

The carrier-being of tuberculosis in prisons: a nursing study

O ser-portador de tuberculose em prisões: um estudo de enfermagem

El ser-portador de tuberculosis en prisiones: un estudio de la enfermería

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ABSTRACT

Objective: Understand the daily life of the carrier-being of tuberculosis deprived of his freedom. **Methods:** The phenomenological research method and Martin Heidegger's hermeneutics were chosen for the analysis of twenty-two interviews of men living with tuberculosis in five prisons in the state of Pará, Brazil. **Results:** The results unveiled an intricate life in which patients see tuberculosis as a hard-to-accept condition, harder than confinement itself. **Conclusion:** The daily life of the carrier-being of tuberculosis deprived of freedom, though more specific, is not different from the manner all humans live: most of the time immerse into the daily life inauthentic way of being. To control tuberculosis in prisons it is necessary to deal with the singularities involving not only the disease process, but the dynamics of life in these places, most of the time characterized by hostility and violence in its different forms.

Keywords: Tuberculosis; Prisons; Nursing; Qualitative research.

RESUMO

Neste estudo objetivou-se compreender o cotidiano do ser-portador de tuberculose e privado de liberdade. **Métodos:** Optou-se pelo método fenomenológico de pesquisa e a hermenêutica de Martin Heidegger para a análise de 22 entrevistas de homens que vivem com tuberculose em cinco prisões do Estado do Pará, Brasil. **Resultados:** Os resultados desvelaram um cotidiano complexo no qual os doentes significam a doença como uma condição difícil de aceitar, mais difícil que o próprio confinamento. **Conclusão:** Conclui-se que o cotidiano do ser-portador e privado de liberdade, apesar de específico, não é diferente de como vivem todos os seres humanos, imersos na maior parte do tempo no modo cotidiano inautêntico de ser. Para controlar a tuberculose nas prisões, é necessário lidar com as singularidades que envolvem não apenas o processo saúde-doença, mas a dinâmica de vida nestes locais, caracterizada, na maioria das vezes, pela hostilidade e pela violência em suas diversas formas.

Palavras-chave: Tuberculose; Prisões; Enfermagem; Pesquisa qualitativa.

RESUMEN

Objetivo: Este estudio visó comprender la vida cotidiana del prisionero portador de tuberculosis. **Métodos:** Se eligió el método de investigación fenomenológica y hermenéutica de Martin Heidegger para el análisis de 22 entrevistas con hombres portadores de tuberculosis en cinco prisiones en el estado de Pará, Brasil. **Resultados:** Los resultados mostraron un cotidiano complejo en el cual los enfermos describen la tuberculosis como una condición difícil de aceptar, peor que la situación de reclusión. **Conclusión:** Se concluye que la vida con tuberculosis en prisiones no es diferente de la que llevan los otros seres humanos, inmersos la mayor parte del tiempo en un cotidiano inauténtico. Para el control de la enfermedad en las prisiones, es necesario lidiar con las singularidades que implican la dinámica de la vida en estos lugares, donde en la mayoría de los casos hay hostilidad y la violencia en sus múltiples formas.

Palabras-clave: Tuberculosis; Prisiones; Enfermería; Investigación cualitativa.

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INTRODUCTION

Of the tuberculosis cases diagnosed worldwide in 2011, Brazil was the 111th country in incidence level and 17th in number of cases among the 22 countries with the highest disease rates¹. In the same year, according to data from the Ministry of Health of Brazil, approximately 73.000 new cases were reported, representing a rate of 38.4 cases for every 100.000 people². Regarding the disease in the state of Pará, the incidence of approximately 49 cases per 100.000 people was the third among Brazilian states, preceded only by Rio de Janeiro and Amazonas.

In this same year, the city of Belém was confirmed as the second Brazilian capital city in incidence rates, preceded by Porto Alegre only². Given the importance of tuberculosis, World Health Organization declared it as a public health emergency in 1993, recommending strategies such as directly observed therapy to achieve the established goals^{2,3}.

Some groups are more susceptible to getting infected by tuberculosis. Of them, the group of persons deprived of liberty stands out - its average risk of infection is 27 times greater than that calculated for the general population in Brazil². In the state of Pará in 2011, the incidence rate of the disease was around 1.150/100.000 to a prison population of 12.000 people; i.e. a level 24 to 25 times greater than the incidence among the entire state population and approximately 32 times higher than the national population in the same year for the citizens in general⁴.

