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RESEARCH | PESQUISA

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Conceptions about treatment and diagnosis of pulmonary tuberculosis for those who experience it

Concepções sobre tratamento e diagnóstico da tuberculose pulmonar para quem a vivencia

Concepciones sobre el tratamiento y diagnóstico de la tuberculosis pulmonar para quienes la padecen

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Abstract

Objectives: to analyze the conceptions of people experiencing treatment and diagnosis of pulmonary tuberculosis. **Method:** this is a descriptive and exploratory research with a qualitative approach, developed in a School Health Center of Belém (Pará) with 30 patients. Data was collected during the period from September 2019 to January 2020 through a semi-structured interview with the aid of a script containing six questions, as well as the observation of the information contained in the medical record and in the tuberculosis record control book. For the analysis of the results, the Content Analysis technique was used according to Bardin's perspective. **Result:** it was identified that the reduced knowledge about the disease and the presence of negative conceptions influence, in a significant way, the search for care or the adherence to treatment, interfering in daily and work activities. **Conclusion:** it is concluded that the need for patients to (re)mean tuberculosis during treatment persists, and it is essential that the health team knows such conceptions in order to provide care that contemplates physical and bio-psychosocial aspects before the Tuberculosis Control Program of the unit.

Keywords: Primary Health Care; Treatment; Diagnosis Social Perception; Pulmonary Tuberculosis.

Resumo

Objetivos: analisar as concepções de pessoas que vivenciam o tratamento e o diagnóstico da tuberculose pulmonar. **Método:** trata-se de uma pesquisa descritiva e exploratória, com abordagem qualitativa, desenvolvida em um Centro de Saúde Escola de Belém (Pará) com 30 pacientes. Os dados foram coletados durante o período de setembro de 2019 a janeiro de 2020 por meio de entrevista semiestruturada com o auxílio de um roteiro contendo seis perguntas, assim como a observação das informações contidas no prontuário e no livro de controle de registro da tuberculose. Para a análise dos resultados, foi utilizada a técnica de Análise de Conteúdo segundo a perspectiva de Bardin. **Resultado:** identificou-se que o reduzido conhecimento sobre a doença e a presença de concepções negativas influenciam, de forma significativa, a busca por cuidados ou a adesão ao tratamento, interferindo nas atividades diárias e laborais. **Conclusão:** conclui-se que persiste a necessidade de os doentes (res)significarem a tuberculose durante o tratamento, sendo fundamental que a equipe de saúde conheça tais concepções, a fim de subsidiar cuidados que contemplem aspectos físicos e biopsicossociais ante o Programa de Controle da Tuberculose da unidade.

Palavras-chave: Atenção Primária à Saúde; Tratamento; Diagnóstico; Percepção Social; Tuberculose Pulmonar.

Resumen

Objetivos: analizar las concepciones de las personas que viven el tratamiento y diagnóstico de la tuberculosis pulmonar. **Método:** se trata de una investigación descriptiva y exploratoria con abordaje cualitativo, desarrollada en un Centro de Salud Escolar de Belém (Pará), con 30 pacientes. Los datos fueron recogidos durante el período de septiembre de 2019 a enero de 2020 a través de una entrevista semiestructurada con la ayuda de un guion con seis preguntas, así como la observación de las informaciones contenidas en el prontuario y en el libro de control de registro de la tuberculosis. Para analizar los resultados se utilizó una técnica de análisis de contenido según la perspectiva de Bardin. **Resultado:** se identificó que el escaso conocimiento sobre la enfermedad y la presencia de concepciones negativas influyen, de forma significativa, en la búsqueda de cuidados o la adhesión al tratamiento, interfiriendo en las actividades diarias y laborales. **Conclusión:** se concluye que persiste la necesidad de los pacientes de (re)significar la tuberculosis durante el tratamiento, y del equipo tratante, de conocer tales concepciones, para subsidiar cuidados que contemplen aspectos físicos y biopsicosociales ante el Programa de Control de la Tuberculosis de la unidad.

Palabras clave: Atención Primaria de Salud; Tratamiento; Diagnóstico Percepción Social; Tuberculosis Pulmonar.

