

## Social representations of nurses on tuberculosis

*Representações sociais da tuberculose por enfermeiros*  
*Representaciones sociales de tuberculosis por enfermeros*

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### ABSTRACT

**Objective:** to describe the social representation of nurses on tuberculosis and identify the implications on nursing care. **Method:** qualitative research with the participation of 52 nurses from 23 Basic Health Units of Belém, Pará. A semi-structured interview was conducted with subsequent analysis of the thematic content according to the Theory of Social Representations. **Results:** the social representations of tuberculosis were organized into two categories: infection, evidencing the clinical-epidemiological aspects of the disease, and stigma and prejudice, representing the social aspect. Care is affected by fear - a fact that explains the distance adopted by some nurses when handling ill people. **Conclusion:** the social representations of nurses on tuberculosis remain grounded in fear, leading professionals to keep a certain distance from patients and generating stigma and prejudice, which may affect adherence to treatment.

**Descriptors:** Tuberculosis; Nursing; Social Psychology; Nursing Care; Social Stigma.

### RESUMO

**Objetivo:** descrever as representações sociais de enfermeiros sobre a tuberculose e identificar as implicações para o atendimento de enfermagem. **Método:** pesquisa qualitativa, com participação de 52 enfermeiros de 23 Unidades Básicas de Saúde de Belém, Pará. Realizou-se entrevista semiestruturada com posterior análise de conteúdo temática segundo o referencial da Teoria das Representações Sociais. **Resultados:** as representações sociais da tuberculose se organizaram em duas categorias: o contágio, evidenciando a vertente clínico-epidemiológica da doença, e o estigma e preconceito, a vertente social. O atendimento é influenciado pelo medo, fato que explica o distanciamento de alguns enfermeiros ao lidar com os doentes. **Conclusão:** as representações sociais de enfermeiros sobre a tuberculose perduram pautadas no medo que provoca o afastamento do doente, gerando estigma e preconceito, o que pode influenciar na sua adesão ao tratamento.

**Descritores:** Tuberculose; Enfermagem; Psicologia Social; Cuidados de Enfermagem; Estigma Social.

### RESUMEN

**Objetivo:** describir las representaciones sociales de enfermeros sobre la tuberculosis e identificar las implicaciones en la atención de enfermería. **Método:** Investigación cualitativa, con participación de 52 enfermeros de 23 Unidades Básicas de Salud de Belém, Pará. Se realizó entrevista semi estructurada, con posterior análisis de contenido temático, según el referencial de la Teoría de Representaciones Sociales. **Resultados:** las representaciones sociales de la tuberculosis se organizaron en dos categorías: el contagio, evidenciando la vertiente clínico-epidemiológica de la enfermedad, y el estigma y prejuicio, la vertiente social. La atención se ve influida por el miedo, hecho que explica el distanciamiento de algunos enfermeros al tratar con los enfermos. **Conclusión:** Las representaciones sociales de enfermeros sobre la tuberculosis continúan pautadas en el miedo que provoca el aislamiento del enfermo, generando estigma y prejuicio, lo que puede influir en su adhesión al tratamiento.

**Descriptor:** Tuberculosis; Enfermería; Psicología Social; Atención de Enfermería; Estigma Social.

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## INTRODUCTION

In the contemporary world scenario of important advances in the control of communicable diseases, tuberculosis (TB) – a disease that has been affecting humans for millennia – enters the 21<sup>st</sup> century as one of the greatest public health challenges, representing one of the leading causes of morbidity and mortality in the world<sup>(1)</sup>. In the world population, nearly two billion people are infected by the *Mycobacterium tuberculosis*, the causative agent of the disease, representing 8 million new cases every year. Every year, two million people die due to tuberculosis, corresponding to five thousand deaths per day or one death every 15 seconds. These cases occur mostly in developing countries, with 95% of the cases and 99% of the deaths<sup>(2)</sup>.

Brazil occupies the 16<sup>th</sup> position among the 22 countries that present 80% of the new cases of the disease<sup>(2)</sup>. In 2013, a total of 71,123 new cases were reported, with an incidence rate of 35.4/100,000 inhabitants<sup>(3)</sup>. The situation in Pará is not different from the general Brazilian and world realities. The state currently has 7,792,561 inhabitants distributed into 144 cities. Of these, seven are part of the list of 181 cities considered by the Ministry of Health as a priority for control of the disease. In 2013, a total of 3,445 new cases were reported, with an incidence rate of 44.0/100,000 inhabitants. In this scenario, Belém stands out as it accounts for 40% of the cases in the state; 1,382 cases were reported - an incidence rate of 98.0/100,000 inhabitants<sup>(4)</sup>.