It is relevant to stress that the increasing prison population in different countries⁵ including Brazil⁶ contributes to the severity of the health problems of the people deprived of liberty, whose right to care should be guaranteed in a personalized and complete way at all levels of health care.

In this context, it is necessary for the nursing professionals to understand the everyday life of the deprived of liberty tuberculosis carrier-being, since it is precisely at the common everyday routine that a method to assist the singularity of this population can be achieved.

Despite this, it is noted the lack of bibliographic reference in Brazil on "health in prisons" subject⁷, as well as about tuberculosis-infected persons in this environment. So, for this study, we tried to unveil the way these people see and deal with in the everyday life of deprived of liberty tuberculosis carrier-being, since this knowledge about their way of living and facing the illness may produce benefits to the treatment, which is also about recognizing the differences on the others⁸.

Given the above, the objective of the study was to understand the daily life of the deprived of liberty tuberculosis carrier-being in an attempt to know the meanings related to their experiences and, with this, contribute to a Primary Care-related nursing practice that enables not only the control of the disease, but a quality health care to all of those who are confined in prisons.

METHOD

We chose to develop a qualitative-nature study based on phenomenology that as a philosophical method is an option to search for knowledge, for understanding the theory of knowledge and the essence of this knowledge^{9,10}. To analyze the results we opted for Martin Heidegger's hermeneutic phenomenology, since it allows the researcher to study the everyday life, and also the lived and experienced by the human being¹¹.

The "being", according to Heidegger, is universal and its concept cannot be defined or determined. To the author, this "being" concept is evidenced by itself and this is used in all knowledge or relationship. Due to the impossibility of defining it, the Heideggerian phenomenology treated the study of existential issues of this being, thus becoming ontology¹².

Every question, according to the philosopher, is based on three structures called poles: the questioned, which stands for what we question; the asked, what we ask about the questioned, and; the interviewed, the one we ask to obtain the questioned¹³. Per example: if one needs to know about the daily life in prisons (the questioned), how it is like (the asked), we interview the person deprived of liberty (the interviewed). In this way, the asked is the "being" sense while the questioned is the phenomenon to be known.

The understanding based on Heidegger Phenomenology is a path to reflection about a specific phenomenon and is founded on its interrogation and description, the moments when the researcher has the possibility to search for the factual life interpretation^{9,10,12,13}. This interpretation, or hermeneutics, which in its Greek origin means clarify, translate, bring the message, represents a new understanding, this time of what is hidden, not obvious about people, the world in which they live, their history and their existence¹¹⁻¹³.

This research was conducted in five prisons of Pará Penitentiary System Superintendence, which concentrate the majority of people with tuberculosis and are located in the two largest prison complexes in the state, in the cities of Santa Isabel do Pará and Marituba, both in Belém metropolitan area. All these prisons are for male prisoners only, and those who were sick by tuberculosis were invited by the researcher to participate in the study. Invitation was made during private meeting, where the participant had an explanation about the study, its objectives and its importance, and also ensured the autonomy of participants to accept the proposal or not. At this meeting the Terms of Consent were signed and recordings of the interviews were authorized.

Twenty-two people were interviewed. The inclusion criteria were: being deprived of liberty, being infected by tuberculosis and being under treatment. Meetings for phenomenological interviews¹⁴ were conducted at nursing clinics, office and visiting rooms, and were guided by a script with the following main question: How is the daily life of the patients of tuberculosis deprived of liberty? Interviews were concluded when no more

information was given, therefore, the sample size followed the data saturation criteria, and data was collected in the period between November 2011 and February 2012.

It is relevant to inform that none of the interviews was performed with patient handcuffed, since it's important in any phenomenological research offer peace and tranquility in order to develop empathy for a conversation, through standing at the same interest dimension of these people¹⁴. Each participant was willing to express himself, even the less talkative ones. At that moment, into their way of being, they let to be known because of their discourse.

Discourses took in average 25 minutes each, were entirely transcript and analyzed in two stages, as performed in similar studies¹⁵: vague and median understanding or comprehensive analysis, which represents the most simple and immediate understanding about the phenomena. In this stage, through close readings of the stories we identified the most relevant topics to the participants, and from this we organized a Single Unit of Meaning with three subunits. In the second stage, there is the interpretation or hermeneutics, based on the concepts described by Heidegger in his Being and Time¹³ (Ser e Tempo, in Portuguese) work, in which he sought the deep sense that bases the everyday life of the carrier-being of tuberculosis deprived of liberty.

