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# The experience of tuberculosis treatment in Family Health Units

## *A vivência do tratamento de tuberculose em unidades de Saúde da Família*

## *La experiencia del tratamiento de tuberculosis en unidades de Salud de la Familia*

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## ABSTRACT

**Objectives:** To understand the experience of patients having tuberculosis regarding the care received during treatment and their relationship with health professionals. **Method**: Phenomenological research carried out with 27 tuberculosis patients in Family Health Strategy Units in the city of Rio de Janeiro. The data were obtained through interviews analyzed by Heidegger's referential. **Results**: The analysis of the discourses evidenced that the users are disposed in the mode of being of the inauthenticity characteristic of health services; the existential fear of death dominates the daily lives of the patients and it keeps them following the treatment. **Final considerations and Implications for the practice**: There is the possibility of performing a care, which integrates the technical knowledge able to dominate the way of being of professionals with the subjective dimension of those who need treatment, overcoming the ontic tradition of inauthentic care for the authentic care, which frees the other for the healing.

**Keywords:** Tuberculosis; Nursing; Family Health Strategy.

## RESUMO

**Objetivo**: Compreender a vivência dos portadores de tuberculose referente aos cuidados recebidos durante o tratamento e sua relação com os profissionais de saúde. **Método**: Pesquisa fenomenológica realizada com 27 portadores de tuberculose em unidades de Estratégia de Saúde da Família do município do Rio de Janeiro. Os dados foram obtidos por meio de entrevistas analisadas pelo referencial Heideggeriano. **Resultados**: A análise evidenciou que os usuários estão dispostos no modo de ser da inautenticidade característica dos serviços de saúde; o temor existencial da morte domina o cotidiano dos doentes e os mantêm seguindo o tratamento. **Considerações finais e implicações para a prática**: Existe a possibilidade de se efetivar um cuidado que integre o conhecimento técnico capaz de dominar o modo de ser dos profissionais na dimensão subjetiva de quem precisa do tratamento, superando a tradição ôntica do cuidado inautêntico para o cuidado autêntico, que libera o outro para a cura.

**Palavras-chave:** Tuberculose; Enfermagem; Estratégia Saúde da Família.

## RESUMEN

**Objetivos:** Comprender la vivencia de los portadores de tuberculosis referentes a los cuidados recibidos durante el tratamiento y su relación con los profesionales de salud. **Método:** Investigación fenomenológica realizada con 27 portadores de tuberculosis en unidades de Salud de la Familia del municipio de Rio de Janeiro. Los datos fueron obtenidos por medio de entrevistas analizadas con referencial Heideggeriano. **Resultados**: El análisis de los discursos evidenció que los usuarios están dispuestos en el modo-de-ser de la inautenticidad característico de los servicios de salud; el temor existencial de la muerte es lo que domina el cotidiano de los enfermos y los mantiene siguiendo el tratamiento. **Consideraciones finales e implicaciones para la práctica**: Existe la posibilidad de realizar un cuidado que integre el conocimiento técnico que domina el modo-de-ser de los profesionales con la dimensión subjetiva de quien necesita el tratamiento, superando la tradición óntica de un cuidado inauténtico para el cuidado auténtico que libera al otro para la curación.

**Palabras clave:** Tuberculosis; Enfermería; Estrategia Salud de la Familia.

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## INTRODUCTION

Tuberculosis is the main communicable infectious disease, surpassing AIDS as the leading cause of death in the world. It is a social problem, affecting mainly the most vulnerable who live in poorly ventilated places, with clusters of people who have information and access to health difficulties.[1,2]

The World Health Organization estimates that, in 2017, there were 10 million incident cases of tuberculosis, the fourth leading cause of death from infectious diseases and the leading cause of death in patients with Acquired Immunodeficiency Syndrome (AIDS). In the same year, 1.3 million people died and 300,000 people were infected by the HIV virus.[1,3]

In 2017, 69,569 new cases of the disease and 4,426,000 deaths from tuberculosis were reported in Brazil; in Rio de Janeiro, for the same year, 5,770 new cases were reported. The municipality had an incidence rate of 88.5/100.000 inhabitants, higher than the incidence rate of the country, of 33.5/100.000 hab.[1-3]

