Original Article
doi: https://doi.org/10.1590/1983-1447.2024.20230302.en

People with pulmonary tuberculosis in primary health care: social networks and repercussions of illness

Pessoas com tuberculose pulmonar na atenção primária à saúde: redes sociais e repercussões do adoecimento

Personas con tuberculosis pulmonar en la atención primaria de salud: redes sociales y repercusiones de la enfermedad

RGE Revista Gaúcha de Enfermagem

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How to cite this article:
Motta MCS, Souza MHN, Zeitoune RCG, Andrade EGR, Rodrigues ILA, Oliveira APR, et al. People with pulmonary tuberculosis in primary health care: social networks and repercussions of illness. Rev Gaúcha Enferm. 2024;45:e20230302. https://doi.org/10.1590/1983-1447.2024.20230302.en

ABSTRACT

Objective: to analyze the perceptions of people with pulmonary tuberculosis about their social support networks and the repercussions of becoming ill.

Method: a qualitative, descriptive study, conducted with 41 individuals undergoing treatment for pulmonary tuberculosis, in Primary Health Care units in two Brazilian capitals: Belém/Pará and Campo Grande/Mato Grosso do Sul. Semi-structured individual interviews were carried out from July to December 2019. The thematic content analysis technique was applied.

Results: among the participants, 21 (51.22%) were from Belém and 20 (48.78%) from Campo Grande. Males (n=23/56.10%), age group from 21 to 40 years old (n=16/39.02%), unemployed status (n=28/68.29%) and who did not receive social benefits (n=23/56.10%) predominated. Three thematic categories emerged, presenting perceptions about social networks and the types of support they offer, the impact of the disease on family budget and its impact on work activities.

Final considerations: social support networks were characterized by the diversity of people and family or emotional ties maintained with the participants, as well as the diversity of types of support. In this context, they found the necessary human support to face the impact of the illness and deal with their socioeconomic condition.

Descriptors: Tuberculosis, pulmonary. Primary health care. Social networking. Social support. Communicable diseases. Public health.

RESUMO

Objetivo: analisar as percepções de pessoas com tuberculose pulmonar sobre as suas redes de apoio social e as repercussões do adoecimento.

Método: estudo qualitativo, descritivo, realizado com 41 pessoas em tratamento para tuberculose pulmonar, em unidades da Atenção Primária à Saúde de duas capitais brasileiras: Belém/Pará e Campo Grande/Mato Grosso do Sul. Foram realizadas entrevistas individuais semiestruturadas, no período de julho a dezembro de 2019. Aplicou-se a técnica de análise de conteúdo temática.

Resultados: entre os participantes, 21 (51,22%) eram de Belém, e 20 (48,78%), de Campo Grande. Predominaram o sexo masculino (n=23/56,10%), a faixa etária de 21 a 40 anos (n=16/39,02%), o *status* de desempregado (n=28/68,29%) e o não recebimento de benefícios sociais (n=23/56,10%). Emergiram três categorias temáticas, apresentando as percepções sobre as redes sociais e os tipos de apoio por elas oferecidos, as repercussões da doença no orçamento familiar e as suas repercussões nas atividades laborais.

Considerações finais: as redes de apoio social caracterizaram-se pela diversidade de pessoas e vínculos familiares ou afetivos mantidos com os participantes, bem como pela diversidade de tipos de apoio. Nesse contexto, encontraram suporte humano necessário para enfrentar as repercussões da doença e lidar com a sua condição socioeconômica.

Descritores: Tuberculose pulmonar. Atenção primária à saúde. Rede social. Apoio social. Doenças transmissíveis. Saúde pública.

RESUMEN

Objetivo: analizar las percepciones de personas con tuberculosis pulmonar sobre sus redes de apoyo social y las repercusiones de enfermarse.

Método: estudio cualitativo, descriptivo, realizado con 41 personas en tratamiento por tuberculosis pulmonar, en unidades de Atención Primaria de Salud de dos capitales brasileñas: Belém/Pará y Campo Grande/Mato Grosso do Sul. Se realizaron entrevistas individuales semiestructuradas, en el período de julio a diciembre de 2019. Se aplicó la técnica de análisis de contenido temático.

Resultados: entre los participantes, 21 (51,22%) eran de Belém y 20 (48,78%) de Campo Grande. Predominó el género masculino (n=23/56,10%), la franja etaria de 21 a 40 años (n=16/39,02%), le estado de desempleo (n=28/68,29%) y la no recepción de beneficios sociales (n=23/56,10%). Surgieron tres categorías temáticas que presentan percepciones sobre las redes sociales y los tipos de apoyo que ofrecen, las repercusiones de la enfermedad en el presupuesto familiar y sus repercusiones en las actividades laborales.

