MEANINGS OF THE CORPOREAL EXPERIENCES OF PEOPLE WITH PULMONARY TUBERCULOSIS: THE CONSTRUCTION OF A NEW IDENTITY¹

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- ¹ Article extracted from the dissertation Meanings of the experience of the illness of people with tuberculosis, presented at the Postgraduate Program in Nursing, *Universidade Federal de Pelotas* (UFPel), in 2015.
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ABSTRACT

Objective: to understand the meanings of the corporeal experiences of people being treated for pulmonary tuberculosis.

Method: qualitative research, carried out in the municipality of Pelotas, Rio Grande do Sul, Brazil. The theoretical reference of Anthropology in Health by Byron Good was used. Semi-structured interviews were conducted with ten people in the second phase of the treatment for tuberculosis, in their residences, between April and May 2015. For the analysis of the data, the Thematic Content Analysis technique was used.

Results: two categories have emerged: The body signaling the disease that reveals itself in the presence of symptoms (fever, weight loss, weakness) and The sick body that manifests suffering, fear, stigma and distancing.

Conclusion: the presence of tuberculosis in the body is capable of generating apprehension, disruption of leisure and work activities, and distancing from family and social life. It is essential to develop a look at care, to understand the unique needs of those who experience the illness, to value their life history and their subjectivity.

DESCRITPTORS: Pulmonary Tuberculosis. Life-changing events. Body. Stigma. Patients.

SIGNIFICADOS DAS EXPERIÊNCIAS CORPORAIS DE PESSOAS COM TUBERCULOSE PULMONAR: A CONSTRUÇÃO DE UMA NOVA IDENTIDADE

RESUMO

Objetivo: compreender os significados das experiências corporais de pessoas em tratamento para tuberculose pulmonar.

Método: pesquisa qualitativa, realizada no município de Pelotas, Estado do Rio Grande do Sul, Brasil. Utilizou-se o referencial teórico da Antropologia em Saúde de Byron Good. Foram realizadas entrevistas semiestruturadas com dez pessoas na segunda fase de tratamento para a tuberculose, em seus domicílios, entre abril e maio de 2015. Para a análise dos dados empregou-se a técnica de Análise de Conteúdo Temática.

Resultados: apreenderam-se duas categorias: O corpo sinalizador da doença que se revela na presença de sintomas (febre, emagrecimento, fraqueza) e O corpo doente que manifesta sofrimento, temor, estigma e afastamento.

Conclusão: a presença da tuberculose no corpo é capaz de gerar apreensão, rompimento das atividades de lazer e trabalho, afastamento do convívio familiar e social. É essencial desenvolver um olhar para o cuidado, compreender as necessidades singulares de quem vive o adoecimento, valorizar a sua história de vida e a sua subjetividade.

DESCRITORES: Tuberculose pulmonar. Acontecimentos que mudam a vida. Corpo. Estigma. Pacientes.

SIGNIFICADOS DE LAS EXPERIENCIAS CORPORALES DE PERSONAS CON TUBERCULOSIS PULMONAR: LA CONSTRUCCIÓN DE UNA NUEVA IDENTIDAD

RESUMEN

Objetivo: comprender los significados de las experiencias corporales de personas en tratamiento por tuberculosis pulmonar.

Método: investigación cualitativa realizada en el municipio de Pelotas, Estado do Rio Grande do Sul, en Brasil. Se utilizó el referente teórico de la Antropología en Salud de Byron Good. Se llevaron a cabo entrevistas semiestructuradas con diez personas en la segunda fase del tratamiento para la tuberculosis, en sus domicilios, entre Abril y Mayo del 2015. Para el análisis de los datos se usó la técnica de Análisis del Contenido Temático.

Resultados: dos categorías surgieron: El cuerpo señalador de la enfermedad que se revela a través de la presencia de síntomas (fiebre, pérdida de peso, debilidad) y El cuerpo enfermo que manifiesta sufrimiento, temor, estigma y alejamiento.

Conclusión: la presencia de la tuberculosis en el cuerpo es capaz de generar aprehensión, finalizar las actividades de placer y trabajo, alejamiento del convivio familiar y social. Es esencial desarrollar una conciencia para el cuidado, comprender las necesidades singulares de quién padece esta enfermedad, valorizar su historia de vida y su subjetividad.