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INTRODUCTION

Tuberculosis (TB) is an infectious disease that remains a serious global public health problem, with high rates of morbidity and mortality. It is estimated that in 2020, TB will have affected about 9.9 million people worldwide, accounting for 1.3 million deaths among people not infected by HIV. In Brazil, 68,271 new cases of TB were reported in 2021, which is equivalent to an incidence coefficient of 32.0 cases per 100,000 population.[1,2]

The disease is a priority according to the Brazilian National Primary Care Policy (BNPCP). Since 2006, the Ministry of Health (MH) has intensified the decentralization of the actions of diagnosis, control, and treatment of the disease to Primary Care services because it is precisely at this level of care that all care for people with TB should be offered.[2,3]

The pulmonary form is the most relevant for favoring the transmission of the pathogen, highlighting the importance of diagnosis for controlling the disease and consequently breaking the chain of transmission, although it can also occur in other organs of the body.[1,4]

TB treatment lasts a minimum of six months, is available at the Brazilian Unified Health System (UHS), and should preferably be carried out under the Directly Observed Treatment (DOT) regimen.[1] Although TB is treatable and curable, the treatment has efficacy of up to 95%, and the low effectiveness can occur due to incorrect or irregular use of the drugs and even abandonment.[5]

It is important to emphasize that it is up to the health care team to guide the user from the suspicion of the disease until the diagnosis of TB: what it is, how to prevent it, the importance of the control of communicants, the time of treatment, adverse reactions and the need to adhere to treatment to obtain a cure.[6,7]

Thus, adherence to treatment is linked to the users' trust in the health services; to the integration with other levels of care; the multidisciplinary team's psychosocial support and encouragement of the user and his family; to the dissemination of information through effective health actions among the population, helping in the social conception of the disease.[8]

From this context, an essential strategy for adherence to TB treatment is the strengthening of patient-health professional integration. This requires the existence of health care that can establish interpersonal, cohesive bonds capable of emanating mutual cooperation between the patient, the community, and health professionals so that they can express their knowledge about the disease and, thus, define whether such knowledge hinders or facilitates their cooperation and adherence to treatment.[9]

Therefore, it is recognized the importance of evaluating the behavior of the health team in care practices for TB patients, since it is essential to mitigate the negative conceptions of the disease. In this step, the nurse and the health team should consider, in their clinical practice, inter-subjective care, which favors the completeness of health care.

Knowing the conceptions of people who live with the disease about the treatment of TB can subsidize the deconstruction of negative aspects that prevent adherence to treatment, favor and continue the high number of dropouts and cases of drug resistance. For this reason, it is necessary to invest in actions and studies that can assess how these problems present themselves and what is the patient's reaction to them.

Studies show the suffering of TB patients and their families and bring to light the stigma, the difficulties of social interaction, as well as the withdrawal from work activities. Such results show that the suffering experienced by TB patients goes beyond the body and compromises their social identity.[3-6,10] Others allude to the low level of knowledge about the disease, which can be related to socio-demographic factors, such as low education, low socioeconomic conditions, and difficulty of access, which influence the continuity of treatment, since the lower understanding of what the disease is can trigger affections such as fear, anxiety states, and other negative thoughts during the course of treatment for pulmonary TB.[7,11-14]

Of these studies, two were conducted in the North region of Brazil,[15-18] focusing on the obstacles to treatment, pointing out the little regional production, and reiterating the need for studies focused on this reality and its respective peculiarities.

Thus, this research aims to analyze the conceptions of people experiencing treatment and diagnosis of pulmonary TB.

METHOD

Descriptive and exploratory research with a qualitative approach, developed in a School Health Center in Belém, Pará, is considered a reference in TB control in the city. The health center is a teaching and assistance unit that provides primary and specialty care services to the residents of the Marco neighborhood. Among the primary care services, it has the TB and leprosy control program, besides Hyperdia, women's health, children's health, and prenatal care.

This study was carried out with individuals on regular treatment for pulmonary TB at the aforementioned health center who met the inclusion criteria: any form of entry into the Sistema de Informação de Agravos de Notificação (SINAN), as long as the regular treatment was for pulmonary TB - New case, Retreatment or Re-entry after abandonment and relapse; to be over 18 years of age and registered at the health center. The exclusion criteria were: people with mental confusion, non-oral deaf people, since the researchers did not master *Libras (Brazilian Sign Language)*, and those who were not present at the time of data collection. Among the 36 who participated in the approach, six were excluded: three for not accepting to participate in the study and three for being deaf, not oral, thus, 30 people were part of the final sample of this research.