Consideraciones finales: las redes de apoyo social se caracterizaron por la diversidad de personas y vínculos familiares o afectivos mantenidos con los participantes, así como por la diversidad de tipos de apoyo. En este contexto, encontraron el apoyo humano necesario para enfrentar las repercusiones de la enfermedad y hacer frente a su condición socioeconómica.

Descriptores: Tuberculosis pulmonar. Atención primaria de salud. Red social. Apoyo social. Enfermedades transmisibles. Salud pública.

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INTRODUCTION

Strategies to address tuberculosis (TB) as a public health problem, especially in countries with a high burden of the disease, where indicators are higher than 10.0/100,000 inhabitants, have been highlighted in several global plans and agreements. In the last two decades, the possibility of eliminating the disease was announced through the Regional Plan for Tuberculosis Control (2006-2015) for the Americas, by the Pan American Health Organization (PAHO), and the Strategic Plan for Tuberculosis Control in Brazil, for the period from 2007 to 2015. As they were not achieved, there was an extension of the deadline to 2030, as described in the Global End TB Strategy(1).

In this scenario, Brazil is part of two lists of 30 countries that have the highest burden of the disease and co-infection between *Mycobacterium tuberculosis* and the Human Immunodeficiency Virus (HIV), which is why the World Health Organization (WHO) has classified it among the priority countries for global control(2). In the national territory, in 2022,78,057 new cases of TB were reported, with an incidence rate of 36.3 cases/100,000 inhabitants. In 2021, there were 4,531 deaths from the disease, with a mortality rate of 2.2 deaths/100,000 inhabitants. Among the states, the highest incidence rates were recorded in Amazonas (84.1), Roraima (75.9), Rio de Janeiro (68.6), Pernambuco (52.8), Acre (52.0), Pará (49.4), Mato Grosso do Sul (47.1), Amapá (43.1), Rio Grande do Sul (40.9) and São Paulo (38.3)(3).

Also in 2021, among the operational indicators, 66.5% and 14.0% of new cases of pulmonary TB, confirmed by laboratory criteria, ended treatment due to cure and abandonment, respectively(3). This shows that the number of cases with abandonment was 2.8 times higher than the 5.0% rate considered acceptable by the WHO and the Ministry of Health(2,4).

A significant challenge for the success of TB control actions is adequate treatment, which should preferably be carried out in Primary Health Care (PHC) for a period of no less than six months(5). Cure as a treatment outcome of treatment has been a constant concern for health management, due to the inherent complexity of therapeutic control, which generates personal repercussions, involving economic, psychosocial and occupational aspects, among others(6,7).

Beyond the repercussions of the illness, it is important for the patient to identify strengthening aspects in their interpersonal relationships, aiming at the necessary support to follow the therapeutic process and achieve the cure(8). In this context, social networks are defined as a fundamental element for understanding how support from family, friends and other people, as well as from social institutions, such as community and religious institutions, provide support to strengthen treatment adherence(8,9).

Social networks can be primary or secondary, and are differentiated by the types of bonds/relationships that people establish in their socialization. The primary network consists of family members, friends, neighbors, and colleagues, and the bond is characterized by trust and reciprocity, which is formed naturally, spontaneously, and autonomously. The secondary network is characterized by the involvement of social, educational, and healthcare institutions and/or services, among others, with which a certain degree of relationship is established(9).

Corroborating the importance of these networks in facing everyday challenges, especially those related to health, authors have proposed different theoretical or theoretical-methodological perspectives, which provides reflections on the relational dynamics between the individuals and the actors in their social network. As an example, the Everyday Network Analysis Method (MARES) consists of conceptual and operational elements that value both the formal, socially established nature and the cultural and sociopolitical determinants of networks (10). In turn, the Social Networks and Health framework characterizes them as a sociological paradigm and as processes strongly linked to public health, as it points out relationships between health and environment, highlights sociability as an inherent element to the idea of community health and reflects on health surveillance actions, which operate in organized network to control diseases and conditions(11).

It is important to highlighting the significant contributions of PHC professionals, as this is a level of care that allows for greater proximity between professionals and human groups in the control of TB(12). Thus, care needs are identified, allowing for significant interventions based on PHC resources and mechanisms, including: consultations in health units, homes and community spaces; home visits for follow-up; educational and health surveillance actions; social assistance interventions; and the establishment of partnerships with other levels of care and with different institutions in the territory(12,13).

