<i>The doctor [nurse], who asked me to do the treatment close to where I live, [...] I liked it, I don't like to walk a lot [to distant health services]. (E3)</i> <i>I chose the [specialty] post because the doctor [pulmonologist] has been with me since I had my first pneumonia. (E4)</i>

Need for autonomy and self-care in choosing the way of “walking life”

The guidelines and the search for information subsidized the participants' autonomy and the way they walked their lives, which occurred individually with health professionals and over the internet - for those who had this technology. One participant reported not receiving any guidance. The feelings regarding the way of walking life were reported, such as satisfaction, encouragement and gratitude to "God". Other discordant reports referred to discouragement, discomfort with self-image and dependence on others (family members).

Chart 4- Need for autonomy and self-care when choosing the way of “walking life” for people with tuberculosis. Crato, CE, Brazil, 2015

Guidance on the health-disease process and source	<i>She [nurse] always says that I had to take care of myself, eat at the right time, take medicine. The doctor [pulmonologist] too. (E4)</i> <i>I didn't receive any guidance, I can't go to the clinic. (E10)</i>
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of information	<i>I searched the internet. Out of curiosity, like that, natural things, juices, vitamins, which helps in our recovery. (E6)</i>
Feeling about how to walk life	<i>I am feeling relieved, happy[...] because I am getting well. (E3) I feel like a sick person. [...] I live in other people's homes, I want to work and I can't. (E1) I feel a little bad[...] the only thing that bothers me is the issue of the weight that is dropping very fast. (E8)</i>

Discussion

In the present study, the analysis of the understanding of the health needs of people with TB is linked to the construction of care. In the element related to the needs of good living conditions, it was noticed that the participants presented contradictions experienced in their daily life in relation to their condition of life and work, when relating health to the quality of life and faith, while illness was associated with feelings of sadness and coping.

Respondents recognize that TB transmission is related to their living conditions, habits and housing when they point out elements that may have favored illness, even with erroneous conceptions when associating it with pollution, smoking, among others. Living and working conditions were related to the higher concentration of TB cases in vulnerable areas that maintain socioeconomic determinants in the reproduction of the disease, such as income, consumer goods, housing and agglomerations.⁹⁻¹⁰

Still in this element, the participants pointed out that their health needs, in response to TB, demand better socioeconomic and environmental conditions, which corresponds to food, lifestyle changes and treatment. Korean study recommends that the use of the brief illness perception questionnaire carried out with TB patients allowed them to understand their behaviors and could help health professionals in the effective management of the disease during the routine of services.¹¹

In this context, perceived barriers, such as socioeconomic status and the use of alcohol, in addition to psychological suffering, interfere in the health-disease process and treatment,

requiring health promotion interventions.¹² Thus, considering that TB is a disease socially constructed, it reinforces the importance for the development of social protection policies that can reduce it.¹³ In practice, they demand that professionals transcend the biological issue and consider the socioeconomic position of people with TB, in the perspective of ensuring access support social networks.

In the element of need to guarantee access to all technologies that improve and prolong life, individuals reported confirmation of the diagnosis in less than 30 days. Smaller intervals were identified in São José do Rio Preto (SP), Brazil, with 6 to 30 days.¹⁴ Another study, in the city of Cali, Colombia, showed an interval of 57 to 72 days.¹⁵ These differences affect the control of the disease and demand the development of indicators that reinforce access to diagnosis and immediate treatment, which can be evaluated by health services.

Participants had access to routine tests and other more specific complementary tests, the latter of which caused additional costs for patients. As for the burden, studies show job losses, expenses with motorized transport and the economic burden, which can exceed the annual income of families.¹⁶ Strategies must be developed to guarantee access to complementary exams, considering the equity of the vulnerable population, among other technologies light and light-hard.

Still on this element, the participants underwent treatment at health services closer to their territories. For those who were followed up in a specialized center, the choice was made due to the link with the health professional or because they were in an FHS discovery area. The patients had limited role in choosing the health service, however they sought different points of care, reporting satisfaction with the service regarding access and treatment.