Data collection occurred in the period from September 2019 to January 2020. Information regarding the clinical and socioeconomic data of the 30 participants was collected from the medical records and the Tuberculosis Control and Registration Book.

The participants were approached by convenience, i.e., according to their days of attendance at the unit, thus not interfering in the work routine of the unit or the participant. They were invited to participate in the research at the end of the nursing consultation, being informed about the purpose of the study and their interest in participating. If positive, they were directed to a second room in the unit with comfort, adequate ventilation, and guaranteed privacy for participants. In this room, they were explained the study's operationalization, objectives, risks, and benefits, and agreed to participate by signing the Free and Informed Consent Term (FICT). The participants had their identities preserved through the use of alphanumeric codes, composed of the letter P (patient) followed by the sequential number of the interview.

The specific questions regarding the object of study were collected through individual semi-structured interviews, with a script composed of closed and open questions that lasted an average of 30 minutes, aiming to encourage patients to report their experiences with pulmonary TB, diagnosis, and treatment, allowing their conceptions to flow, knowledge, fears, and expectations, based on a script with six questions to explore the conceptions of the disease, the feelings and attitudes towards the diagnosis and treatment, the perceptions of the drug effects on their bodies, the facilities and difficulties encountered, the access and accessibility to diagnosis and treatment.

In compliance with the ethical aspects, the research was approved by the Ethics Committee of the University of the State of Pará (UEPA) under number 3,545,674/2019. All the ethical precepts contemplated in Resolution 466/12 of the National Health Council were followed.[19] Access to patient records only occurred after the signature of the person responsible for the program in the Consent Term for Data Use (CTDU).

The statements were transcribed with the application of Content Analysis techniques: pre-analysis, exploration of the material, and treatment of the results.[20] Thus, the themes were mapped, which made it possible to know the patients' conceptions, which covered the social repercussions of the disease, the knowledge, and practices that imply caring for oneself and for others, the treatment of the disease, and its impacts on the patients' lives.

RESULTS

A representative sample of 30 participants was obtained, residents of Belém, with a predominance of males (19=63.3%); between 18 and 49 years (15=50.0%); single (17=56.6%); complete High School (10=33.3%), followed by incomplete Elementary School (6=20.0%); 18 (63.3%) participants were employed and five were on health leave (16.66%) due to pulmonary TB; 17 participants (56.6%) had family incomes less than or equal to one minimum wage, and 19 (67.33%) participants said they were Catholic.

Regarding the clinical and epidemiological variables, OST predominated (18=60.0%); 27 (90.0%) were virgins of TB treatment; 16 (53.3%) were in the first two months of treatment; 13 (43.2%) complained of pruritus and nausea as the main side effects of treatment.

Social repercussions: images and prejudices

When the diagnosis is disclosed to people who are close to the patient, the reaction may be to distance oneself due to different motivations, among them, disgust. From there, classifications or qualifiers can be attributed to the sick person, further increasing the risks of distancing and even social isolation in the face of a negative image of the patient.

> [...] *one person I told acted in a prejudiced way towards me, I could see on her face a reaction of disgust. She almost completely withdrew. This shows that many people are not prepared to receive a TB patient* [...]. (P9)
>
> [...] *I want to get well, because there, where I live, I am known as the tuberculosis man, so I want to get well soon to take away this image they have created of me* [...]. (P21)

Knowledge and practice: the dialectic expressed in the care of the self and of the other

It is observed that the care supported by effective educational work produces good results in the self-care of the person with TB; however, information alone is not enough, because there are other elements that surround people's decision-making, as can be seen in the situations experienced and reported by patients.