Among these actors, nursing professionals, especially nurses, represent a driving force in the care for people with TB, as they perform important actions ranging from prevention to rehabilitation. According to official recommendations, regarding treatment, nurses are responsible for initiating the basic regimen for sensitive TB, guiding patients regarding the specificities of medications, requesting tests to monitor their clinical progress, and identifying/contacting those who miss appointments and directly observed treatment (DOT), among other activities that strengthen bonds, enhance therapeutic adherence and health surveillance actions⁽⁴⁾.

This demonstrates the importance of developing studies on TB in the social and economic contexts of people undergoing treatment, including their social support networks, due to the need and the big challenge of controlling the disease, especially in countries with low or medium socioeconomic development, such as Brazil⁽²⁾.

In this context, understanding the social networks of people undergoing treatment, as well as their implications for the disease, identifies how different actors and institutions contribute, or can contribute, to patients in overcoming the challenges in the daily treatment, supporting the collective construction of strategies to strengthen healthcare services, especially in PHC. Thus, it is understood that this knowledge can contribute with evidence to achieve favorable therapeutic outcomes, with higher cure rates and reduced abandonment, as it fosters opportunities for discussion and reflection in the interdisciplinary, multiprofessional and intersectoral spheres.

Considering the relevance of the topic, the guiding question was formulated: what are the perceptions of people with pulmonary tuberculosis about their social support networks and the repercussions of their illness? To answer this question, this study aimed to analyze the perceptions of people with pulmonary tuberculosis about their social support networks and the impacts of the illness.

■ METHOD

This is a descriptive study with a qualitative approach, guided by the guidelines of the COnsolidated criteria for REporting Qualitative research (COREQ) checklist⁽¹⁴⁾. It constitutes the first stage of the multicenter project Longitudinal Study of the Impacts of Social Support and Operational Indicators of Tuberculosis (*Estudo Longitudinal dos Impactos do Suporte Social Indicadores Operacionais da Tuberculose* – ELISIOS-TB). The study was conducted in two capitals in the North and Central-West regions of Brazil: Belém (PA) and Campo Grande (MS). The choice of these capitals is justified by the fact that the states of Pará and Mato Grosso do Sul are among the highest incidences of TB in the national territory⁽³⁾.

The data were produced between July and December 2019, in PHC health units that performed diagnosis and treatment for pulmonary TB, located in peripheral neighborhoods and with a significant number of cases of the disease. In the city of Belém, the study took place in two Municipal Health Units (MHU). In the city of Campo Grande, the settings were four Basic Health Units (BHU).

The participants were 41 people undergoing treatment for pulmonary TB, approached individually, when they attended routine consultations at health units. It was decided to invite all new cases, regardless of the month of treatment. Thus, people aged 18 or over and who were undergoing regular follow-up at the selected units were included. The exclusion criterion was the fact that the person had a cognitive disorder and/or any other physical, psychological or emotional conditions that would prevent participation in the interviews.

However, during the data production, there were no exclusions, refusals or withdrawals, reason why the number of 41 participants was defined by theoretical saturation, when the data to understand the object of study were sufficiently achieved, not requiring the inclusion of new participants. In this production, a semi-structured script was used to guide the individual interviews, conducted by the research team and scholarship holders. The researchers are nurses/with doctoral degrees, faculty member at the Higher Education Institutions (HEIs) executing the research. The scholarship holders, who were linked to these HEIs, were regular master's students in nursing and were trained by the researchers, aiming to standardize procedures to avoid potential biases.

The script was developed by the researchers and consisted of two parts: the first, with objective questions, allowed for the understanding of the sociodemographic profile, health status, and government social support of the participants; and the second, with subjective questions, allowed the exploration of the study object.

In line with the characteristics and purposes of the script, the last part was adapted by the interviewer, whenever necessary, to improve the participant's understanding of the subjective questions and encourage dialogue to understand the subject. This part consisted of four questions and were discussed in conversations with the participants: "Talk about your support network"; "What expenses have you and your family started to incur due to the illness?"; "Regarding expenses, what have you and your family been doing?"; "Talk about your employment/work during this period". It should be noted that the script was not subjected to a pilot test or validation study, and that all data were produced using this instrument, without using a field diary or other collection techniques.