DESCRIPTORES: Tuberculosis pulmonar. Acontecimientos que mudan la vida. Cuerpo. Estigma. Pacientes.

INTRODUCTION

The persistence of tuberculosis as an emergency public health problem in developing countries, with emphasis on Brazil, makes it a disease feared by its contagion risk and by the strong stigma that generates suffering in the family, in addition to the risk of becoming ill in the community and its burden on the health system. The problem of tuberculosis is due to the fact that this is a disease that should be under control, however, its relationship with precarious social conditions makes it a difficult health problem to be solved.

To advance in the disease control, the commitment of the society and its government is necessary; this commitment must be based on a joint action, seeking to eradicate the misery, hunger, and the bad housing conditions of poor people.³ Somehow, it is essential to consider the individual and subjective dimension in order to understand the illness and its impact on people's lives, families, health services, and society. Health policies and actions based on this perspective tend to impact the detection and the cure of the disease.²

In this sense, studies that make it possible to know, understand and interpret the meanings of the individual experience in tuberculosis are relevant. Thus, from the personal experiences arise the meanings of the sick body, consequence of a subjective reality for those who live with the illness.

A study about the illness experience, which intends to understand the subjective, social and cultural dimensions of the disease as important factors for the recognition of the complex phenomenon of the experience.⁴

The illness is full of meanings that are always present for those who experience it, however, the

way people attribute these meanings has a direct relationship with their individual and social identity. The effects of the disease on the body and the events that occur in people's lives as a result of the illness are constant marks in their lives and transform their routines.

The body, besides being a physical object, is also the creative agent of experiences and represents different meanings and values for those who live. When people go through this experience, there is the singularization and detachment of the conditions of life that preceded the disease.⁶

The moment when the illness is discovered brings uncertainties, suffering and resignification about the body and the new health condition, which results in actions to confront the disease through the search or not for care in the health services. In this sense, it is essential to produce knowledge about experiences and their meanings in people's lives, which aim at contributing to the recognition of the need to base health actions on the individuality of each individual and to interfere in the process of illness that may have an impact on the disease control.

From this perspective, it is questioned: What meanings do people with tuberculosis attribute to their experiences of illness? In order to answer this question, the present study aimed at understanding the meanings of the corporeal experiences of people under treatment for pulmonary tuberculosis.

METHOD

This is a qualitative study that used the theoretical reference of anthropology in health to understand the meaning of the corporeal experiences in people's illness.⁵ This theoretical reference is based

on the understanding of the experiences of people under treatment for tuberculosis.

The illness experience is produced from the body, generating several meanings for the discovery, treatment and cure. Thus, the body is understood as a global phenomenon, which represents the basis of experience and intentionality in a given context.⁷⁻⁹

The study was carried out with ten people under treatment for pulmonary tuberculosis from a Tuberculosis Control Program, in the city of Pelotas, RS, in southern Brazil. The Program is considered a reference in the treatment of the disease, both for the city and for the 22 neighboring municipalities, and it carries out the monitoring of the person and their relatives until the cure of the disease.

For the identification and selection of the study participants, a search of information was carried out in the medical records and in the form of the National System of Notification of Injuries (SINAN - Sistema Nacional de Notificação de Agravos). The selection criteria were: to be in the second phase of the treatment for tuberculosis (in the four last months, corresponding to the standard pharmacological treatment that lasts six months), and to be over 18 years old. Nobody with extra pulmonary tuberculosis, hospitalized or those deprived of liberty were included. The inclusion criterion in relation to the period of treatment is due to the understanding that from this period the subjects have more experience about their illness.

After collecting information to identify and select the study participants, a telephone call was made to each one of them, in order to know if they would be interested in participating in the study. If they were interested in participating, a meeting would be scheduled, according to the availability of the person regarding the day, time and, place for the interview.

The data collection was performed in the participant's homes, through semi-structured interviews, with an average duration of 40 minutes, between April and May 2015, and guided by the following questions: What was it like getting sick with tuberculosis? Talk about your treatment for tuberculosis. Talk about your family, how long have you been sick? How did you feel in the health service?