Despite the achievements in tuberculosis control over the past decade, one of the main challenges in coping with this disease is maintaining adherence to treatment. This led to the recommendation to adopt the Directly Observed Treatment Short-Course (DOTS), in 1994, in countries with high tuberculosis burden, which began in Brazil in 1998.[2] The DOTS strategy consists of five pillars, which include: medication supervision; the political commitment of countries; the guarantee of laboratory tests for diagnosis; the continuity of medication supply; and a system of evaluation and monitoring.[1,2,4]

Even with the adoption of DOTS, Brazil has been taking other actions recommended by the World Health Organization to make this global response possible, as was most recently done by the End TB Strategy, which aims to end the global tuberculosis epidemic, with goals to reduce new cases in 90% and tuberculosis deaths in 95% until 2035.[1,5]

Adherence to treatment is a multidimensional phenomenon, with several associated factors, such as the conception of the disease, the treatment itself, the relationship between the health system and professionals.[6] It is worth considering that the scientific and cultural conceptions of health professionals do not always come close to those presented by health service users, which influence their behaviors. Each person experiences a particular illness and treatment process, which can be obstacles to the success of treatment and the consequent reduction in the number of cases in the population.[6,7]

A bibliographic survey was carried out in the Latin American and Caribbean Health Sciences Literature (LILACS), Scientific Electronic Library Online (SciELO) and in the Online Medical Literature Search and Analysis System (MEDLINE), for the period of 2007 to 2018, aiming to know the qualitative scientific production in health about tuberculosis and the state of the art about the experience of treatment of people with tuberculosis. It was established, as criteria for bibliographic investigation, to be an original article of national and international origin, published in Portuguese, Spanish and/or English that addressed the treatment of tuberculosis from the perspective of patients. A total of 127 articles were identified, and nine met the established criteria. Of the nine selected, four used the phenomenological research method and Martin Heidegger's hermeneutics for the analysis of the material.

In general, qualitative studies have shown, in their results, that sociocultural aspects influence therapeutic adherence and coping with the disease. Phenomenological studies have revealed that, in the process of treating tuberculosis, the social imaginary of the disease reinforces for the patient the anguish, the guilt for falling ill and the social withdrawal imposed by the diagnosis. They also indicated that in the treatment process, despite the difficulties that the disease imposes, the person can take an existential turn that makes him or her accept the illness and go towards the cure, in which the support of health professionals plays a fundamental role.[7-10]

Despite several nursing studies on the subject of tuberculosis using different methodological approaches, the issue of adherence to treatment remains important and still little known, as it is a particular experience lived in multiple and different contexts, which requires the construction of affective bonds with health professionals.[6-8] These ties seem to be diluted in the care context due to the routines that work processes impose on professionals. Nevertheless, treating and clinically curing a chronic disease such as tuberculosis is an experience that cannot be generalized.[10,11]

It is in this perspective of giving voice to the person who experiences the course of tuberculosis treatment that this study is justified and complements the knowledge about the existential dynamics of a treatment. That is, even today, it is the technical-scientific possibility to overcome the disease and recover the naturalness as a person, because adherence cannot be focused exclusively on the patient, the offer and supervision of drug regimens.

Moreover, the nurse being the professional who in primary health care services assumes the monitoring of the actions recommended by the Tuberculosis Control Program, studies that favor the knowledge of the patients' personal dynamics and enable the use of strategies aimed at the uniqueness of people are important to increase the effectiveness of health and nursing care.[12]

Given the above, the objective of the research was to understand the experience of patients with tuberculosis regarding the necessary care during treatment, in units of Family Health Strategy in the city of Rio de Janeiro.

## METHODOLOGY

To know the care dynamics of treating and caring for people with tuberculosis, we chose phenomenology as a resource to access the social reality of treatment of this disease, conducted in primary health units, such as family health. Phenomenology seeks to describe the phenomena that involve the individual from the interrogations and questionings of what remains veiled in daily life, in an attempt to understand the other, considering them in their singularities – that is, men in his existential wholeness – and questions their experiences in order to know their meanings.[13,14]

Martin Heidegger's phenomenology was chosen as the theoretical-methodological framework, as it sought to understand the treatment of tuberculosis for patients, considering that its meaning is hidden by the daily naturalness present in care services and fulfilled at home. It is an interactive relationship between who takes care of, who receives the care and the way it is lived in everyday life, thus being an experience that gives meaning to existence.[15,16]