After the initial approach, to ensure comfort and privacy, the participants were taken to a reserved room on the health units, where the research was presented in easy-to-understand language, inviting them to participate. For those who accepted, the interview took place immediately after the approach, or was scheduled, according to their availability. Since they were individual, the interviews took place exclusively in the presence of the interviewer and the participant. They lasted, on average, 15 minutes and were recorded digitally, after prior consent. The recordings were documented in MP3 format, using audio recording to capture only the voices.

The data related to the participants' profile were organized, processed and analyzed using the Statistical Package for the Social Sciences (SPSS) software, version 21.0, and presented descriptively to highlight the absolute numbers and their percentages. The interviews were transcribed to form a textual corpus, subjected to the thematic content analysis technique(15), performed manually, without the support of software, through its three stages: pre-analysis; material exploration; results treatment, inference, and interpretation.

In the pre-analysis, a panoramic reading of the corpus was carried out (floating reading) to assess its content, construct initial ideas (assumptions and possible explanations) and decide how the data would be coded and categorized to meet the study objective. Based on the first stage, the exploration of the material allowed coding the data, through the identification of the recording units (short excerpts, selected as themes) that occurred and co-occurred throughout the statements, as well as their context units (longer excerpts that allowed a better understanding of their meanings). The themes were then categorized by semantic criteria, aggregating them into thematic categories (groups that combined record units with similar or complementary characteristics) that together represent the investigated phenomenon. As a critical-reflective process, the stage of results treatment, inference, and interpretation was conducted to understand the data and discuss them in light of the updated scientific evidence, establishing dialogues with national and international literature(15).

Following this technique, three main themes were identified: 1) social networks and types of support they offered in the daily lives of patients; 2) the impact of TB on the family budget; and 3) the impact of TB on work activities. Thus, three thematic categories emerged, named according to their respective themes: "Social networks and types of support"; "Impact of the disease on the family budget"; and "Tuberculosis diagnosis: impact on work activities". To organize them, the statements of all participants were considered; however, since they were the most emblematic, it was decided to show the excerpts corresponding to nine participants, demonstrating the perceptions that best represent the content of the categories.

Based on Resolution No. 466/2012 of the National Health Council/Ministry of Health, which regulates research with human beings in Brazil, the participants signed the Informed Consent Form, formally declaring their voluntary acceptance. To protect their identities, alphanumeric codes were assigned, composed as follows: letter U, for "user", cardinal number indicating the order of the interviews, underline and the acronym of the Brazilian state (PA or MS) where the participant lived and was being treated for pulmonary TB.

The study was approved by the Research Ethics Committee of the Health Sciences Center of the *Universidade Federal do Espírito Santo* (Opinion No.3,280,915/2019 and CAAE: 09351919,0,0000,5060), s it is the host institution of the last author, the general coordinator of the multicentric project. This Opinion was accepted by the Ethics Committees in Belém and Campo Grande. Additionally, institutional approval was obtained from the Health Departments of these municipalities.

RESULTS

Among the 41 participants, 21 (51.22%) were from Belém, and 20 (48.78%) were from Campo Grande. Regarding sociodemographic characteristics, the majority were male (n=23; 56.10%) and the age group of 21 to 40 years (n=16; 39.02%), considered economically active. Regarding education, 15 (36.59%) declared incomplete elementary education and, regarding marital status, 17 (41.46%) reported being married or living in a stable union. In addition, 28 (68.29%) lived in their own home; 28 (68.29%) stated they were unemployed; 20 (48.78%) had a family income between R$1,001.00 and R$2,000.00, and 27 (65.85%) shared this income with three to five people. Regarding religion, the majority declared as evangelical (n=22; 53.66%) or Catholic (n=13; 31.71%).

Regarding their health status and the types of social benefits received, all reported using medications provided by BHU or public hospitals. In addition to pulmonary TB, 14 (34.15%) lived with other chronic diseases or associated conditions, such as diabetes mellitus (DM), systemic arterial hypertension (SAH), HIV infection, asthma and depression, with DM being the most prevalent comorbidity among participants (n=5; 12.20%), followed by SAH (n=3; 7.32%) and HIV infection (n=3; 7.32%).

The majority (n=23; 56.10%) did not receive any government benefit. From the 18 (43.90%) who reported receiving some type of benefit, nine (21.95%) received support from the *Bolsa Família* Program. The others stated that they received support through the Continuous Cash Benefit (*Benefício de Prestação Continuada* – BPC), Senior Citizen Card, National Institute of Social Security (*Instituto Nacional do Seguro Social* – INSS), Social Light, Meal Voucher and Transportation Voucher.

The three thematic categories generated by the content analysis are presented below, with their most emblematic excerpts.