This study complied with the principles of ethics in research with humans, regulated in Brazil by Resolution 196/96 of the National Health Council. The speeches of the participants were identified by the letter E, standing for "Interviewed" ("Entrevistado", in Portuguese) followed by the number assigned to each one, sequentially. The research was submitted for analysis of Ethics in Research Committee of Magalhães Barata Nursing School from Pará State University, and approved by the authorization protocol number 0054.0.321.000-11.

RESULTS

Comprehensive Analysis

Meaning Unit - Living with tuberculosis in prisons.

Subunit 1 - Disease as a confinement consequence

When interrogated about their experience of living with tuberculosis in prisons, the participants told, from the confirmed diagnosis, how they bethink their life inside and outside these spaces, pointing some reasons for their illness. The first of these reasons is related to the confinement hard conditions like the cold temperatures at night, bad alimentation and lack of autonomy to take care of themselves.

Another explanation is the association with legal and illegal drug use into prisons, a habit that deteriorates organism defenses and creates or stimulates drug physical and chemical addiction. The third reason is the belief in a penitence imposed by God by previous crimes, as a possibility of paying for their mistakes, as noted in the speeches:

[...] I think I got this disease because I got grounded into prison [...] We have no mattress there [...] I passed a month sleeping on a stone, got it? [...] (E13).

[...] if I hadn't smoke weed... because this was the ultimate thing to cause me this disease, tuberculosis [...] I believe God allowed this disease to come and act into my life [...] and no one can play with God, right? (E7).

[...] I'm aware that I'm paying for the mistake I made [...] (E19).

Subunit 2 - Tuberculosis brings feelings that affect and limit daily life among the others

Patients in prisons experience hard feelings such as shame, embarrassment, sadness and segregation; they have their daily life gradually changed as the symptoms progress, since at the beginning they still could attend to the common spaces for sunbathing, play ball and other perform activities. They lose weight, feel pain, tiredness, weakness and have no strength for leisure:

[...] if you pay attention, it brings just destruction, torment, crying... just this[...] (E7).

[...] my daily routine was different, I didn't have the same freedom for the things I used to do [...] I feel ashamed [...]. Before this, I used to play ball, I used to do a lot of things [...] but after, I was too tired, couldn't stop coughing, got feeling seasick, it forced my throat, and got worse if tried to run! [...] (E16).

[...] The daily life was hard... I used to lay down, had no strength to walk. I was too weak, too slim, I was even spitting blood! [...] (E20).

The severity of tuberculosis and physical and emotional consequences of the illness weaken the persons and causes them to experiment conflicting feelings, like dying to get rid of the disease or accept treatment to avoid death:

[...] I had to be satisfied with that thing the person was telling me, but in my mind, I really wanted to kill myself [...] they told me it was curable, but to me, at that moment, I wanted to end it quick, kill me and kill it too [...] (E2).

[...] I got tormented [...] I got tormented, because it's a disease that kills you a little at a time, I got scared, thinking I was going to die [...] (E18).

The desire to die seems to be for some tuberculosis patients deprived of liberty the opportunity they have to stop their physical and social suffering. On the other hand, knowing that the disease can kill makes some to want to get treated immediately and avoid this ending.

For the person with tuberculosis in prisons, most of the time, the illness is experienced with loneliness, which is expressed by the absence of family and friends and the removal of cellmates, who, feeling threatened by the disease become distant to avoid the risk of being infected. Another kind of isolation is given by order of professionals or from the prison unit management, for the treatment to be carried out in a "safe" environment for the patient:

[...] in my daily life, it was me to myself, right? Because there is a lot of prejudice [...] there are so many people with prejudice, they are afraid to be infected, right? (E17).

[...] we have to go to nursing room, we have to be isolated or you may infect them [...] it's a very bad contempt, got it? [...] (E13).

Despite this social isolation, the patient also imposes himself a distance from others, for fear of transmitting tuberculosis to family and colleagues. He prefers to suffer alone to feel guilty for infecting other people close to him, especially those emotionally tied to him; it is easier to get distant from them, away from their sight and their judgment, accepting himself as a "different" person:

[...] my daily life in such a way I decided to be distant, to be with myself, to think in what I want... It made me think more about life [...] (E5).

[...] I used to feel different... Different because I was lived virtually alone, got it? I had nothing, had no contact with anybody [...] (E14).