The context described above shows that although access to TB treatment is guaranteed by public policies and available in Basic Health Units (BHU), it is often guided by technical procedures that do not consider the most important aspect in the daily care of these patients: the relationship established between them and the professionals responsible for their care<sup>(5)</sup>.

Both the experience of patients and nurses providing care and the results of studies related to the understanding on tuberculosis by patients<sup>(6)</sup> suggest that their thoughts and attitudes should also be considered in the analysis of the success or failure in the control of this serious disease. For a better understanding on the aspects related to treatment and its process as a whole, it is important to understand the paradigm that guides the practices of professionals in handling patients. This understanding is directly related to their action of providing care, as thinking and acting are closely related to the familiarization that is built in view of the social phenomena.

Since its appearance in human history, tuberculosis has generated a social impact that remained for centuries fed by the lack of logical explanations for its appearance and permanence. The disease is not only a set of symptoms, an individual event that affects people; it is also a strange factor that threatens society. Therefore it is not only a biological entity, but also a social phenomenon that deeply marks individuals and social groups.

As tuberculosis is a relevant social phenomenon, the history of its control is permeated by the nursing work. Nurses have always played an important role in its control throughout Latin America. In Brazil, this may be evidenced since the

first governmental and non-governmental actions to fight the disease<sup>(7-8)</sup>. With the evident progress in this area, the work of these professionals in the current context of TB control is driven towards the strengthening of a humanized care to patients and the integration with multidisciplinary teams, which may significantly favor adherence to treatment.

Although tuberculosis is an object of study extensively explored in the scientific literature, there are various nuances in relation to the theme that need to be further investigated in order to enable a better understanding on this social phenomenon. Therefore, this study suggests that evidencing the understanding by nurses on TB is essential. According to the theoretical field of approach of this study, this thinking process mobilizes emotions and raises attitudes that can provide approximation and a higher level of care to patients, or an attitude of keeping a distance from them. These may be permeated by social representations (SR) on the disease, crystallized over time and circulating with the intense mark of stigma and fear. Considering the fact that in TB control in the BHUs nurses are the professionals who usually stay in contact with patients over the entire treatment, the way they deal with these patients may make a difference in their adherence or not to treatment. In this context, the objective of this study was to: describe the social representation of nurses on tuberculosis and identify the implications on nursing care.

## METHOD

### Theoretical-methodological framework and type of study

This is a qualitative study, using a descriptive approach with the Theory of Social Representations (TSR) as framework in the procedural aspect. Social representations, due to their practical nature, guide the actions of individuals in the world<sup>(9)</sup>. Thus, the application of the TSR favors the identification and understanding on how social representations operate in motivating people and interfering in their choices. In the case of the present study, the decision on handling or not TB patients is approached. In light of the TSR, the disease was characterized in two areas: clinical-epidemiological and social, denominated: Infection: clinical-epidemiological aspect, and Stigma and prejudice: social aspect.

### Methodological procedures

**Scenarios of the study:** The scenario of this study consisted in 23 BHUs distributed into six of the eight existing administrative districts in the city of Belém. They were selected based on epidemiological criteria, such as: having higher number of cases and unfavorable results in TB control and aspects related to the conditions of production of SR as these BHUs handle most of the cases, consequently leading the nurses to have more contact with patients – a fact that certainly qualifies them as subjects of an SR study on the theme. In this increased proximity with the object lies the experience to be evidenced in the daily work of interaction with these patients, both to those working directly in care and to the others that, despite not working directly in care, are in constant contact with the disease in such spaces.

Data source: Fifty-two nurses participated in the study, namely 26 that provide care to TB patients, and 26 that work in other sectors of the BHU, elected through intentional selection. Those who were not in the full development of their professional activities and who were working in the BHU for less than one year were excluded.

Data collection: data were collected between March and July 2010, through individual interviews following a semi-structured script with questions aiming at learning what nurses think and know about the disease and patients, their characteristics and illness process, emotions, and images on both, as well as in relation to what they consider as the ideal profile of nurses to work with such patients.