Social networks and types of support

Considering that most participants stated not receiving benefit from government social programs, both in Belém and Campo Grande, the primary network was the main social network highlighted in the statements, consisting of family and friends, such as neighbors. These actors provided affective and emotional, financial and material support, especially to acquire food during TB treatment. Other types of support were also mentioned, such as support with household taks, according to the excerpts:

> [...] *my uncles, my aunts, my grandparents, my father and my mother support me. They are all together and support me financially too.* (U3_PA)
>
> [...] *from the neighbors, I received financial support. They made collections so I could travel and stay here too. My friend helped me support my family, which was left unattended because I couldn't work.* [...] *when I got home [after] consultations, my friends came to visit me to talk, to offer me psychological support. It helps the mind!* [...] *my brother-in-law welcomed me when I was here, and I stayed at his home. This was the help they gave me: food, transportation [and other types of support]. It was a very good help! A friend also contributed with collections, sending me some things, such as a basic food basket, financial aid, and some money.* [...]. (U6_PA)
>
> *From my family, I receive emotional support. They support me so I can continue the treatment and not stop, and my mother helps me financially.* (U1_MS)
>
> [...] *she [the friend] helps me around the house, cleans, cooks food for me. If I need to go to the doctor, she goes with me.* (U2_MS)

This shows that family and emotional ties were essential to transform, to some degree, the challenging reality face by those affected. Therefore, without the types of support offered by the primary social network, patients would not have the minimum conditions to cope with their illness and, possibly, would develop complications resulting from their clinical condition.

Impact of the disease on the family budget

To speed up the diagnosis of the disease, due to the operational limitations of public health services, participants used their own resources, to perform laboratory and imaging tests in private network services, generating repercussions on the family budget. In this context, expenses were added with medication to treat symptoms associated with TB and for other clinical manifestations, in addition to expenses on food and the use of alternative transport or collective public transport to travel to health units, straining the budget, as show the excerpts:

> *I spend more on medicine for fever. I have a fever every day, a fever that doesn't go away, and a lot of headache. My daughter and I spent a certain amount per month; as I got ill, expenses increased. She borrows money from her father.* (U1_PA)
>
> *We ran after it and took the exams at the private [service]. We are buying medicines to [stimulate] appetite and to [treat] fever.* [...] *I'm going to change my glasses, I don't know if [the visual impairment] is because of tuberculosis. Spending on food also increased.* (U2_PA)
>
> *When they diagnosed me with this [TB], I spent money on tests, everything was [carried out] in private [service], because in [health] unit, it would take time. To be faster, because of the illness, I was forced to pay. I paid for the exams to advance the treatment. In addition to the help that my friends gave me, I also accumulated a debt for grocery items [referring to food expenses]. I got into debt trying to get better, work, and pay it off over time.* (U6_PA)
>
> *I had travel expenses to go to the [health] unit and when I went to the UPA [Emergency Care Unit] for the X-ray [imaging test]. There is a cost for getting around by Uber® [private urban transport app] and by bus [public transport].* (U1_MS)
>
> *I go to the doctor by Uber® or by bus. I took a loan from my daughter-in-law. My retirement helps, but it's not enough, it's very little and things are very expensive.* (U3_MS)
>
> *I spent it on the exams I took at the private [service]. Even the X-ray was [performed] at private service. I was very bad, and [at BHU] t would take about 30 days, so I took it privately and took it to the doctor. I bought medicine twice, and every time I go [to the health unit], I have to take Uber®.* (U7_MS)

Faced with the demands of the illness, participants made efforts to cover unexpected expenses in their financial planning and which, therefore, exceeded their socioeconomic status. For this reason, additional resources were acquired, allowing them to diagnose and treat the patients, a fact that also led to debt for them and their families.

Tuberculosis diagnosis: impact on work activities

In the participants' experiences, TB symptoms made it difficult to carry out work activities and, sometimes, contributed to a reduction in working hours or even to job loss, as can be observed in the excerpts:

> *I can't work. I'm not in good condition due to the fever, and I also try to avoid passing on [transmitting] these things [referring to TB] to people. I used to wash clothes outside [that is, for other people, in other homes], I cleaned, but I had this illness, and I couldn't do it anymore.* (U1_PA)
>
> *I'm not working. I used to work, helping my father. He worked with painting, and I accompanied him. When I got sick, I stopped working.* (U3_PA)
>
> *My work has a big impact on the illness. I'm a painter, I used strong toxic paint materials, and* [now] *I can only work with paints that don't smell. So, [this] means that my work has been reduced by half and my income has decreased a lot, [as] I can't do all the services I used to do. I'm from the interior [rural municipality of the state of Pará] and, and at minimum, what I spend here [in the capital, Belém], to undergo treatment, is a week. In a week, in addition to spending, I don't have a [financial] return.* (U6_PA)
>
> *I don't work anymore because I couldn't stand it, my leg hurt. I used to walk, there [at work] was a stair to climb and I couldn't stand it, so I stopped working. I became so weak that I couldn't get out of bed, I felt nauseous and I couldn't eat.* (U3_MS)
>
> *I was working,* [but] *I lost my job because they [the employers] wouldn't let me go there anymore. Because of the tuberculosis, they laid me off.* (U4_MS)
>
> *I'm not working, I'm just doing "odd jobs" [working informally]. I can't do heavy work all the time. When I start moving around a lot, I feel tired. Since I got this disease [TB], I haven't taken on regular job [that is, I haven't held down a job or I haven't been able to fully develop a work activity that required significant physical effort].* (U7_MS)

It is worth noting that the disease had a strong impact on the daily lives of those affected, limiting their physical ability to work and, consequently, their individual and family income. Along with the previous data, this category shows that, as it is a complex condition, TB generates many biopsychosocial repercussions, which require the involvement of various actors, forming networks to support those affected in the face of these repercussions and to help them achieve a cure.

DISCUSSION

The sociodemographic characteristics of the participants are in line with the Global Tuberculosis Report(2), when highlights the predominance of males. In this context, the data on education, income and unemployment status, found in this study, show that TB is still characterized as a phenomenon marked by deprivation and suffering, requiring multisectoral actions(16). This situation is reinforced by the fact that the majority stated that they were not covered by government social programs, despite the socioeconomic and operational impacts of the disease, widely reported in national(12,17) and international scientific literature(16,18).

It was identified that the participants' social networks, especially primary networks, were generally diverse, consisting of family members with several kinship ties and friends/neighbors who made joint efforts to support these individuals throughout treatment. In addition to the financial and material issues inherent to the challenges of living with the disease and dealing with the demands of treatment, this support also made by emotional and affective support. Thus, it is possible to infer that the network members perceived or demonstrated an understanding of the need to help patients cope with the biological and psychosocial aspects resulting from their health condition.

Regarding the types of support received, similar to the results presented, a study conducted at a PHC unit in Rio de Janeiro (RJ) found that the primary social network was also consisted by family members who were important in seeking treatment and in the regular follow-up of patients(8).

The data highlight financial support as an important element of support offered by the network, since the resources were used to cover the costs of food, medicines, laboratory and imaging tests, as well as to cover travel expenses by public transport or through private urban transport apps.

Consistent with this result, financial support was also found in a study with 62 TB patients, conducted in all regions of Brazil, observing that the highest proportion of annual family income used to cover the costs associated with the disease was identified among extremely poor people (40.37%, compared to 11.43%, in the least poor individuals)(19). A study with 1,178 TB patients in Uganda revealed that, due to the expenses generated by the disease, 48.5% of families requested loans, used reserves (savings) or sold their assets to cover treatment costs(20).

Thus, despite the efforts of the networks, reflected by all types of support offered, the data reveal high expenses by patients. This happened due to the need to diagnose, treat and control the disease in the face of the insufficiency of public health system, which did not opportunely provide the corresponding resources, mobilizing patients and their networks to seek different alternatives to solve this situation with their own resources.

Reports highlight the debt resulting from the emergency use of these resources by patients. In contrast to this result, despite the support possibilities offered by the Unified Health System (*Sistema Único de Saúde* – SUS) throughout the national territory, it can be inferred that a significant portion of patients' health needs was not met by the Brazilian State, as defined by the Federal Constitution(21).

This demonstrates that, in order to be solved or better managed, the health problems of the population still require significant investment from public authorities and the competent administrative bodies. In the context of TB, this need is corroborated, for example, by Joint Operational Instruction No.1, of September 26, 2019, which presents robust guidelines for collectively addressing the disease(22).

Therefore, it is necessary to strengthen the provision of protective mechanisms, through government social support and income transfer programs(12,17). Corroborating the importance of these mechanisms, a cohort study conducted with 426 TB patients in Bhavnagar, India, analyzed the association between not receiving assistance from a benefit transfer program and unfavorable treatment outcomes, showing that not receiving assistance was associated with a five times higher likelihood of obtaining unfavorable outcomes (95% CI: 2-12)(18).