Heideggerian phenomenology brings in its core the question of the Being that we are, the Dasein. For the author, the term means men from the relationship he establishes with his being.[15] The problem of Being is not only its existence – the way it presents himself in the world – but his essence, the meaning that is hidden, hidden in appearances, in the daily way of being as it makes himself known. It is in this conception that relationships happen and relational experiences have meaning and sense. The philosopher developed his existential analytic, interrogating the meaning of Being, which reveals both being-there and being-there in the world, immersed in occupations that allow him to understand life, relationships and the possibilities of fulfillment.[14,15]

This research was conducted with people who were undergoing treatment for tuberculosis in five Family Health Strategy units, located in the northern area of Rio de Janeiro. Participated in the study 27 people diagnosed with pulmonary tuberculosis, who met the following inclusion criteria: over 18 years old registered at the unit; using the basic scheme for the treatment of tuberculosis and; being in the last month of treatment, which could be the sixth month of the standard regimen or up to the ninth month if the treatment was extended due to irregularity in medication taking or clinical/laboratory criteria.

In compliance with ethical aspects, the research was approved by the Research Ethics Committee of the Anna Nery School of Nursing/Universidade Federal do Rio de Janeiro, according to Opinion No. 839,730, and the Research Ethics Committee of the Municipal Health Secretariat of Rio de Janeiro, under favorable Opinion No. 857,488.

After approval by the Committees, data collection began, which took place from December 2014 to March 2015. The phenomenological interview was the way of access to interviewees, using a semi-structured interview script containing items for the characterization of the participants and questions that addressed the experience of tuberculosis treatment.

The interviews took place in a private room at the unit or at the residence, according to the user's preference, and on previously scheduled days and times. It was sought to make clear to users the concrete interest in the particular experience of their treatment, respecting the way they expressed themselves, without formulating value judgments from the established dialogue. When the interviews took place at the residence, support was obtained from the micro area Community Health Agent to enter the community, without him being present during data collection.

All interviews were recorded, with consent, and transcribed, according to the original speech, and were completed when all survey participants were interviewed. Anonymity was guaranteed by their coding with the letter U of user and numbered according to the order in which they were performed.

To understand the participants' experience about the treatment of tuberculosis, a comprehensive analysis or phenomenological interpretation was performed. Heidegger says that in the understanding lies the foundation for interpretation. The previous conception, in the case of tuberculosis, refers to what is already known about it, the treatment, its side effects, the care needs and other fundamentals. Thus, the new understandings of the phenomenon transcend what is immediately shown in the existence of the human being, in an interpretation of his attitudes and the way he experiences the world and himself.[13,15]

The analysis proposed by Martin Heidegger took place in two methodical moments: the first began with the vague and median understanding, which is that of the deponent when asked about what one wants to know. That is, what comes immediately to consciousness, the most familiar, the immediate understanding that houses the meaning that starts from common sense, but hides its meaning.[15,17] Firstly, several readings of the interview speeches were made, moment in time which the researchers, free from any assumptions, identified the meanings expressed by individuals with tuberculosis, organizing them into meaning units with a general statement, whose content presented the common excerpts of the speeches that illustrated the answers to the questions formulated in the interview.

In the second moment, it was proceeded to hermeneutics, that is, the interpretation of the meanings of the treatment of tuberculosis, hidden in the meanings attributed by the research participants. This stage was supported by excerpts from Heidegger's philosophical thinking contained in his work Being and Time and articles on the topic.[13,15-17]

## RESULTS

Regarding the characterization of the participants, 15 were male and 12 female, whose ages ranged from 20-59 years. Twenty participants declared themselves black. Regarding education, nine had incomplete elementary school and seven had incomplete high school. At the time of the interview, 16 participants were unemployed.

Regarding the hermeneutics of the transcribed interviews, three meaning units were produced, expressing the classification and grouping, by similarities and divergences, of the meanings attributed by the research participants. These units conform the discursive block, which expresses the understanding that individuals with tuberculosis have about themselves and the disease during the course of treatment followed in Family Health Units (Chart 1).