Organization and analysis of data: The collected data were analyzed according to the thematic content analysis technique<sup>(10)</sup>. Data were treated through the classification of themes contained in the answers of each participant to each question. Thus, an internal analysis of the testimony of each participant on the most present themes per participant and a global analysis by questions of all participants were conducted. Eventually the set of similar themes were grouped, making up the classification categories. These categories were organized based on the elements that characterize the disease, patient, and care environment. The registration units (RU) in these categories were then separated; thematic classification was carried out with the identification of words and ideas by the occurrence and co-occurrence of these in the selected RUs. Only at the end, through the interpretation of the content of the RUs in each category of analysis, the nomination was made based on the ideas transmitted by them.

Ethical aspects: The project was submitted and approved by the Research Ethics Committee of the State University of Pará. The participants signed a free and informed consent form, and their anonymity was guaranteed by the use of alphanumeric codes as follows: N (nurse), M (male), F (female) ATB (provide TB care), NTB (do not provide TB care). The number corresponding to the order of the interviews was then added.

## RESULTS

Regarding the sociodemographic data of the participating nurses, 50 were women and 2 were men; the predominant age group was over 45 years (46.1%). Those graduated for more than 20 years represented 61.5%, experts 88.5%, 73% were in a stable employment situation, and 77% had more than one employment contract. Half of them had a monthly income between six and ten national minimum wages. Among those that provided care, 100% received specific training; 38.4% had been working in the unit for 6 to 10 years and in the TB sector for the same period of time. Among those who did not provide direct care to patients, 69% worked in the unit for 1-5 years, and 80.7% received training.

Regarding the content analysis of the testimonies, nurses characterize the disease in two aspects: clinical-epidemiological and social. Based on these, SRs on TB are organized around two major themes: infection and stigma. Both are interconnected to the prejudice resulting from them. As a

consequence, the environment was also present in the results considering that the infrastructure was found to be directly involved in questions that primarily approach infection.

### Infection: clinical-epidemiological aspects of the disease

The translation of TB through clinical-epidemiological explanations is previously established in the scientific environment and present in the speeches of experts. Moreover, due to the nature of their daily work, the testimonies of nurses reveal elements of information present in the reified universe, considering that nurses have access to this information during their academic training, in conversations in their environment, or through more qualified information on the theme, as even the group that does not directly deal with such patients had access to specific training courses on TB. The idea of infection is present at the point that nurses describe the disease through expressions such as: *highly communicable disease* (NFATB12), *contagious infectious disease* (NFNTB2), *disease that is contracted* (NFATB3).

### Environmental symbolism in the SR on TB

The environment of health units is important in the clinical-epidemiological aspect, as it assumes symbolisms to the nurses for being the locus of connection between individuals and the object of representation, even to those who do not deal directly with patients. For them, the characterization of this environment represents an important element to give meaning to the idea of risk and concern around the disease – an expressed aspect that affects them. They aim at the occupational (in)security in the conditions offered by the environment. Therefore, the environment becomes important in the elaboration of its SR on the disease. Depending on the characterization of this environment and the symbolism it assumes, it represents one of the elements that make up these representations, supporting the behaviors that they will adopt in the relationship with patients.

The physical structure of the clinics is described as unhealthy spaces that keep the professional in permanent occupational risk. This situation is reported by a number of professionals due to the environment of the BHU where they develop their professional activities as well as their experiences working in other units:

*What worries me is that most of these units do not have a good physical space. Small rooms without proper ventilation; I think our colleagues are too exposed to risks [...] we often hear colleagues complaining that the rooms have no windows to be open; in fact, there is no working conditions.* (NFNTB15)

*We do not have an adequate room; these things worry me. We need to have an adequate room, with ventilation, windows, open doors, that allows air circulation and is exclusive for this type of program; in fact, there are various programs in the same room.* (NFATB20)

The environment is also assessed in terms of risk of contamination to other people that are present:

*My major concern is in relation to the environment, the [physical] structure. There is not a good structure to provide care to these cases; patients remain together with children and everyone else; there is always a risk of contamination. (NFNTB6)*

*I'm also afraid in relation to biosecurity as there is no appropriate room to provide care, there is no specific room. Because we have to keep TB patients, children, and pregnant women in the same space [...] sometimes the patient is transmitting. This worries me. (NFATB7)*

The environment, not only because of the physical structure, but also because of the conditions it offers to the provision of care, is unfavorable to patients as it does not guarantee their well-being or the required privacy for quality care:

*Having an adequate environment, a breathable place that offers conditions for nurses to work, avoiding a closed environment with a patient and consequently reducing contamination [...] providing more safety to professionals and even patients [...] if a nurse feels safe he/she will be more attentive to patients. How can someone provide quality care if he/she feels afraid? (NFNTB22)*

*It is necessary to adequate these units in order to provide safety to professionals and more quality to the care provided; because if you work without stress, you will provide better care. (NFATB15)*

### **Stigma and prejudice: social aspect of the disease**

Over the last two centuries the meanings and symbolisms socially constructed on TB have guided the reactions and behaviors of society in relation to infected people. In this study, they gain importance in the construction of the SR of nurses on the disease, as these are their objective.