> [...] *as I received a lot of information from the nurse at the clinic, I didn't need to separate my plates and cutlery, because TB is a bacteria that is transmitted by breathing, in the air, just washing the utensils with soap and water is enough* [...]. (P26)
>
> *On the first day, I received information from the nurse about the treatment, which is for six months, the medications, and side effects such as nausea, changes in urine, and skin reactions* [...]. (P29)
>
> [...]*I don't want to transmit it to my family or anyone else, I have also separated dishes and glasses, every day, and my wife boils some water and throws it on my dishes to kill the causer of the disease* [...]. (P3)
>
> *I am sleeping in a separate room, wear a mask all the time, and separate my things from the rest of the people in the house, like clothes, spoons, plates, cups, toothbrushes* [...]. (P14)

Drug treatment in alliance with complementary care

Drug therapy for TB is effective, but it can be complex for people to manage in their daily lives. Besides that, it causes adverse effects that impact the body and change the individual's daily life. Moreover, it is evident the use of other therapies, complementary, as adjuvants in treatment, need to be known and considered by health professionals, especially with regard to the possibilities of interactions with the active ingredients of allopathic drugs.

> *These drugs are complicated, when I took them, my body itched, my joints ached, and my blood pressure dropped* [...]. (P7)
>
> *Besides the medicines the doctor gave me, I am taking Mexican tea with milk because my mother said it is good for the lungs* [...]. (P3)
>
> *Along with the medicines, I drink mint tea, made by my mother; it helps to alleviate the effects of the TB medicine. I also use bee honey with absorbent cotton for my breathing. I see these remedies as a form of help, even if they don't cure 100%* [...]. (P5)

Impacts on practical life and the consequences of treatment adherence

Diseases, in general, impact human lives, individually and socially. When it comes to an infectious disease, such impacts reverberate both in the personal and in the public sphere, and this is evidenced in the practical life of people with TB. The treatment works as a more effective strategy to regain the previous state, considered functional, understood as opposing the current state, diseased.

> *I quit my job, and it hurt me the most because I depended on this income to support my family. I come to the station every Monday, Wednesday and Friday and take two buses each time* [...]. (P3)
>
> *A person with tuberculosis has to give up many things to follow treatment; this includes work* [...]. (P27)
>
> *With the treatment and the care I am getting now, I hope to get better every day from this disease and be able to go back to work, go out again with my friends, to have a normal life, like before I had tuberculosis* [...]. (P25)
>
> *I hope to get well and go back to work so that everything will be normal. I'm going to change my lifestyle from now on: I'm not going to drink; I'm going to avoid rain and sun* [...]. (P14)
>
> *Today I take better care of myself, I worry about my diet because I lack appetite, lost weight, and had a fever. Now I have to recover the kilos that I lost* [...]. (P23)

DISCUSSION

TB brings about different alterations in daily life: family, with self-isolation; work, when patients stop working or change their pace of work; social, with the restriction of conviviality; psychological, generating shame, guilt, fear of death and of transmitting it to the closest people. Such changes have the stigma and prejudice shading several places where people living with TB live. The confirmation of the diagnosis interferes with the self-image and self-esteem of patients, affecting interpersonal relationships since prejudice is evident and causes rejection of the patient.

The imaginary about TB is that of a separatist disease, which is becoming more common nowadays, even with the biomedical advances in terms of treatment and cure.[21] In view of this, prejudice emerges in the participants' conceptions through reports of situations experienced daily.

Revealing the diagnosis brings up prejudice and generates social isolation, and may even lead the person to fear losing his or her job. The results of a study on the social representations of patients with TB point out that the preservation of secrecy about the disease aims to protect the prejudice that guides it.[22]

The prejudice of others and the self-concept persist, directly or indirectly, even though the guidance on the modes of transmission of the disease, the treatment, and its effect on the bacillus, makes it unable to infect other people in the first months of treatment. Nevertheless, the beliefs about contagion still populate the social imaginary, surfacing the beliefs, which generate self-discriminatory attitudes such as: separating clothes, dishes, and cutlery; sleeping in separate rooms even at the end of the treatment. Similar attitudes emerged in a study on leprosy,[23,24] indicating that they are relatively common in diseases associated with stigma and prejudice.

When discriminatory acts come from close people, such as family and friends, they produce feelings and attitudes of spontaneous isolation and seclusion. This distancing is justified as a way to preserve the health of the family and other loved ones. Social representations about the disease reveal that stigma and prejudice lead the patient to social isolation, compulsory or voluntary.[22]

The patient's care with health education and the dissemination of technical information on transmission and treatment has an effect on self-care and should be encouraged and strengthened in Primary Health Care and health programs aimed at caring for people with infectious diseases. In the conceptions of participants, it is evident that the guidance provided by the health team during consultations with different health professionals reached the goals, reflected in their self-care attitudes.