The number of participants was not predetermined, since it was necessary to obtain the contents that would allow the achievement of the study objective. Thus, we decided to conclude the interviews when a repetition in the speeches was identified. This process is based on the understanding that in qualitative studies the researcher is more concerned with the deepening, comprehensiveness and adversity in the process of understanding the group to be investigated.¹⁰

Before data collection, a pilot study was conducted with five people who were not included in the data analysis. In this way, the interview script was validated regarding the understanding of the guiding questions of the study.

The data were analyzed from the thematic content analysis process, which includes the phase of pre-analysis, material exploration, and treatment of results. ¹¹ In the first phase, the *corpus* of the study was constituted. This phase corresponded to 10 interviews, organized according to an analytical framework for grouping them, and composed of columns distributed to the left, containing the numerical order of 1 to 10; and to the right the fictitious names of the participants and the original material of the speeches. In this way, the participants' anonymity was respected.

In the material exploration phase, exhaustive readings of the interviews were carried out, and the recording units were determined; that is, words, phrases or paragraphs related to the content and context (tuberculosis, body, experience, changes, stigma), and the two analytical categories that guided the third stage of the study. The last stage of treatment of the results corresponds to the interpretation of the data, which in this study resulted in two thematic categories: the body signaling the disease and the sick body.

The research was approved by the Research Ethics Committee of the Medical School of the Federal University of Pelotas (968.466/2015), in accordance with the Resolution N. 466/2012, conducted in accordance with the ethical standards required. The participants signed the Free and Informed Consent Term and also had their anonymity respected, being identified by fictitious names.

RESULTS

The findings of this study indicate that the participants manifested a variety of meanings attributed to the illness experiences, and that the sick body signaled several symptoms, as well as the breakdown of social relations and distancing. The categories show the repercussion of a body that suffers due to the presence of the disease, and because of the changes imposed by tuberculosis due to a long treatment, which produces new meanings to the body.

The body signaling the disease

For the participants, the body signaling the disease refers to the presence of cough, backache, vomiting, weight loss, fever, tiredness and shortness of breath. Signs that have caused physical, emotional, and social changes in the people's lives and in their family environment. For them, the signaling body meant that something was wrong with their body, changing their daily routine of work, relationships, affection, leisure, eating habits, sleep, and locomotion.

According to Claudia, the body signaling the disease prevented her from working and continuing the life she had lived until then; weakness and pain in her legs made walking difficult. The body has acquired a meaning of absolute exhaustion due to the fact that it does not support its current physical condition. [...] It's the second time, I started with a lot of cough, cough, cough. Then I started to lose weight, to lose weight, but I have always been thin, I have never reached 50 kg, but now I weight 40 kg, can you imagine? I was feeling weak, weak legs, walked and felt pain in the legs, very tired, and I had no strength to walk. I immediately stopped working and could not take it anymore (Claudia).

For Marco and Maia, what signaled changes in the body were the sleeping disorders. Marco reveals his difficulty in sleeping due to sweating and excessive sputum. Maia reveals other signs that affected her sleep, in addition to what had been reported by Marco: "backache", "pain in the lungs", "vomiting", and "headache". I weighed 70 kg, I did not sleep at night, and when I slept, it was bad, I woke up sweating and had to take off all the clothes and, in a matter of seconds, it was already cold and I had to put everything back on. So it was not good, this experience was very bad. The sputum problem, I was spitting very hard. (Marco).

The symptoms are terrible. You cannot sleep at night; it is an unbearable pain, in the front, in the back and in everything. Some days I could not sleep, I would feel a pain in the lungs, in the right lung and I would spend all night groaning in pain. I would vomit everything I ate. Sometimes, every time I would eat, I would think, 'Am I going to eat or will I not eat? If I do not eat I will dehydrate and if I eat, I will vomit'. It is a horrible headache, the coughing never ends. I had night sweats, I'd come home from work super cold, everyone was feeling hot and I covered myself with two blankets folded in two and changed my blouse three times in the middle of the night. And the symptoms are terrible, it's terrible (Maia).

