Perception of homeless people about the treatment of tuberculosis

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ABSTRACT

Objective: To understand homeless people's perception in relation to the treatment of tuberculosis. **Methods:** A qualitative study based on thematic oral history. Twenty-four homeless individuals from the city of São Paulo undergoing treatment for tuberculosis and linked to two Basic Health Units were interviewed from June to July 2018. **Results:** Three categories emerged: Homelessness as a challenge to coping with tuberculosis; The impact of treatment on users' lives; and The potential and limits of health services in supporting the tuberculosis treatment. The participants highlighted that the fact of living on the streets exerts impacts on their treatment, as isolation and monitoring measures are less effective. On the other hand, the possibility of cure and the relationship established with health professionals were fundamental for adherence to the treatment. **Final considerations:** Tuberculosis in the street population must be understood from the perspective of the social determination of the health-disease process. Added to the challenges inherent to the treatment of tuberculosis, life conditions on the street, as well as individual, collective and programmatic vulnerabilities of the services and public policies need to be considered in the care strategies.

Descriptors: Homeless people, Tuberculosis, Adherence to the treatment, Social conditions, Health services.

INTRODUCTION

Growing inequalities in Brazil have resulted in a higher number of people being deprived of rights and work, with an impact on living conditions and repercussions on the right to housing¹. This context triggers and intensifies a multivariate process of weakening social bonds and a progressive increase in the number of people forced to live on the streets, especially in large urban centers, scenarios strongly marked by poverty and social inequalities.

In Brazil, there are no official data on the Street Population (SP), but the 2021 Street Population Census Survey in the city of São Paulo revealed a total of 31,884 individuals in this condition, of which 60.2% were recorded in streets, squares and other public spaces and the rest in welcoming centers. Most were cisgender men (80.1%), black- or brown-skinned (70.8%) and with a mean age of 41.8 years old. This survey revealed a sharp and worrying increase of 31% in the number of homeless people as a result of the economic and social crisis related to the COVID-19 pandemic².

Although the right to health was instituted by the 1988 Brazilian Federal Constitution, its guarantee

directly affects SP, which faces obstacles to health care and access to the services³. Social vulnerabilities, in addition to individual vulnerabilities such as nutritional deficiency, abusive use of alcohol and other drugs, sleep deprivation, insecurity, advanced age and difficulty meeting needs, among others, result in greater susceptibility to various diseases, including tuberculosis (TB)⁴.

TB is a socially determined disease, and the option of interpreting it, supported by the Social Determination of the Health-Disease Process, allows for greater understanding of its complexity and alternatives for the implementation of health policies that contribute to its control and that consider the specificities of each social group. In the case of SP, adherence to the treatment involves a series of constraints, given the particularities of this group. Thus, TB management requires the recognition that the living conditions faced by SP reflect on illness and on the epidemiological indicators. For this, it is fundamental to overcome this unfair reality and seek strategies that allow for the universalization of citizenship and dignity⁵.

SP has a 56 times higher risk for contracting TB when compared to the general population.

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An active search for respiratory symptoms is recommended at every contact opportunity with a professional or health service, regardless of the time since the onset of cough⁶. In 2011 and through the National Primary Care Policy, the Brazilian Ministry of Health instituted a health work strategy called Street Medical Office, which includes guidelines to guarantee SP access to health actions and services in a timely and integral way, considering their particularities and health needs⁷. Its creation aims at establishing a new way of offering health care and managing the work process⁸. This strategy has the potential to exert impacts on health care, contribute to TB control actions and modify the epidemiological indicators.

Thus, creation of the Street Medical Office presents new health care modalities and, consequently, new ways of managing the work process. From this articulation between care and management, this article discusses three intervention plans where the practice of the Street Medical Office teams takes place: the streets, the headquarters/reference unit and institutional networks, its relationship with other Primary Health Care (PHC) services and its contribution to reconciling PHC with its fundamental duties, beyond the geographic territory attachment. From the knowledge about the particularities of life on the streets and the dynamics of the urban space, which generate conflicts and precarious living conditions, it is understood that adherence to the treatment and actions aimed at TB control in SP constitute a challenge, with the need to rethink the health practices, seeking to respond to the needs of this social group. The complexity involved in living on the streets implies a lower percentage of cure and a higher occurrence of abandonment and death⁷.