Negative SRs on the disease remain rooted and entrenched in a social imaginary constructed around it, referring to fear and shame. Therefore, nurses reported that when a patient is infected with TB, he/she will necessarily feel constrained due to their condition:

*[...] a disease that is still seen with prejudice [...] the patient feels ashamed, although the nurse instructs and tells them that there is no reason to be ashamed as that disease will be healed [...] it is impossible that he/she does not feel ashamed. (NFNTB3)*

*[...] These patients do not raise their shoulders. Such bending may have two causes: the first one is organic, as an accommodation to avoid pain and breath better; but it also reflects the debilitation for being sick, because the patient is ashamed to be sick. (NFATB16)*

According to the participants, the idea of stigma and prejudice on which the social representations on the disease are based may lead the patient to a compulsory or voluntary social isolation. This condition of being infected with TB as a relevant fact in the social life of individuals and the consequent isolation may go beyond the moment of getting sick,

permeating their social life. This idea is based on the understanding that the disease is a stressing event in the individual history of each patient. In relation to TB, it transcends the individual and extends to the collective level:

*It is like the patient becomes marked. I see TB as a really significant human damage, because of prejudice and even the distance that the family keeps from the ill person; the mark never disappears, it seems like the person becomes marked by TB. (NMATB25)*

*If I have diabetes I can live normally with other people, but it seems that if I was infected with TB this mark would be printed in the life of the individual, even after the healing process; it is not something that stays in the past; it stays somewhere else. (NFATB26)*

*TB is a disease that causes deep marks; there is prejudice, it seems that everyone will be afraid of that individual because he or she is or was infected with the disease; this is a fact in the life of these patients. (NFNTB8)*

There is an intense controversy between social and scientific knowledge. On the one hand science produces knowledge and invests in the circulation of information on the disease and patients in order to provide more clarity to the illness process, treatment, and healing of TB; on the other hand, the emotions and practices produced in the daily conversations contribute to keep the circulation of elements that feed the images of old models that remain in the social thought.

## **DISCUSSION**

It is a fact that this disease is historically relevant from the social and epidemiological perspective as the doubts regarding the possibility of infection intensively fed fears in society. Therefore, for nurses, SRs on TB as an infectious disease seem to be forged by both the fear impregnated with doubts of the social imaginary<sup>(11)</sup> and the certainties of science. These are based on the explanatory model of etiopathogeny of the disease that aggregates the elements of transmissibility and source of infection established by the scientific knowledge that there is an etiological agent causing the pathology, which may be transmitted between individuals<sup>(1)</sup>.

When thinking about TB, nurses communicate theme words that make up biological and social categories. The disease acquires a meaning and symbolisms that transcend the biological (dis)order aspects potentially caused by any pathology in the organism of patients as the social disorder promoted by TB crosses centuries, affecting people and how patients and professionals deal with it<sup>(12)</sup>. These ideas associated with TB have endured over the centuries in the common sense thought, in old representations on the disease that were crystallized in society<sup>(11)</sup>.

Therefore, in the light of the TSR, social and scientific knowledge do not dissociate and meet different aspects that are convenient to each individual in the construction of their thought on a given phenomenon<sup>(9)</sup>. Thus, nurses build SRs on

TB imbricating the consensual and scientific knowledge in a movement that shows that SRs are produced and changed in a slow process of construction, deconstruction, and (re)construction of ideas. This process is mainly applied to classical and metaphorical diseases such as TB. Metaphors about serious diseases are usually related to symbolic associations that may lead to serious effects to patients, affecting not only their perception on themselves but also the behavior of other people in relation to them<sup>(13)</sup>. This situation also applies to TB cases, considered a metaphoric disease permeated by meanings and symbolisms that affect both the individual and social spheres<sup>(11,14)</sup>.

Social representations of patients on TB show that they adopt behaviors related to maintaining secrecy about the disease because of the existing prejudice. This attitude is explained by the fear of social judgment, that is, fear of humiliation and shame<sup>(6)</sup>. This social construction of shame and consequent isolation elaborated around TB patients is old (as mentioned before) and persisted over time because of the lack of logical explanations from the epidemiological perspective to the illness process. And even after the appearance of these explanations, there was certain resistance to introduce them to the existing mosaic of explanations in the social imaginary.