Mateus reports the presence of a body signaling the disease marked by the lack of air, fever, and excessive tiredness, which changed his feeding and

locomotion. These events prevented him from performing simple activities such as eating and walking. I lost a lot of weight, I was weighing 67 kg but my weight was 94 kg. I felt a great lack of air. The chest pain increased, the pain continued. [...] I felt very bad, I had a lot of fever, and I felt very bad. [...] I use to cough a lot, I used to have a lot of back pain, I did not use to eat, at work, we have coffee breaks, I did not use to eat anything, I was always tired, I was crawling. [...] fever every day, I used to feel so tired that I could not even walk from here to there, it seems that I was dying and I felt very weak, so I do not recommend it to anyone. It's awful (Mateus).

Differently from the other interviewees, for Julia, the signaling body, according to her experience, did not alert her to tuberculosis. She possibly associated that the flu triggered tuberculosis. It started with a flu and I did not care much, then the flu passed and the cough stayed, I did not know what it was. I was treating myself as if it were an infection that took the lung, and that it was not tuberculosis (Julia).

Maia recognized the disease; however, she did not want to believe in the possibility of tuberculosis. Her body signaling the disease meant the denial of tuberculosis. And everyone said it was a not properly healed flu or pneumonia, but all the symptoms pointed to tuberculosis, and they say the worst blind is the one who does not want to see, and I did not want to believe it (Maia).

The body signaling the disease was in the presence of symptoms (fever, weight loss, weakness), then, people perceived these symptoms as warning signs or identified that there was something wrong, that until then they had not felt in their bodies. From this, personal, social and economic transformations were unveiled. Feeling the impact of the physical changes caused by the symptoms of tuberculosis has changed their daily activities, those that are essential for a decent life and for the maintenance of the well-being, such as walking, being able to feed yourself, having a quality sleep pattern, being able to relate to family and social surroundings, as well as giving and receiving love through those relationships and breaking the bond with work.

The sick body

For the study participants, the sick body meant that having tuberculosis was being recognized as someone who poses a risk to the health of others, distancing from family and friends, and subtle changes in the family relationships, especially concerning the daily activities, mainly by the separation of the household items, which are symbolic and daily shared by all.

The separation of objects (household items) is still present in the imagination of many people. The participants attribute ambivalent meanings to the act of separating such objects, because, at the same time as this attitude indicates care towards the other, it also promotes stigma, expressing the lack of full social acceptance as shown in the testimony of Paula and Jeremias: There was that situation of separating the things, because I was sick and I shared everything from the kitchen, plates, glasses, cutlery. I have all my things separated until today, because there is a risk, right? you can get it. I have a small child and I can pass the disease on to him. That's why I chose to separate the dishes (Paula).

My family was terrified because I got this disease, and they separated the cutlery and these things so as not to get infected. My wife washed the cutlery well, everything separated, and she never got it (Jeremias).

In Laureano's opinion, when performing his dialysis treatment at another health service, the sick body meant suffering due to the rupture of the relationships with the health team, lack of interaction, dialogue, and the distancing of the professionals from the unit. Laureano also reveals the inadequate professional approach in the care of people with tuberculosis: the professionals are poorly informed about the disease, they do not know anything about tuberculosis: most people who treated me for tuberculosis do not know anything about the disease, especially here at the hospital [Hemodialysis Unit] for disrespect and disorganization. Here, for someone to talk to you is a struggle, when they found out that I had tuberculosis they did not want to come and talk to me, no one cares about you, it is a fight for people to call you, a huge argument every day. [...] they are poorly informed about what tuberculosis is. [...] Three years later, instead of raising the level of the hospital, the hospital came back decades ago. [...] within the hospital they still treat it as complicated, they do not know the meaning of the disease (Laureano).

According to some participants, the sick body meant something undesirable through the eyes of their own relatives, which led people to be excluded from their social relations. The meaning of loneliness and feelings of exclusion for Julia aroused heartache and depression. The sick body imposes physical segregation and lack of affection to her life. My son's godfather used to come to our house before my illness. After he discovered that I had tuberculosis, he would not let his children come here, and when they came, they would come to the door and stay three meters away from me, it hurts and I became depressed because of that (Julia).