Faced with the singularities and challenges that homeless people face in relation to illness and to the TB treatment, the current study had the following guiding question: Which are the perceptions of people living on the streets about the TB treatment?

OBJECTIVE

The general objective of the study was to know the perception of homeless people in relation to the

treatment of tuberculosis. The specific objectives were to identify the potential and limits of the TB treatment in this population and to know the role of health services in supporting such treatment.

METHODS

Type of study

This is a study with a qualitative approach and of the oral history type, in its thematic modality, as it corresponds to a more restricted narrative of the interviewee about a given topic. It was decided to interview homeless people undergoing TB treatment who could tell their experiences about living on the street sand suffering from TB. The starting point was the assumption that life is marked by historical experience; therefore, the act of listening to their stories in an empathic and cooperative way brings up deep human experiences⁹.

Study setting

The study was carried out in two Basic Health Units (BHUs) covered by the Street Medical Office, located in the central region of the city of São Paulo. This option was due to the fact that they had the largest number of homeless people undergoing TB treatment.

Data collection and organization

The inclusion criteria to select the participants were as follows: homeless people aged 18 years old or over, who had been undergoing TB treatment for at least one month, were able to answer the questions included in the interview and/or had preserved ability to maintain a logical conversation throughout the interview.

Testimonies were obtained from 27 participants, although three were excluded for not meeting the established criteria. The sample comprised by 24 participants was due to data saturation, a moment in the field work when collection of new data with the inclusion

of more participants, hypothetically, would not contribute any more clarification to the object studied¹⁰. Thus, the number of participants was not pre-defined, as the study aimed at knowing the singularities and meanings associated with the phenomenon under study, expressed through opinions, representations, behaviors and practices of a particular social group. The fact that the participants reflect a set of characteristics, experiences and expressions that provide data complementarity was also considered¹⁰.

The eligible subjects were invited to participate in the study when attended the health service for drug therapy supervision or medical appointments. The data were collected from June to July 2018 through semi-structured interviews, carried out by a properly trained researcher in a private room inside the BHUs. The questions that comprised the script for the interviews were the following: "Tell us a little about yourself and what it's like to live on the streets.", "How was the first moment you started to feel ill?", "What do you think tuberculosis is?", "After you found out you had TB, which changes happened your life?", "Which are the practicalities and difficulties to undergo the treatment?". The interviews lasted between 15 and 40 minutes and were audio-recorded and fully transcribed by the researcher who conducted them.

Data analysis

To ensure the confidentiality and anonymity that was agreed upon with the participants, they were designated in the text with the letter E for interviewee ("entrevistado" in Portuguese), followed by an identification number. The study respected the COREQ criteria recommended for qualitative research with interviews, except for the participants' validation of the interviews' transcripts due to the difficulty locating them again¹¹.

Data analysis followed the procedures indicated below: 1. Reading and re-reading of the transcribed material, in search of guiding axes for data organization; 2. Textualization of the testimonies, by incorporating the questions asked during the interviews to the narrators' speeches and the approximation of the texts from the narratives that referred to the same topic; 3. Coding of the

excerpts from the testimonies, according to the topics addressed, to identify the nuclei of meaning; and 4. Content analysis of the statements and definition of thematic groupings, according to the thematic analysis model¹⁰.

In order to elaborate the thematic categories, the similarity, relevance and equivalence between the topics found via the coding process were analyzed. The categories were analyzed in the light of the Social Determination of the Health-Disease Process. This theory argues that the way the individual is inserted in society reflects on the illness process, as the way of life and the perception of health and disease have repercussions on the production, distribution and consumption social characteristics^{5,12}.