A broad scoping review, which included 63 studies conducted on five continents (Africa, South America, Asia, Europe and Oceania), analyzed strategies and measures aimed at ensuring social protection as a set of rights for people with TB, identifying that such protection unfolded in different aspects: the right to adequate nutrition, the right to income, the right to decent housing conditions, the right to health insurance and rights that include assistance and social welfare. By ensuring these rights, the possibilities to improve the quality of life of those affected, reduce the costs resulting from illness, strengthen access to healthcare services and adherence to treatment are expanded, providing higher cure rates(23).

These studies reinforce that TB is a socially determined disease, since many factors condition its occurrence and possible aggravation(18,23). The social determinants of health (SDH) are everyday elements that generate risks of illness and weaken the health of a population, represented by cultural, behavioral, economic, ethnic-racial, psychological and social factors(24), with interference also from biological factors(25). Thus, it is understandable that vulnerability to TB is influenced by factors such as advanced age, comorbidities, malnutrition, inadequate housing and work conditions, difficult access to health services and social protection mechanisms(24), some of which were significantly found in this research.

National and international literature indicates that there are many challenges in living with chronic diseases, especially infectious diseases such as TB, considering the historical and social trajectory of this pathology, strongly marked by conceptions, attitudes and behaviors that demonstrate stigmas, fears and prejudices, which remain active in the sociocultural memory and disseminated among human groups(26–30), including among healthcare professionals, despite the evolution of technical-scientific knowledge about the cause and feasible control of the disease(6,27,29).

This contributes to distancing patients from their social life and distancing them from healthcare services, often leading to unsatisfactory therapeutic follow-up by services and abandonment of the treatment indicated(28,29). Social marks are an important characteristic of the disease as they permeate collective thinking and incorporate subjective elements about those affected, reinforcing stigmas, as evidenced by research in the municipality of Bolgatanga, in the northeast of Ghana(31).

Among the possible consequences of this scenario, stand out the extension of the expected therapeutic period, the development of resistant and multiresistant forms of the disease, the search for specialized health services, the increase in hospital admissions due to worsening of the clinical condition and the consequent increase in costs to the SUS(4,32,33). Therefore, patients' social networks are fundamental elements in facing the challenges and providing the necessary conditions for them to be monitored by healthcare services, in order to avoid interruptions that can fragment treatment, worsen the disease, and lead to complications(8).

Reinforcing the importance of a support network in monitoring chronic conditions, a study conducted in six European countries, in the social context of people with diabetes, demonstrated that if this network is characterized by proximity to the patient and by the diversity of its components, it will be more likely to mobilize and offer adequate support, aiming at contributing to managing the condition(34). Furthermore, when changes in behavior regarding health care are necessary to improve quality of life, encouraging the formation of collaborative networks increases the chances of achieving healthier living conditions, as evidenced in research with community groups in rural Bangladesh(35).

In this context, the importance of PHC and the tools it should offer to provide biopsychosocial monitoring of patients and control of their clinical condition is highlighted(4). Thus, it contributes to the effectiveness of the actions of the National Tuberculosis Control Program (*Programa Nacional de Controle da Tuberculose* – PNCT), currently the General Coordination for Surveillance of Chronic Respiratory Transmitted Diseases (*Coordenação-Geral de Vigilância das Doenças de Transmissão Respiratória de Condições Crônicas* – CGDR), of the Ministry of Health.

Considering its characteristics, which should guide the democratic and resolutive relationship of healthcare professionals in close contact with human groups, PHC is essential to welcome and monitor patients and those involved in their social networks, in order to provide primary care and guide them on all pertinent issues(6,36). This should aim to equip patients and their networks for self-care and effective self-management of the disease and the individual and collective needs that arise from it.

Due to the interaction of *Mycobacterium tuberculosis* with the host, individuals with advanced pulmonary TB and/or without adequate treatment commonly present signs and symptoms, such as fever and fatigue(4). These manifestations were reported by participants as factors that limited the performance of work activities after the diagnosis and contributed to reducing the volume and/or intensity of tasks or to keeping the patient away from their occupation.

Due to the physical impairment and its consequences on the functional capacity of those affected, it is evident that TB can strongly interfere in daily life, by limiting the patient's independence and willingness to undertake satisfactory physical effort. This finding is similar to those of a study conducted in the city of Cajazeiras (PB), with seven TB patients, which identified reports of debilitating manifestations associated with the disease, such as dyspnea, pain and dizziness, even after the start of treatment(27).