The meaning of the family members' distancing had an impact on the emotional state of Maia, who felt dissatisfied with the stigma of the disease in

the family, which generated the distancing of close people (nephews) and others more distant from the family nucleus. She also feels upset for the need of being away from work. However, Maia had to deal with the distancing of the family members in a positive way, understanding them, since such attitudes were related to the protection of the family members and the fear of contagion. From time to time, I was upset because I like children and my sister would ask the children to go somewhere else in the house. No one came near me because I was sick. [...] one of my uncles walked away because he always came to see my grandmother and then he did not come anymore. At first, I was upset, then I did not care anymore, I do not need him anyway. [...] when people walked away, then I understood (Maia).

In the case of Claudia, the body sick from tuberculosis meant self-isolation, that is, this act was voluntary. This attitude was justified by the concern of transmitting tuberculosis to her relatives, because she avoided being close to her children: I always wanted to be more alone in the first month, which is said to be the most dangerous, that's when we start taking the medicine, I was very careful not to touch my children (Claudia).

The sick body meant the perception of collective health risk to the participants, due to the fear of transmitting the disease to relatives, friends and community. There was a distancing of the social relations, since many relatives, when they have found out about the tuberculosis diagnosis, began to isolate the patient, maintaining no contact during the treatment period, generating a break in the intra-family relationships, such as living with nephews and uncles, enhancing the presence of the stigma in the society. The isolation was also revealed by the action of separating the household items (glasses, cutlery, beds), forcing people to eat and to sleep separately from other members. In addition, the self-isolation was mentioned as a way to protect the children, with the purpose of avoiding the transmission of the disease in the first days of treatment.

The results, presented in two different categories, evoke the sense of experiencing the tuberculosis: the disease that presupposes the life condemnation, which imposes the limitation of life, physical and social, imposed by it and its treatment. The experience was suffering and limiting. The sense of experiencing the illness due to tuberculosis was manifested through the signaling body, characterized by symptoms that altered the daily life of people and the simplest activities of life, work, study and leisure. The sick body was translated into the fear of the tuberculosis contagion, social distanc-

ing, changes in the relationships, persistence of the stigma, separation of utensils, isolation, and self-isolation. This has caused the breaking of bonds and the transformation of the lives of all those involved, especially those who suffered from the disease.

DISCUSSION

The body is the physical and subjective agent of the experience, from which meanings and actions are produced, therefore, it is the creative source of the experience of life, health and illness.⁷⁻⁹ In the present study, the body with tuberculosis produced several meanings, which changed over time and over the course of treatment. If people initially experienced a period of limitations, both physical and emotional, they also felt positive changes due to the treatment, creating effective strategies to overcome the difficult moments and envisioning a new life.

The first meaning of the body with tuberculosis is reported by the study participants through the physical distress by the presence of symptoms as also identified in other studies. ¹²⁻¹³ These symptoms are frequent in a body that signals that something is organically in disarray, and it reveals the flourishing of feelings, sensations and emotions of a new reality: having and living with tuberculosis.

Therefore, it is understood that the disease is experienced through the body, yet it is not simply a physical object or physiological state, but an essential part of the self.⁹ Thus, the body (physical object) cannot be differentiated from states of consciousness.

Although the meanings are built from the daily life, from previous experiences, and from the experiences of each one, the signaling body manifested itself from the construction of a reality that is common to this social group.⁷⁻⁹ This reality refers to people who had as meaning for the signaling body symptoms as cough, backache, vomiting, weight loss, fever, tiredness, and shortness of breath; signaling that there was something wrong and disrupting their daily activities.

People are ashamed of having tuberculosis, and associate the disease with something bad and disturbing, with the attribution of the term 'dirty disease'. ¹⁴ These meanings, which have an unpleasant connotation, are present in this study, especially when the participants Maia and Mateus reveal that their family members have distanced from them or separated household items after discovering the disease. The mystification of tuberculosis and the prejudice associated with it can be clearly observed then.

In this case, there is a popular distinction between the world of the objective reality and that of the subjective experience, which ends up reflecting on the social and political body. This means that the corporeal experiences, in addition to intersubjective meanings, reflect experiences of illness and social practices that channel the behavior of being and feeling sick.

A research, whose objective was to understand the nurse's commitment to care for the person with tuberculosis, demonstrated that this professional is able to help the person to be free of the fear of the disease, breaking prejudices and stigmas. Thus, it is essential that all the professionals are committed to helping the patient recover in a less painful way and, above all, to influence the family to encourage the person with tuberculosis in the face of illness.¹⁵

The meaning of the sick body results in permanent social isolation, because people stop having contact with the social environment, precisely because they are sick. Julia went through this experience when she revealed that she felt isolated due to the rejection and distancing suffered by her uncle, who, after discovering her niece's illness, changed his behavior and moved away from her.