Subunit 3 - Daily life in prisons demands to patient defensive behaviors as survival resource

Way of life in prisons contribute to that the people deprived of liberty have limited access to health care, which does not seem to be different for those who are sick, because even if they still need assistance and monitoring during the treatment, these people choose to respect the "law of silence" imposed on prison environments to reduce their communication with professionals and avoid being recognized as informers and unworthy to receive respect from others:

[...] I got limits, right? Because many people think (low voice) that going upstairs here (go to nursing room) is the way to "snitch" (denounce) things [...] so we can't keep getting up here, got it? That's why sometimes I refuse to come here, because here we live in a village among 29 thieves inside here [...] so we must respect the space of all of them to be respected [...] (E2).

Some patients believe it is necessary to lie about their tuberculosis diagnosis, replacing the disease by other conditions

that may be better accepted by the prison population, cardiac pathologies, for example. This behavior for the patient is a care with himself, since he states that the others do not care about his life:

[...] there are the guys (other prisoners) [...] if they know something like this [...] I tell them I got a heart condition and this medicine is for my heart [...] I'm afraid they beat me up there inside [...] (E3).

Avoid being known as a tuberculosis patient seems to be for the person deprived of liberty a protection action against threats and aggressions that may cause harm to their physical and moral integrity or which may cause his death.

DISCUSSION

Hermeneutics

After the vague and median understanding we sought to grasp how the people with tuberculosis in prisons experience their daily life facing this illness and what meaning is revealed in his speeches about the studied phenomenon. This sense, according to Heidegger, is almost always hidden, is a support for the understandability and is related to the possibility of something being conceived as what it really is in essence and not only as apparently shown to be¹³.

To understand the deep sense that bases the everyday life of the carrier-being of tuberculosis deprived of liberty we searched their ways to interact with their world. Through their speeches, and even in the moments of silence, we saw that life in prison has a very particular way, with rules, specific limits and hostile personal relationships, in which the main challenge is almost always to stay alive. In everyday life, the person deprived of liberty turns his look and interests to the dynamics of what is in prisons: drug use, the need of demonstrating power and strength, and the desire to be close to the strongest ones.

The everyday way of life of a person defines his routine of existence in the world. It is how we are most of the time, living day after day in a way not defined, not autonomous, not distinctive in relation to others, normal, ordinary, predictable, inevitable, public and necessary, characterizing a dependence on world, and the monotony of the sequence of events in the past, present and future¹³.

In everyday life, people who live with tuberculosis in prisons do not want to be different. Being different is not a benefit to them, because the difference established by the disease makes them less worthy people, socially and physically less strong in front of the groups, less useful and also less human in a way. A similar thing happens with the carrier-being of tuberculosis outside these spaces, since the disease causes changes in personal, family and social life, moving the carrier away from the usual living with the others¹⁵.

To be seen as equal to the others, patients in prisons are always fleeing from the differences, threats, penalties, transgression of certain rules and even from diseases. They realize their possibilities of being from the possibilities of those who live among them, suppressing their own choices and their existence from and for themselves, building an inauthentic way of being.

Heidegger termed as inauthentic the way of one not being himself, which it is not a way of being mistaken, false or illusory, but the way we all almost always remain: the everyday way of occupation and preoccupation, essential to our own presence while existence^{12,13}. The inauthentic way of being limits the self understanding and interpretation facing the world and even if one says: I think I do, I am, one thinks, does and is from the others, in the way which each individual becomes accessible in a multitude of the "we"¹³.

Being a patient with tuberculosis deprived of liberty is to almost always need to justify to himself and to those living among him why he is sick; it is to be anchored in a Mid-understanding, which can occur in the ambiguity mode of being which daily manifests itself in different ways. The median and ambiguous understanding is, for example, the behavior of the other that sometimes show solidarity to the patient, sometimes rejection.

In the ambiguity way of being it is possible to reside what characterizes and segregates the carrier of tuberculosis inside and outside the prisons, because maybe there is no other way of everyday life in which the understanding of the disease by the patient himself turns to be as this, where tuberculosis is perceived as an evil that steals, that anguish, that hurts and that can lead to death, but also as a good, that take him away from drugs, that brings religiosity, that brings the opportunity to redeem himself from his mistakes and become a better person and that can give access to certain concessions in prisons, which no one could have when not sick.

According to Heidegger, the ambiguity is the possibility of improper interpretation and understanding of the phenomena, with alternatives and meanings that generally exclude each other^{12,16}. The ambiguity extends to the being-in-the-world, to the being-with-others and to the being-oneself and into daily life it creates conflicts in the relations with the others, unveiling the being-one against the other in life together¹³.