The first unit of meaning expresses human frailty in the diagnosis of tuberculosis. Being with tuberculosis is a difficult experience to be understood, accepted and lived, because the idea that it can still lead to death remains. In the collective imagination, fear of the disease is justified by social stigma, ignorance of its causes, long treatment and the association of tuberculosis with behavior that deviates from social norms. When

**Chart 1.** Presentation of meaning units.

| Meaning Units | Extracts from the Speech |
|---|---|
| The diagnosis of tuberculosis brings fragility before life | *At first, I was scared as hell, I thought I was going to die, that something worse would happen. I already knew tuberculosis at its worst* (U5). |
| | *We start thinking it is an evil disease and we will die. I thought of my daughters, my husband* [...] *I don't wish to anyone the fear I experienced when I discovered this disease* (U22). |
| | *It was a huge scare because I thought tuberculosis would only happen to underprivileged people. I have a good diet, I don't smoke and I don't drink and I do physical activity. My house is ventilated and I don't live in community. So, I don't know why I got this disease* (U25). |
| | *I never thought that I would have tuberculosis, for me it was a disease of the past, extinct [...]. My grandfather was bohemian, drank, smoked and lived without worries, he died of this disease. I don't do any of that and I got it. I can't say how, but I got it* (U23). |
| The impersonality of the health service makes the treatment very difficult | [...] *you have that obligation to come to the center every day and take bunch of medicine, which is not easy. But, having to come here every day to take medicine is boring!* [...] *The bad thing is having to wait for them to give me the medicine... and they want to see me taking it... have you seen that?! They think I'm a child* (U11). |
| | [...] *sometimes you can't even blame the agents, in this case the agents who are responsible for giving the medication. You leave home or work, get here to have the medicine or even to take the medicine, and then what happens?* [...] *starts that feeling of discouragement, because you have to wait* [...] *then the girl says "wait there I'll get it". Then another person arrives and she has to pay attention to that person and I, we both end up waiting* (U2). |
| | *Now I'm the one who picks it up at the clinic. But it's boring because it's never the same person who attends me and I have to wait for the girl to get my medicine. Sometimes there are a lot of people in front of me to talk to her and I have to keep waiting* [...] (U7). |
| | [...] *at this time the unit is closed and she didn't want to give me the medicine for a week. Finally, it had to be almost a fight for her (professional) to accept it. If I had a weak head, I would have long stopped taking the medicine! People sometimes have to be flexible with situations. There was no point in her sending the CHA to my home at six o'clock in the morning* (U25). |
| Feeling supported by professionals makes a difference in the course of treatment | *It was the staff* (emphasis), *they stay by you side for you to take the medicine! I thought that was bad, but today I recognize that sometimes it's necessary. If it wasn't for the nurse, maybe today I wouldn't be well and finishing the treatment. She made me realize that I also have to want to be healed* (U19). |
| | [...] *at first, when I was afraid, they helped me, both the doctor and the nurse. They said I was not going to die and that if I took the medicine every day until the end, I would be healed. Then it encouraged me, I ... I was already thinking that I was going to die* [...] (U10). |
| | *What helped me continue were the doctor's explanations of the disease. I never imagined that we caught it in the air, that we didn't need to separate things and above all the faith in GOD that I was going to be healed* (U21) |
| | *What helped was to see that they care about us. Every time I had some problems I could come here without the appointment, that they would always attend me* (U23). |

it reaches men, tuberculosis takes away the force that keeps him active in his social environment. Society in general still retains many representations that have made it one of the most feared diseases of all time. Individuals affected by tuberculosis suffer not only from clinical manifestations, but mainly due to the death resulting from falling ill from such a serious disease.

The second unit points out that for people diagnosed with tuberculosis, staying under treatment as directed by the health professional is almost always very difficult, as it requires routine attendance at the health unit. For participants, it is not always possible to combine attendance for the treatment directly observed in the health unit with work, due to the little flexibility of hours in health services.

In general, the units do not consider that the user has a life routine that can make such attendance unfeasible. There was also an absence of an organization that favors the rapid availability of medication as soon as users arrive at health services. Supervision of medication intake also adds difficulties to treatment.

However, the third unit of meaning demonstrates that individuals with tuberculosis recognize that the support of professionals in the difficulties inherent to drug treatment is one of the most important actions for the acceptance and continuity of therapy. The attention they receive from professionals, the interest they show in their recovery, favors the acceptance of treatment and can positively alter decisions about health maintenance.