The sick body meant living with a new identity, which is deteriorated by the aspects of prejudice and isolation, which are socially constructed and perpetuated in the imaginary of people. This identity arises because of tuberculosis and its physical, emotional, social and historical multidimension, permeated by a particular way of being in the world, based on previous experiences and social influences.

The findings collaborated with other studies in pointing to isolation, self-isolation, stigma and distancing from the social life of people with tuberculosis. ¹⁶⁻¹⁸ The experience of the sick body, for Maia, was strongly constituted of signs of detachment from her relatives, revealing a context characterized by the distancing of the family against the supportive attitude, so necessary for the copying with the disease, characterizing the presence of the stigma.

Emphasis is placed on the nurses' concern about overcoming the stigma, prejudice, and rejection that still exists in many contexts, both within families and among friends, and in the work of people with tuberculosis. This was made up of actions and efforts to help people realize that those were baseless concepts.¹⁵

It should be highlighted the effort of nurses not to isolate the person with the disease or make them feel inferior because they have a communicable disease. ¹⁵ Thus, several participants in this study, if they had

received guidance and support from the professionals, as guidelines to the person and his family about what should, in fact, be done in the home, putting away myths such as totally isolating the person affected by the disease, the outcome of many anxieties and fears would have turned into moments of peace .

It was identified the multiplicity of feelings that permeates the life path of people with tuberculosis. 18-22 The emotions and feelings mentioned in studies are: shock, self-discrimination, fear of infection risk, crying, doubts about diagnosis and treatment, feeling of shame, and the need to keep the disease a secret. 14-18 In the present study, the disturbance, isolation, rejection, and sadness were the feelings and emotions revealed by Paula, Julia, Maia and Laureano.

A study on quality of life showed changes that occurred in the lives of people with tuberculosis; half of the people reported that the disease affected the movements to walk long distances and health issues that have caused difficulties for daily activities and to work.²³ This aspect has also been identified in the speeches of Claudia and Mateus, in their experiences of the body signaling the disease, in which they mentioned difficulties to walk, making simple daily tasks impossible.

Another study revealed the physical impact of tuberculosis on body experiences, which made the adherence to the pharmacological treatment difficult due to the presence of debilitating symptoms. ¹⁶ These physical symptoms were also reported by Mateus and Maia in the present study.

A study carried out in a developed country, where tuberculosis is not a threat to the public health, has shown that people with the disease have requested their resignation from the workplace so there would be no investigation of the presence of tuberculosis among colleagues.²⁴ In Claudia's experience, the presence of the disease meant self-isolation, mainly due to the concern of transmitting the disease to other people. In this way, it is identified that the common reality associated with the disease is fear, shame, and the constant concern and care not to transmit the disease.

A study with professionals and students who became ill with tuberculosis showed the presence of stigma, self-segregation, and defense mechanisms, such as denial, isolation and concealment of the disease. ¹⁶ The sick body means living with the disease, dealing continuously and variably with this unknown world of having tuberculosis.

For people who experience tuberculosis, there are several feelings and consequences of getting sick,

this process is multifaceted. The disease at a time is hidden, it is discriminating. It can be touchable in any *status quo*, however, each person will feel their illness differently and create a range of meanings.

CONCLUSION

The analysis and interpretation of the study data pointed to two thematic categories: the body signaling the disease and the sick body, revealing the repercussion of tuberculosis in the lives of people and their families, such as: transformation in family, social and work life, fear, rejection and insecurity.

People referred to the sick body as a transforming experience, attributing to it meanings in the sense of daily readaptation to the new life condition, choices and decisions. The meanings have also allowed to identify the way people are perceived in society, before and after the presence of the disease.

The corporeal experiences were strongly influenced by the subjectivity of people (previous experiences, experienced and socialized by common sense, beyond the particular universe of beliefs, values and cultural aspects). Therefore, they should be understood as an issue that transcends the merely biological aspect.