Ethical aspects

The recommendations set forth in Resolution No. 466/2012 of the National Health Council were safeguarded, and the study was approved by the Ethics Committee for Research with Human Beings of the University of São Paulo, under opinion number 1,553,500.

RESULTS

Of the total of 24 participants, most were aged between 50 and 59 years old (33.3%), 91.6% were male, 45.8% were from the state of São Paulo, 66.6% had complete Elementary School, 75% were single, 45.8% had three or more children, 75% had contact with their family, 45.3% have been living on the streets for two to 10 years, 66.7% smoked cigarettes and 29.2% made use of illicit drugs. As for income, 79.2% did not work and 41.7% reported earning up to R\$ 81.00 per month. In relation to the type of supervision, all were undergoing directly observed treatment and 83.3% presented the pulmonary form of TB.

Three empirical categories emerged from data analysis: The street situation as a challenge to face tuberculosis; The impact of treatment on users' lives; and The potential and limits of health services in supporting treatment.

The street situation as a challenge to face tuberculosis

The street life context was identified as harmful to health and, consequently, favorable to TB, in addition to constituting a challenge for effectiveness of the treatment. The interviewees stressed that lack of housing exposes them to the weather (rain, temperature), which ends up making them even more vulnerable.

If you're on the street, you don't have a roof, sometimes it rained, you got wet, you're sleeping with a wet blanket, on a cold floor, on concrete. (E3)

I'll tell you, I haven't know what a roof is for 30 years now, getting calm, sun, rain, lightning, but I'm there, I'm living. (E17)

In addition to the weather, the interviewees mentioned the absence of a support network and difficulties obtaining food and maintaining personal hygiene.

It's not easy because you don't know anyone on the streets, you don't have anyone. Everything is difficult, you don't have access to almost anything, taking medications is difficult because it takes time until you settle down in a place, until you have certain affinity to talk to someone about your disease, yeah, that takes a while, right? (E1)

The worst things you go through are lack of food, cold, the desire to take a shower and having no place. You see a lot of people taking drugs, drinking, killing themselves, and you're very vulnerable. (E3)

It's very difficult, because we don't have the support of anyone who can help. I spent ten days without eating, without being able to get up, I was in pain. (E18)

It was observed that the fact of living on the streets was more likely to transmit the disease, as the investigation of contacts was limited due to the absence of a fixed address. On the other hand, it was verified that the spaces intended for temporary shelter also consist of a risk space due to the fact that there is no control over diagnosis and treatment of the disease.

I stayed on the streets normally, they didn't put me in quarantine, I put the lives of several people at risk, this disease could spread, then it would complicate everything. (E3)

Tuberculosis is a shelter disease, I got it after I stayed here for 5 months, everyone stays together, if one gets it, the others get it, I'm afraid to treat it and get it again living here. (E17)

The interviewees also reported the need to keep the diagnosis and treatment confidential due to the prejudice associated with the disease. Likewise, they expressed concern about transmitting TB to the people they live with.

Look, on the streets you have to measure what you say, because there's a lot of prejudice, people think that they'll catch the diseases if I touch their hand. Nobody wants you around, if they know you have tuberculosis then... sometimes it's better not even to say that you are undergoing treatment. (E4)

At first I was worried about spreading the disease, but now the risk period is over, because I need to respect others, there are a lot of people. (E10)

The homeless condition was understood as an aggravating factor for users infected with TB, as it is not possible to maintain all the care measures prescribed by the care protocols.

The impact of treatment on users' lives

Despite the reports made by some participants who pointed out the side effects of the medications for the treatment of TB as a difficulty, they did not mention the desire to abandon the treatment, which showed knowledge about the disease and the importance of completing the therapy.

I think the medications need to be improved, I was taking one and then my stomach started to hurt, and there's nothing for stomach pain. (Interviewee 14) Taking medications is bad. It doesn't seem that way, but when I take them, I get a bad deal. (Interviewee 2)

Some of the participants mentioned that addiction to licit and illicit drugs represents a challenge for the treatment in the street context. Thus, their abusive use is often an important reason for treatment discontinuation.