Dissatisfaction was related to obtaining a late diagnosis or because it still has clinical manifestations. A study points out that access to the diagnosis and treatment of TB cases has been carried out especially by primary health care, while the weaknesses in the management of atypical cases occur due to delay, errors and the need for diagnostic confirmation.¹⁷

An evaluative study also pointed to satisfaction with access to primary and secondary services.¹⁸ As in the present study, dissatisfaction also occurred due to the failure to carry out home visits for both services.¹⁸ It is noticed that universal accessibility occurs through the search adequate for TB control. In this sense, overcoming deficiencies in access to the diagnosis of the disease requires an appropriate organization of care services to meet health needs and ensure access to services.

Regarding the need to have a bond with a team professional, the interviewees mentioned that the nurse and other health professionals welcomed them during consultations, as well as providing guidance and home visits. In a unique and different way, one participant reveals that the relationship with the nurse was fragile. These same professionals encouraged patients to self-care throughout the treatment with a relationship of care and trust, expressed during consultations through zeal, attention and good relationship.

A study points out that the welcoming of health professionals, especially in primary care, has strengthened the bond and contributed to the monitoring of people with TB.¹⁹ The bond and the embracement are part of the light technology that can be established and represent tools to optimize the care for patients.²⁰ In view of the above, the promotion of care centered on the person with TB should be valued in the perspective of improving the work process and the quality of care.

Regarding the last element of taxonomy, the need for autonomy and self-care in choosing the “way of walking life” was identified that patients received guidance from health professionals regarding health care regarding nutrition, adherence to treatment and the return of consultations. Internet access was restricted to most patients, who sought other care and information about TB.

In fact, all the guidelines on the disease, adherence to treatment and the need for lifestyle changes supported the construction of patients' autonomy, who reported on the health actions they should follow. Encouraging patient autonomy and care centered on the individual have an interface with democratic construction, thus allowing them to be part of the discussions about their treatment and care plan. However, this practice in nursing actions was unfavorable in the cities of João Pessoa and Manaus, while in Porto Alegre, Brazil, it was partially favorable.²¹

Thus, the shared construction of knowledge in the search for autonomy and democracy presents itself as a possible way for the realization of dialogical and participatory models. Thus, the incorporation of these can contribute to the relationship of trust between patients-health professionals and, consequently, enhance the results in the care of people with TB.

Still, in this element, the feeling regarding the way of walking life, the interviewees expressed gratitude and were uncomfortable with self-image and dependence on family members. The singular needs must be recognized by the health teams in the care, because, in addition to the symptoms, there is the stigma and disruption of leisure and work activity.²² It is emphasized that the issue of TB must be expanded to be grounded in ethics with dignity, social justice and welcoming people who live with unfair social conditions.²³⁻²⁴ In this context, there is a need for the involvement of the FHS team to intervene in the search for care with the person with TB, in the perspective of resume life, as well as guarantee social and psychological support to help the process of coping with illness.

As a limitation of the study, the number of participants is pointed out; this prevents the generalization of the findings. However, the study highlights relevant issues related to access to health in the local context, which must be taken into account by managers and health professionals.

Conclusion

In the analysis of the health needs of the person with pulmonary TB, it was evident that the concept of good living conditions was linked to the conditions of illness reflected in the environmental context in which they live due to lack of food and changes in healthy habits.

As for access to all technologies that improve and prolong life, access to hard technologies, such as exams, was emphasized. They reported satisfaction with the accessibility to services close to their home, but were dissatisfied with the lack of monitoring of symptoms and disease progression, as well as the costs they had to carry out complementary tests.

Regarding the bond with a professional on the team, the patients were satisfied and indicated that they had a bond, especially with the nurses. It should be noted that autonomy and self-care in choosing the way of “walking life” were subsidized by the information and guidelines that they sought almost exclusively with the health team.

In view of the meanings and senses about the health-disease process experienced, the nurse and the other professionals of the health team valued the subjectivity and individuality of the sick person aiming at the success of the therapeutic process. Although satisfied with the available health resources, they require health and social protection assessment, through comprehensive care interventions, with Primary Care as the organizer of the health network.

Regarding considerations for health practice, the study points out that the taxonomy elements related to the health of people with TB can enhance care through interdisciplinary and intersectional strategies that minimize suffering and consider their social inequalities.

It is believed that the development of other researches that analyze the perception of professionals in health care for people undergoing TB treatment is relevant, as well as the description of the strategies launched during care to reach them.

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