There is no doubt that the meanings attributed to the body in the presence of the disease may influence the person's self-care and their co-participation in relation to the diagnosis and treatment of tuberculosis. Feelings of fear and shame, as well as the stigma and prejudice that still exist in the imaginary of people can cause the delay in the search for the health services for the diagnosis of the disease.

Although the corporeal experiences resulting from the condition of having tuberculosis point to physical changes of the body due to the disease, the meanings of the participants extrapolate these experiences. They produce meanings in the social and affective dimension. There are experiences in all their sensory modalities, which are the result of listening to others, of observing the distancing of people, and of the impossibility of touching.

The study pointed as a methodological limitation the subjectivity of the researcher, which implies the risk of loss of objectivity and influence in the analysis and interpretation of the statements. Moreover, the understanding of the other and their reality may be reduced to something that involves the introspection of the researcher himself, based on his familiarity, estrangement, something said, done, celebrated, or crystallized.

It is suggested for future research the valuation of the person (patient) and health service (professionals) in order to identify a reality in which the needs of the health service context and the particular dimension of people would be known. Thus, it will be possible to think about changing and/or overcoming the prejudice and the distancing that still permeates the care process in the health services.

Acknowledgement

To those people who have experienced tuberculosis and have had their lives transformed by disease and that, even while facing this moment of ruptures, were willing to share their experiences of illness, making possible the construction of this research. To FAPERGS for the contribution of the financial resources for the elaboration of the research.

REFERENCES

- 1. World Health Organization (WHO). Global tuberculosis report 2013: WHO report 2013 [internet]. Geneva (CH): 2016 [cited 2016 Apr 08]. Available from: apps.who.int/iris/bitstream/10665/91355/1/9789241564656_eng.pdf
- 2. Piller RVB. Epidemiologia da tuberculose. Pulmão RJ [internet]. 2012 [cited 2016 Apr 07]; 21(1):4-9. Available from: sopterj.com. br/profissionais/_revista/2012/n_01/02.pdf
- 3. Barreto ML, Teixeira MG, Bastos FI, Ximenes RAA, Barata RB, Rodrigues LC, et al. Sucessos e fracassos no controle de doenças infecciosas no Brasil: o contexto social e ambiental, políticas, intervenções e necessidades de pesquisa. Lancet [internet]. 2011 [cited 2016 Mar 07]; 6(3):47-60. Available from: http://bvsms.saude.gov.br/bvs/artigos/artigo_saude_brasil 3.pdf
- 4. Charmaz K. From the "sick role" to stories of the self: understanding the self in illness. In: Ashmore RD, Contrada RA. Self and identity: interdisciplinary explorations in physical health. New York (NY): Oxford University Press; 1999.
- Conrad P. The experience of illness: recent and news directions. In: Roth JA, Conrad P. Research in the Sociology of Health Care. Connecticut (CT): JAI Press; 1987.
- Gadamer HG. O mistério da saúde: o cuidado da saúde e a arte da medicina. Porto (PT): Edições 70; 2002.
- 7. Good BJ. Medicina, racionalidad y experiencia: una experiencia antropológica. Barcelona (ES): Edición Bellaterra; 2003.
- 8. Dodor EA. The feelings and experiences of patients with tuberculosis in the Sekondi-Takoradi metropolitan district: implications for TB control