People who live on the streets and have tuberculosis take the medication and then drink alcohol, because they're addicts, as they prefer to take drugs, they stop taking the medicine and die. (E3)

I want to go there so I can be cured. And on the streets it's quite a thing, addiction always comes in the way. (E2)

On the other hand, another percentage of the participants highlighted that the concern regarding effectiveness of the TB treatment was responsible for stimulating the reduction or interruption of the abusive use of licit and illicit drugs, promoting a change in this behavior.

About four of my peers have already died, because they took the medication and drank. I stopped drinking. (E13)

Honestly, it's not easy, because you see people drinking. People who drink, want to drink, but are afraid. [...] I took a break, I take a few sips from time to time, but all the same I was smoking before, no way. (E22)

The participants reported that discovering the disease contributed to resumption of family contact. The desire for a cure was expressed as a goal and the wish to resume family life proved to be an important support point for health care and adherence to the treatment.

For the love of my grandchildren, I'm taking the medication properly, so I can finish the treatment and see them without worry. (E17)

After I finish the treatment, I go home to be with my family. They want me to leave, but I need to finish the treatment first. (E18)

It was also observed that the treatment itself was responsible for triggering changes in the users' perception of health and in their daily lives, in addition to mentioning the adverse effects caused by the medications.

I think the medications need to be better, I was taking one and my stomach started to hurt. (E14)

In relation to changes in everyday life, the users highlighted the need to attend the BHU daily and length of the treatment in time.

Wow, it's a lot [tiredness], in life itself, I have to come here every day, I'm dying to stop taking this medication. (E16)

The problem is coming here to take the medication, the tests take a long time, negligence, neglect, I think it's that. (E3)

However, the participants pointed out that these difficulties adhering to the treatment were not so relevant in view of the importance of the therapy and its free nature in terms of cost.

The potential and limits of health services in supporting treatment

As potentialities of the care received in the PHC units, the dialogue established between professionals and users and the support for treatment adherence were highlighted.

They're treating me well during this treatment. They always talk to me so I'm not ashamed to say what I need. (E21)

If it weren't for these boys here (professionals from the Street Medical Office), I wouldn't take the medication. I can't walk much because of my disease, so they bring me the tuberculosis medication every day, they help me want to take care of myself. (E25)

The bond established between professionals and users was understood as crucial for treatment continuity and for curing the disease.

The health agent always passes by, exchanges some ideas. She asked me for an exam, she brought me here to start the treatment. At first I thought about giving up, it was very difficult to walk to the center there, but it was she and the nurse that convinced me to continue, I'm grateful now, I'm much better. (E23)

Physician turnover was pointed out as a situation that hinders bonding and, consequently, exerts impacts on treatment adherence.

Before it was Doctor X [physician's name], he left, then it was doctor [physician's name], he left, now I'm with this other doctor there. (E17)

The participants also mentioned the prejudice and disrespect expressed by the professionals due to the fact that they live on the streets and have a TB diagnosis.

People here at the health center don't speak directly, but you feel it prejudice]. This is a serious thing, people that lives the way I'm living, on the streets and with tuberculosis, ain't respected anywhere, if they say they are, they're lying. (E9)

Negligence in the care of homeless users infected with TB was understood as a risk to life, as it exerts a direct impact on the diagnosis and treatment process.

This person can die due to the doctor's negligence, and if he waits longer, he'll die. It seems they don't believe what I'm feeling. (E3)

The participants' speeches also highlighted the role of the members of the Street Medical Office teams, such as the health agents who welcomed and established bonds with them, in order to ensure access to the health care network to meet other needs, transcending those of a biological scope.

They're treating me well during this treatment. They always talk to me so I'm not ashamed to say what I need. (Interviewee 21)

DISCUSSION

The results revealed challenges related to TB control in the context of life on the street, implicit through the perception of homeless people who were undergoing TB treatment. Despite the precarious subsistence conditions, the participants expressed a desire for a cure, accompanied by changes in the consumption of licit and illicit drugs, in the relationship with family members, and in the everyday routine of their personal life. The Street Medical Office teams were described as welcoming, as they provided a bond of trust between users and professionals and favored adherence to the treatment.