Regarding the professional care environment, its conception as a risky space is constructed based on the knowledge that TB is an infectious disease. Therefore, since the BHU is the space of physical interaction among professionals, users, and other people, when it does not meet some requirements it becomes a potential threat for those who attend the place. The environment also appears in the field of SR in research involving patients, disease, and nursing care<sup>(15)</sup>. SRs are not engendered in individuality but in a social context that is part of their training process<sup>(9)</sup>. Thus nurses perceive the environment of the BHU as an element of the construction of their SR on TB, as it is part of their daily working life and the place from which ideas/information on the disease emerge/circulate. Besides, it is the place where they interact with patients and other professionals.

The building of SR on TB by nurses is structured according to a content-integrating model that refers to the idea of transmissibility of the disease, an element constructed in the scientific knowledge, and stigma, prejudice, and shame generated by this disease and that are crystallized in the collective memory.

These contents related to the knowledge of nurses are closely related to the institutional environment that is contextualized as a space for interaction among nurses, patients, and users in which the stigma may be expressed. Feelings of fear and shame may be also experienced. When this place is considered unhealthy, it works as a facilitator with potential for transmission of the disease. Therefore, reified knowledge and common sense knowledge, social and personal experiences, and the institutional environment are integrated, organizing the thought of nurses on TB and generating feedback. Thus, they serve as a basis, promoting the idea of fearing infection, which in turn crystallizes the fear of patients.

As SRs represent a practical knowledge that implies action (in the case of nurses the action of providing care to ill people), such action is affected by fear - a feeling generated by this

knowledge and that explains the distance maintained by some nurses, including those who provide care for patients and those who do not provide this type of care - in their daily work with these individuals. This distance is not always physical; sometimes it is subjectively implied and described by some of them. Examples include the "service in a hurry" or "being more attentive". This is an important implication of SRs on TB for the nursing care; if the care has a relational nature (besides the clinical), it cannot lack the necessary affection and proximity between professional and user in the scope of the service<sup>(16)</sup> so that patients may feel motivated to adhere the treatment.

The establishment of relationships between patients and health professionals may represent the weak link of this chain, as these relationships are often mainly based on professional skills. Therefore, it is necessary to overcome this model in order to provide quality care in which nurses share with users an environment that presents the required safety, resulting in tranquility to establish with them the approximation deemed necessary in the daily clinical care.

Although this study substantially covers the field and participants in relation to the context of its production, the fact that it was conducted in one single city is considered a limitation as it does not allow generalization. Nevertheless, the results are significant and have the potential to contribute to the nursing field as knowledge on SRs of nurses on TB enables an understanding of what affects them, leading to the possibility of establishment of strategies to improve the quality of the care provided to patients and, consequently, the quality of nursing care, considering the fact that adherence of both professional and patient is decisive for a satisfactory progress of the treatment. Therefore, it is possible to contribute to the success of standardized treatments that are cost-effective and present a potential to generate intense social impact by reducing the human suffering caused by the disease.

## CONCLUSION

Despite the facts that the epidemiology of the disease is widespread, the forms of infection and treatment are known, and the possibility of healing is high, SRs on TB remain based on a fear that leads nurses to stay distant from patients, thus generating stigma and prejudice - a fact that may influence adherence to treatment.

It is important to emphasize that such SRs are not exactly related to laypeople, as this research was conducted with health professionals and nurses that work directly in the TB control program. This shows how this theme is current and relevant, demanding investments in professional training, not exactly in the clinical field, but in the psychosocial area.

In relation to the care environment, it is important to mention that the privacy/confidentiality of any situation involving the professional-user relationship must be guaranteed. Therefore, the right to privacy is not only a prerogative of TB patients. However, it is important to consider the fact that, particularly for these patients, the results show that these conditions directly affect professionals, families, other users, and patients that adopt behaviors influenced by the knowledge built on TB

and that has the existing ideas of infection and prejudice in the social environment as its elements, organizing the SRs on it, reinforcing fear, stigma, and distance from patients.

From the technical perspective, the study emphasizes that TB treatment is predominantly conducted in BHUs. Therefore, it is critical that the installations of these units are appropriate

to the provision of care in relation to human resources and administrative and physical structures, enabling a good relationship between patients and professionals. This will enable the provision of quality care, minimizing the possible risks of transmission of the disease to professionals and other people attending these places.

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