In the ambiguous way of living, the carrier of tuberculosis in prisons understands the disease as something that could not be avoided, since it occurs as a consequence of its own existence and it is it, for him, beyond any of his desires and possibilities. Thus, given the limitations imposed to him, either by disease or by the rules of social coexistence in prison, the patient feels lost, alone and sad and, as a result, his being gets opened and shown as the fear.

The fear for Heidegger is always about what is in the world, about the threat that keeps the possibility of always being removed, extinguished and has the character of approach, because staying away does not seem to be in itself threatening, which consequently disrupts the fear^{13,17}.

The everyday fear of the carrier of tuberculosis deprived of liberty is the real possibility of losing himself, of not being able to care for his life, his activities, of not having somebody to count on, and not being able to help others. Tuberculosis symbolizes a social death and therefore disables the patient for socializing with others, keeping on him a fear for the loss of the being-with-others, which is in a way anticipated by his loneliness and isolation in which he lives.

In the prisons, this fear is fed by the very nature of imprisonment, whose goal is to separate people from living in society, contradicting, somehow, the nature of human existence, in which the being-with and being-with-others is, according to Heidegger, an essential way of being to link the man to the world^{13,16}.

To the carrier of tuberculosis deprived of liberty, the disease almost always brings to the everyday life a despair that, together with the physical weakness, encourages him to seek the end of his suffering, to reflect on some possibilities to overcome the disease and in an inauthentic of being he may desire his own death, since he understands that life in prison is not having a life somehow.

These considerations allow us to state that the living with tuberculosis in prisons does not occur in a common daily life, but in an own specificity and singularity, which make this experience perhaps unique. To ensure the rights of access to health services in prison, to the patient with tuberculosis is not enough only to be sick, but also to be recognized by his group as someone trustworthy and who deserves attention and care, someone who can travel into other spaces and live closer to health care professionals and security without acting as an informant about what happens into prison, because in most cases an informer, considered a traitor, is punished to death.

In this way, defensive behaviors such as refusing to be go into nursing area or lying about his diagnosis are taken as needed by the patient who does not feel protected by and in the group. For some of these people, the others whom they live do not care about their life, even those who once were seen as companions in prison. In everyday life, many of these partners get distant and their inauthentic ways of being run from the disease and the possibilities it represents.

Being a carrier of tuberculosis and deprived of freedom is to accept the rules imposed in the daily life and to recognize the relations of existing forces, especially those within the prison population, with favors and duties shared between groups, through which respect and rights are only achieved by who is submissive to the prison order.

CONCLUSION

This research allowed us to explore the understanding about the everyday life experienced by persons with tuberculosis in prisons that, although specific, in a sense, is no different to the living of all human beings, immersed most of the time in the everyday way of being that characterizes the inauthentic way of man.

In his inauthentic way of being, the carrier of tuberculosis deprived of liberty is immersed in a multitude of occupations, which keeps him in a state of escape from himself and prevents him from assuming the possibilities of an own being-more state. In his daily sufferings and limitations, his existence is characterized as thrown into the world of impersonality.

In his impersonal way of being he believes to know his possibilities and impossibilities; behaves as others expect him to behave, as it is a way to protect and assert himself socially since prisons are environments where it is important to be strong to live with the others, where the behaviors are molded from the dynamics of the everyday life, in which there are specific rules to be accepted into the groups, to be considered worthy of respect and to receive any benefit, whether in favor of his health or to ensure his survival.

For the patient with tuberculosis, surviving with the disease in a prison intricate everyday proves to be a hard condition to accept, almost always harder than the confinement itself. Therefore, to control the disease in these areas is necessary to deal with the singularities that involve not only the health-disease process, but the dynamics of life in prison, which is most often characterized by hostility and violence in its many forms.

This control of tuberculosis in prisons means preventing its transmission to everybody in society, considering that people come in and out of these spaces all the time. Entering, they can take the disease can to others who are deprived of freedom; when leaving, the transmission can occur for anyone considered "free".

There is still a lot to be known about the health of prisoners in Brazil, considering the limitations of this study, which may be related to the small number of participants and to the subjective aspects that characterize each experience as unique, making it impossible to generalize the results. However, it contributes to knowledge about the subject and enables us to state that care practices supported by the principles of the Brazilian Health System enables professionals to position themselves in an available way for the integral care of people afflicted with tuberculosis, regarding their individualities, being them inside or outside prisons.

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