The precarious social and health conditions of homeless people are known, which in general are invisibilized and disregarded by the State and society, especially by those who control the social production processes. Expropriation of this marginalized class is materialized by the difficulty accessing fundamental rights such as housing, education, health, safety, income and other public services⁴.

TB is associated with homelessness and to the profound vulnerabilities of SP and more susceptibility to unfavorable outcomes is observed, including treatment abandonment and death¹³. A systematic review that aimed at analyzing the diverse evidence on the occurrence of TB in people living on the streets revealed that the unfavorable outcome of the treatment was more common in SP when compared to the population with a fixed address¹⁴. Thus, adherence to TB treatment is a challenge for the professionals working in the health services responsible for providing care to this population.

A research study on the perception of professionals from the Street Medical Office regarding actions against TB in SP evidenced that the difficulty adhering to the treatment was combined with the social vulnerability context and with the particularities of life on the streets. It also highlighted the bond and welcoming offered by the street workers and the flexibility of the health professionals' agenda as the main facilitating elements of the assistance provided. Due to their living conditions and to the fact that they are more prone to non-adherence to the treatment,

care strategies should be developed to cope with the disease, from actions of active search for respiratory symptoms to monitoring of these individuals in the health care network, as free access to medications and health services alone does not guarantee success of the treatment¹⁵.

The results highlighted that dialogue and the bond between professionals and users were fundamental for adherence to the treatment, as the participants felt supported for its continuity and conclusion. This relationship brought about new meanings to life, enabling a reduction or abandonment regarding use of licit and illicit drugs. Thus, treatment conclusion was pointed out as a stage that would make it possible to carry out plans, such as leaving life on the streets and reestablishing family ties¹⁶. In addition to that, the bond created between health professionals and users contributed to autonomy in decisions about their own health¹⁷⁻¹⁸.

SP care should not be imposed in a prescriptive and authoritarian way, but constructed considering people's social context and life history, so that they are the protagonists of their own care. Important elements are highlighted, such as the following: understanding homeless people, valuing network care and emancipatory care, in addition to valuing the health professionals who provide care¹⁹.

In this sense, care strategies and specific public policies must be established that favor sharing care between the health team and the users, as well as the urgent need to implement intersectoral actions to overcome the street situation as the only possibility of life for many people¹⁶. Care must not fragment the social aspects of the health practices; otherwise, the principle of integrality is neglected. There must also be no polarity between the "biological" and the "social" being²⁰. The intersectoriality of public policies for SP must involve strategies for social assistance, health, housing, work and income generation and educational opportunities, among others²¹.

The perception of the potential and limits of TB treatment with the SP corroborates the findings of another research study that revealed the following as positive aspects: creation of a bond, agreement and flexibility to supervise the drug therapy. On the other hand, the difficulty

commuting to the health service, the absence of social incentives to undergo the treatment and the difficulty following the treatment in another territory were seen as situations that may have interfered with treatment continuity²².

The way in which TB is still perceived is associated with the representation that the affected people are not citizens and that they do not have the right to a social place, to work and to a dignified life, as well as that they should be excluded and have their singularity abolished, evidencing violence of multiple dimensions³. For success of the treatment, challenges related to the health services are added, which, despite experiencing the reality of precarious social conditions, often do not seem to be prepared to recognize the health needs of SP²³⁻²⁴.

A research study carried out in Rio de Janeiro to understand the therapeutic path of people with TB and who lived on the streets showed the health professionals' unpreparedness to deal with SP, highlighting welcoming practices that fail to establish bonds, absence of qualified listening and adequacy of routines, and standards practiced by the services with these users. On the other hand, the work developed by the Street Medical Office was highlighted as positive²².