- efforts. Ghana Med J [internet]. 2012 [cited 2016 Mar 15]; 46(4):211-8. Available from: http://www.ncbi.nlm.nih.gov/pubmed/23661839
- 9. Good BJ. Medicine, rationality and experience: an anthropological perspective. Cambridge (ENG): Cambridge University Press; 1994.
- Deslauriers JP, Keriset M. O delineamento de pesquisa qualitativa. In: Poupart JA. Pesquisa qualitativa: enfoques epistemológicos e metodológicos. Rio de Janeiro (RJ): Vozes; 2008.
- 11. Bardin L. Análise de conteúdo. São Paulo (SP): Edições 70; 2011.
- 12. Cirino AC, Juskevicius LF, Alves H, Silva WV. Aspectos emocionais vivenciados por pacientes portadores de tuberculose. Rev Paul Enfermagem [internet]. 2009 [cited 2016 Apr 01]; 28(2):50-5. Available from: http://bases.bireme.br/cgi-bin/wxislind.exe/iah/online/?IsisScript=iah/iah.xis&src=google&base=LILACS&lang=p&nextAction=lnk&exprSearch=755295&indexSearch=ID
- 13. Silva JB, Cardoso GCP, Netto AR, Kritski AL. Os significados da comorbidade para os pacientes vivendo com TB/HIV: repercussões no tratamento. Physis [internet]. 2015 [cited 2016 Mar 11]; 25(1):209-29. Available from: www.scielo.br/pdf/physis/v25n1/0103-7331-physis-25-01-00209.pdf
- 14. Juniarti N, Evans DA. Qualitative review: the stigma of tuberculosis. J Clin Nurs [internet]. 2011 [cited 2016 Mar 22]; 20(13-14):1961-70. Available from: http://www.ncbi.nlm.nih.gov/pubmed/21040040
- 15. Cavalcante, EFO, Silva, DMGV. O compromisso do enfermeiro com o cuidado à pessoa com tuberculose. Texto Contexto Enferm [internet]. 2016 [cited 2016 May 26]; 25(3):5-10. Avaiable from: http://dx.doi.org/10.1590/0104-07072016003930015.
- 16. Andrade EDT, Hennington ÉA, Siqueira HRD, Rolla VC, Mannarino C. Perspectives of Patients, Doctors and Medical Students at a Public University Hospital in Rio de Janeiro Regarding Tuberculosis and Therapeutic Adherence. PLoS One [internet]. 2015 [cited 2016 Feb 25]; 10(9):1-17. Available from: http://journals.plos.org/plosone/article?id=10.1371/journal.pone.013757
- 17. Mohammed S, Nagla S, Morten S, Asma E, Arja A. Illness perceptions and quality of life among tuberculosis patients in Gezira, Sudan. Afr Health Sci [internet]. 2015 [cited 2016 Abr 07]; 15(2):385-93. Available from: http://www.ncbi.nlm.nih.gov/pubmed/26124783
- 18. Dodor EA. The feelings and experiences of patients with tuberculosis in the Sekondi-Takoradi metropolitan district: implications for control efforts. Ghana Med J [internet]. 2012 [cited 2016 Mar 15]; 46(4):211-8. Available from: http://www.ncbi.nlm.nih.gov/pubmed/23661839
- 19. Basu G, Chatterjee C, Singh R, Biswas S. Prevalence of depression in tuberculosis patients: an experience

- from a DOTS clinic. IJRRMS [internet]. 2012 [cited 2016 Mar 15]; 2(4):1-4. Available from: http://www.ijrrms.com/pdf/2012/oct-dec-12-pdf/04.pdf
- Nunes TTS. A tuberculose em Kafka: corpo, escrita, vida e morte. Pulmão RJ [internet]. 2007 [cited 2016 Mar 26]; 16(2-4):111-13. Available from: sopterj.com. br/profissionais/_revista/2007/n_02-04/12.pdf
- 21. Duarte LFD, Leal OF. Doença, sofrimento, perturbação: perspectivas etnográficas. Rio de Janeiro (RJ): FIOCRUZ; 1998.
- Baral SC, Karki DK, Newell JN. Causes of stigma and discrimination associated with tuberculosis in Nepal: a qualitative study. BMC Public Health [internet]. 2007 [cited 2016 Mar 27]; 16(7):211. Available from: http://

- www.ncbi.nlm.nih.gov/pubmed/17705841
- 23. Farias SNP, Medeiros CRS, Paz EPA, Lobo AJS, Helman LGG. Integralidade no cuidado: estudo da qualidade de vida dos usuários com tuberculose. Esc Anna Nery [Internet]. 2013 [cited 2017 Dec 22]; 17(4):749-54. Available from: http://www.scielo.br/pdf/ean/v17n4/1414-8145-ean-17-04-0749.pdf
- 24. Faccini M, Cantoni S, Ciconali G, Filipponi MT, Mainardi G, Marino AF, et al. Tuberculosis-related stigma leading to an incomplete contact investigation in a low-incidence country. Epidemiol Infect [internet]. 2015 [cited 2016 Mar 22]; 143(13):2841-8. Available from: http://www.ncbi.nlm.nih.gov/pubmed/25600903