On the other hand, the technical-scientific information coexists with beliefs and with the imaginary about contagion and separatism. It is expressed in real situations experienced by other patients and, also, in the fear they feel of passing it on to family members, even though they are being treated at the health unit and receive orientation about the disease.

Conventional drug treatments are widely disseminated, but they do not overcome practices rooted in social and family traditions, in the so-called traditional medicine demarcated by culture. The knowledge that supports and builds such practices was historically constructed through ancestry and passed on from generation to generation through orality, establishing interactions with other knowledge in time and space, transforming it, and adding new historical and social elements to it, becoming know-how related to therapeutic resources.[25]

According to the National Policy of Integrative and Complementary Practices (NPICP) in UHS, such practices are ways to stimulate natural ways of dealing with signs and symptoms of disease and/or possible aggravations. These must be taken into consideration by means of welcoming listening since it is a way for man to interact with his environment.[26]

TB patients resort to some of these traditional practices in search of solutions to their problems regarding the prevention and aggravation of diseases through the use of medicinal plants, understood as palliative measures, for relief from the side effects of medications.

The difficulty in managing the treatment and inserting it into the activities of daily living (ADL), mainly due to the lung limitations caused not only by the disease but also by the treatment, is a reality in the lives of patients. This has negative repercussions on work activities, leading to financial losses and expenses with accessibility to the unit.

The fear of having one's life condemned as a result of the disease since one's routine is altered by work limitations, strengthens conceptions that the TB patient is an incapacitated being, since work is an important activity for the configuration of human dignity.[27] The return to routine activities is a perspective of the patients portrayed in expressions such as going back to what they did before the illness and having a normal life.

The commitment to self-care in favor of a cure stems from the review of unhealthy lifestyle habits in an attempt to rescue the health they had before getting sick with TB. Adherence to treatment provides an opportunity to start over, however, this new beginning demands change in the way of operating daily life, especially for those who were already marginalized before getting sick, which is characteristic of these people.[27]

This review of habits can be conceived as a positive side of the disease, since it leads the person to reflect on the importance of self-care, such as: improving diet; increasing water intake; not smoking; not drinking alcohol; protecting oneself from rain and sun.

CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

It is concluded that the conceptions of people who experience pulmonary TB about the diagnosis and treatment of this disease converge on the importance of correct information about transmission, guided by the health team, denoting a difference in the process of self-acceptance and living with family members in their homes so that, from the guidance, several feelings, such as fear, were attenuated.

It was concluded that the need for patients to (re)signify TB during treatment persists, and it is essential that the health team knows such conceptions in order to provide care that contemplates physical and bio-psychosocial aspects before the Tuberculosis Control Program of the unit.

Regarding the treatment, even if patients consider the importance of the regular and correct intake of medications, they are unhappy with its adverse effects and seek to mitigate them with palliative measures, drawing attention to the need to know and consider the different therapeutic routes used by the patient for the relief of their illnesses.

It is appropriate to highlight that the convictions about the condition of illness of the participants generated reflections about their altered functionalities, especially considering the removal from their jobs, which led to concerns about financial and social aspects, implying a thought of loss about the period of treatment, causing the desire for cure and change of life after this phase.

The findings of this study bring, as implications for professional practice, the direction of care strategies and monitoring of participants diagnosed with TB, ensuring comprehensive, longitudinal care, as well as focused on the needs of this public, expressed through their speeches.

As for the limitations of this study, the fact of not having, as an aid, the knowledge of sign language for the possible approaches to patients who might have reduced hearing acuity stands out. Moreover, the illegibility of some of the registers in the unit's record book presented here made it impossible to collect some information, making it necessary not to include them as information records in this study.

AUTHOR'S CONTRIBUTIONS

Study design. Lucas Miléo Teixeira. Rosimere de Freitas de Sousa. Yasmin Cristino Monteiro. Iaci Proença Palmeira. Camila Carvalho do Vale. Leticia Lima Oliveira.

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Data analysis. Lucas Miléo Teixeira. Rosimere de Freitas de Sousa. Yasmin Cristino Monteiro. Iaci Proença Palmeira. Camila Carvalho do Vale. Leticia Lima Oliveira Widson Davi Vaz de Matos.

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