Reinforcing this perspective, a prospective cohort study with 155 participants, in two health units in Mae Sot, a border territory between Thailand and Myanmar, aimed to analyze the changes in health-related quality of life over six months after the start of TB treatment, as well as the associated factors. It was found that the majority (n=52; 33.5%) presented four or more initial symptoms, suggesting that this condition may be associated with more severe cases of the disease at the time of diagnosis, resulting in a significant reduction in quality of life(37).

In addition to physical interference, the data indicate possible psychosocial interference, considering the reports indicating self-inflicted absence from work activities or inflicted by third parties. It is noted that certain social understandings about the disease and/or ways of symbolizing the patient are still based on archaic thoughts that generate stereotypes even among those affected(27,30). Such perceptions and symbolisms need to be reviewed to support patients and contribute to solving the problems arising from their clinical condition, creating possibilities to improve their quality of life. It is understood that interferences on the physical and psychosocial dimensions can be better managed in the patient's daily life when they have a strong and proactive social network.

In this context, health education is considered an important tool to mobilize social groups, in the reality of healthcare services and in various community spaces, to reflect on TB and review archaic thoughts in relation to the disease and those affected, as well as to reflect on the stereotypes that result from such thoughts.

This imaginary was naturally constructed and crystallized, reason is why it has been perpetuated throughout the human history(29,30). To confront it, relevant and timely actions are needed, based on critical-reflexive and dialogical health education strategies to stimulate new ways of understanding the disease, perceiving those affected and dealing with them in everyday human relationships(38). This can contribute to bring patients closer to their social life, especially with their primary networks and with the health professionals who monitor their clinical condition.

Such consideration is made taking into account that treatment abandonment is associated not only with issues inherent to the social networks of those affected, but also with factors such as the structure of health services, the dynamics of interpersonal and intergroup relationships in these services and the difficulties in accessing government social support and income transfer programs(12,17), reinforcing the social determinants of TB.

Given that the study was conducted in PHC units located in only two Brazilian municipalities, with specific sociocultural, administrative and operational characteristics, the limited geographic representation of the data is mentioned as a limitation. However, it is understood that it is possible to compare the data with other realities in the national and international territory, including other levels of health care complexity (secondary/specialized care and tertiary/hospital care). Additionally, the data contribute to encouraging critical-emancipatory attitudes in the daily work of healthcare professionals involved in patient care and by managers who implement, execute or operationalize public policies to control infectious diseases such as TB.

Therefore, it is highlighted that the study shows evidence that can foster discussions and qualified practices in the fields of nursing and health, aiming to guide work processes related to the provision of biopsychosocial care to people and groups affected by TB; to the management and administration of health and nursing services, providing support for implementing and improving care actions; teaching practices in higher education, through which guidelines on TB control are shared and reinforced to enable learning; in addition to the production and dissemination of research on TB and its interface with patients' social networks.

The reflective process inherent in the discussions can favor the construction, review and/or reformulation of health care strategies that address the needs of those affected or contribute to effectively meeting them, including the components of these individuals' social networks.

FINAL CONSIDERATIONS

This study made it possible to analyze the perceptions of people with pulmonary TB, identifying that their social support networks were characterized by the diversity of people and family or emotional ties that they maintained with those affected, as well as by the diversity of types of support they offered. Additionally, it was found that the repercussions of the disease were related to the strain of the family budget, due to the need to bear the costs of tests, medications, food and transportation throughout the diagnostic process and treatment. These repercussions also encompassed work activities, as they weakened working hours or resulted in job loss, configuring a close relationship with the SDH.

Despite the challenges inherent in controlling TB, it was demonstrated that the participants found the necessary human support to cope with the impacts of the disease and deal with their socioeconomic condition. Therefore, given the relevance of the topic, it is expected that the results will support studies aimed at understanding or clarifying other aspects of the illness, which should be investigated to understand its characteristics and guide, as much as possible, the behavior of human groups and health professionals in overcoming the TB as a public health problem.

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Acknowledgments:

To the financial support of the Ministry of Health – Note 2018NE803480 (CGDR/DEVIT/SVS/MS) and the Coordination for the Improvement of Higher Education Personnel (*Coordenação de Aperfeiçoamento de Pessoal de Nível Superior* – CAPES) – Funding Code 001.

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The authors declare that there is no conflict of interest.

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Received: 01.06.2024
Approved: 03.27.2024

Associate editor:
Carlise Rigon Dalla Nora

Editor-in-chief:
João Lucas Campos de Oliveira