It is noted that the Street Medical Office represents an advance in the health care provided to SP, as the care practice recognizes the social determinants and the transforming potential from the bond established. These particular ways of practicing care go beyond the institutional barriers of the health system itself and overcome the absence of sectoral articulation across the public policies⁷. In addition, it can contribute to adherence to the TB treatment, as it allows for an approximation between homeless people and health professionals, who must be able to offer care without discrimination, associated with educational and harm reduction practices, and that consider the needs of this group²³.

A nationwide study on TB in SP revealed, for the period from 2014 to 2018, predominance of male, black-skinned, low-educated and economically active people. The treatment abandonment rate was 39% and can be related to the high rate of re-entry in the therapeutic regime and disease recurrence. In view of the results

found, the authors stated that TB in SP represents a marker of the violation of the right to health and highlighted the need for several points for the health care of this population, such as: strengthening and response capacity of the care and social assistance networks and actions that guarantee social repair and promotion of citizenship, in addition to others related to organization of the health services such as training for TB and awareness raising in health professionals²⁵.

In addition, SP presented a 50% lower probability of success in the TB treatment. Treatment abandonment and evolution to death were respectively 2.9 and 2.5 times higher in SP when compared to the general population. Vulnerability to TB calls for new tools capable of addressing the health care and health needs of this social group and strengthening intersectoral actions²⁶.

In view of that, it is considered that overcoming TB requires prioritizing investments in the health field, in addition to intersectoral articulation and development of public policies that combat social inequalities. It is also necessary to broaden understanding of the health-disease process as a social phenomenon and to recognize health needs, providing answers by the health services, but also by other sectors⁵.

With regard to prioritizing investments, it is important to note that Constitutional Amendment 95 of the Public Expenditure Ceiling, enacted in 2016, erroneously listed health and social security expenses as the cause of Brazil's fiscal imbalance. Consequently, this Amendment has further increased the health services' difficulty meeting the needs of the Unified Health System users, particularly SP²⁷.

The research results evidenced that TB cannot be understood as an isolated fact and without consequences for the collective, as the way in which this disease affects this population in particular materializes the social determination of the health-disease process. Consequently, the study contributes to the health area and to the knowledge about the potential and limits of the process of adherence to TB treatment with SP, reiterating that success of the treatment permeates the complexity of human existence.

It is understood that the research loci were only two BHUs from a single municipality represents

a study limitation. However, the relevance of the findings certainly brings about contributions to rethink the practices aimed at TB control in this social group.

The COVID-19 pandemic, ongoing since 2020, therefore, after collecting data for this study, highlighted the State's insufficiency in guaranteeing homeless people's basic life and health needs. The recommendations of social distancing, avoiding agglomerations, washing hands and wearing masks exposed the unhealthy living conditions and precariousness of many social devices for specific care, similar reasons that have challenged the fight against TB for years. Multiple strategies have been used to protect SP from COVID-19, with apparent success. However, the social crisis aggravated by the pandemic caused a significant increase in the number of people living on the streets and the consequences are still not fully known, even with regard to the TB treatment, object of this study.

FINAL CONSIDERATIONS

Knowing the homeless people' perception about the treatment of tuberculosis made it possible to identify challenges that need to be overcome. The following stand out among the main ones: the unhealthy conditions of life on the street that favor the disease and hinder adherence to the TB treatment and its conclusion, in addition to health services and professionals who are unaware of or ignore the specificities of this population. On the other hand, targeted public policies such as the Street Medical Office and the bond with trained health professionals were identified as facilitators and stimuli for maintaining treatment.

Tuberculosis in the street population must be understood from the perspective of the social determination of the health-disease process. On the other hand, challenges inherent to TB treatment regimes, living conditions on the streets and individual, collective and programmatic vulnerabilities of the services and public policies need to be considered in the elaboration of care strategies.

Finally, the research highlights the importance of the Unified Health System, especially the work developed by the Street Medical Office teams, to ensure access and care for homeless people.

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Received: oct 04, 2021 Approved: sep 02, 2022