Even when a person expresses a desire to discontinue treatment, they might not go on with such desire because of the trust and bond established with the healthcare professional. The health team is an important care resource that stimulates the completeness of treatment. Users feel supported by their caregivers and confident that they will overcome the disease and the difficulties it imposes on them.

## DISCUSSION

Getting sick is an existential possibility of the human being in the world and a unique experience, because it refers to the alteration of their naturalness as a person, placing, in a different world, those who need to perform behaviors that can restore the health they lost.[6,11]

The units of meaning showed that the treatment of tuberculosis affects the lives of people affected since the diagnostic confirmation. Knowing oneself sick with tuberculosis immediately brings death closer due to a disease that does not even pass through the imagination. With it comes the stigma that one has to live in social isolation to protect family, acquaintances and friends, thus preventing the transmission of the disease.

In addition, the impersonality of the technical norms that guide the treatment, when not flexible to the patients, generates discontent, which can lead to therapeutic abandonment. Schedules and routines that do not foresee the needs of patients and their difficulties are factors that distance the team professionals, because they do not put themselves in the perspective of the other – they just follow the traditional care, which mischaracterizes the uniqueness of each one –, making him one more who is in the service to receive care and therefore must accept the established rules.

Despite the problems of organization of care, the interest of professionals for the restoration of health positively marks the long period of treatment, as they can show concern for the health of patients by stimulating, encouraging and offering appropriate management of complications. Informing clearly about the therapeutic process creates bonds of confidence that help overcome difficulties, and patients recognize how important those ties are.

Unit I showed the negative force and impact of the diagnosis of tuberculosis, as the disease takes on the dimension of social punishment. Isolation with withdrawal from family and friends, depression and unwillingness to follow treatment are difficult feelings to overcome due to the stigma of the disease, which is still strong enough to immediately remove the naturalness of social living.

Other studies also confirm these findings, since they identified the diagnosis of tuberculosis as one of the main causes of stigmatization, and emphasize that the lack of knowledge about the disease can strengthen discriminatory attitudes in the family and community.[6,7,11,18,19]

In interpreting the facticity of the condition of being with tuberculosis and the necessary treatment, it was possible to identify in the reports the fragility of being-there in the face of tuberculosis. The disease is a threat that has become concrete, and the patients, even in treatment, live with the fear of death that dominates the being-there, the Dasein and characterizes the force of talking.[15]

Concerning fear, Heidegger says that "…what is feared has the character of the threat… what is feared comes to meet because it has the circumstantial mode of harm… Fear confuses and makes you lose your mind..." and presents for the being a world full of threats, such as the physical limitations caused by illness, social exclusion and the fear of death.[11,13,15,20]

Speaking means a phenomenon that constitutes the way of understanding and of quotidian interpretation.[14,15] This pronunciation of communication refers to the coexistence that moves within a common speech, but this communication is not presented in the mode of an original appropriation and is content to repeat and pass on the speech, lacking solidity.

It is observed in Unit II that, in daily care, the relationship between technical knowledge and individualized practice is not always harmonious, because the routine of services does not favor the exchange of subjectivities between those who care and who receives or needs care.[11,20] In seeking the end of their suffering, there is the possibility of the person finding barriers in the health service, which reinforce the impersonal nature of care, despite the commitment to treat the patient. In the speeches, it was observed that professionals are destined to fulfill what they were prepared for: to diagnose, treat and cure clinically, following routines and schedules that do not often meet people's needs.[7,17]

Impersonality is felt by the being diagnosed with tuberculosis, as for the lack of confidence of professionals regarding the taking of medication in a space other than the health unit, since many did not have the option to take it home. Similar results pointed to the precariousness of care and access difficulties as possible causes of non-adherence to treatment, including the long waiting time as a factor of dissatisfaction with the health service, and it does not favor the team to put itself at the same horizon as the other; that is, the patient who has as objective the healing.[6-11,20,21]

In Heidegger, one sees that impersonality usually dominates the relations between men and that, although it is one of their ways of being, it is not the proper way of dealing between them. Although dispersed in a family environment, as are the health units with routines and care procedures presented to patients as soon as they begin their treatments, the Dasein, by delivering themselves to these routines, allows the obscuring of their most-self-being.[10,11,15-17,20,21]

Thus, the Dasein, dispersed in the mode of impersonality, is characterized by being absorbed in the world that comes to him

and presents himself with the character of familiarity. In view of this, every immediate interpretation of the world phenomenon and its own being-in-the-world ends up being determined by this impersonal interpretation. The gap in the professional-patient relationship points to the need to take into consideration the patient's thinking and feeling, and not just the horizon of clinical healing, making it necessary to implement effective actions by health and nursing professionals who accompany the person through the course of the disease in relation to community guidelines on tuberculosis, prevention, family management and achieving the cure.[16,22]

It was observed in the speeches that only the supervision of the medication does not guarantee the success of the treatment. It is necessary for the patient to feel welcomed, to consider his/her life history, beliefs and opinions.[6,9-11] Thus, strategies for adherence to treatment must be agreed upon so that the being affected by tuberculosis can assume treatment and, by admitting it, decide on the possibility of healing and reintegration into their daily life.[10,11,20,21]

Unit III shows that, despite the impersonal mode that reigns in health services, the opposite also occurs; that is, the opportunity of authentic care, which provides the understanding of the patient's experience by professionals. In this meeting, there is the possibility of them striving in order for the person to understand the disease and assisting them in the decision to follow the treatment.

By sharing with the patient the coping with the disease and the difficulties inherent to drug treatment, the professional approaches the being-there of his patient, living with him a special situation, and may, in this relationship, show more and more interest and consideration for the other; that is, worrying and caring in the broad sense of the word.[14,16-18,21,22] Even when the person with tuberculosis expresses a desire to interrupt treatment, this situation may not materialize due to the support and link created between the user and the health professional. This openness to the other enables the more proper performing of the humanity of men – who dialogues and does not dominate – and can transcend the technical care based on normative aspects.[7,8,16,17]

According to Heidegger, men is not alone in the world, being-in-the-world is always being-with others.15 Thus, the being diagnosed with tuberculosis recognizes the co-presence of professionals and values it as essential to their treatment and believes that by overcoming occasional difficulties, will regain the solidity of the essential structure of their existence, the being-with.[10,11,20,21]

## FINAL CONSIDERATIONS AND IMPLICATIONS FOR THE PRACTICE

By unveiling the experience of being-there treated with tuberculosis, it was found that it is disposed in the way of being of the impersonality characteristic of health services. Such indications point out important directions that imply rethinking the care offered in the family health units of the municipality. Despite the impersonality and operational limitations of the care routines in the units, people with tuberculosis value the care received. Health professionals were identified as important elements of the support network to relieve the pain and fear resulting from the disease process.

The study revealed that the strengthening of the bond and the welcoming by the health team are factors that can contribute to the success of the treatment, as they are conditions that allow the patient to transcend his facticities and difficulties in search of cure of the disease, unveiling his authentic mode to live in the face of tuberculosis and its treatment.

In this sense, Nursing can greatly contribute, given its participation in the daily routine of primary health services, favoring access to them – the moment of dose supervision, the examination of contacts, in health education actions in the community and in actions to expand coverage in care programs, such as of tuberculosis control, performing care guided by empathy and affection.

It is intended that the reflections presented in this study can contribute to the practice of professionals working in primary and family health units, in order to enable discussions and reflections between managers and professionals about care methods that consider the ontological sphere, with a view to the implementation of strategies that enable integral care and positively impact the indicators of tuberculosis cure.

This study has as limitation the small number of participants, a fact that does not allow generalizations of its results. Although the study was developed in a unique care context, its results may indicate positions that will help people to see them throughout their existential context, contributing to the treatment focused on the essence of the being-there, the authentic care.

## AUTHORS' CONTRIBUTIONS

Conception and design of the study. Data collection, analysis and interpretation. Discussion of the results. Writing and critical revision of the manuscript. Approval of the final version of the article. Responsibility for all aspects of content and integrity of published article: Shirley Ribeiro dos Santos Linhares. Conception and design of the study. Analysis and interpretation of data. Discussion of the results. Writing and critical revision of the manuscript. Approval of the final version of the article. Responsibility for all aspects of content and integrity of published article: Elisabete Pimenta Araújo Paz.

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