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Social representations of nurses about tuberculosis patients

Representações sociais de enfermeiros sobre o portador de tuberculose

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Abstract

Objective: To describe the social representations of nurses about tuberculosis patients.
Methods: A qualitative research was undertaken, based on Social Representations Theory. To produce the data, the individual interview technique was applied, involving 52 nurses, using a script with closed questions about the personal and professional profile and another script with 27 open questions that explored knowledge and action in their daily work with the patients. For analysis, thematic content analysis was applied.
Results: The nurses build social representations based on the stereotyped patients, associate them with the idea of receptacles of the disease, besides linking vulnerability with illness and social conditions.
Conclusion: Social representations about ttuberculosis patients are organized based on fear, resting on physical, psychological and social characteristics that help the nurses to outline fhe type-figure of the patient as dangerous.

Resumo

Objetivo: Descrever as representações sociais de enfermeiros sobre o doente com tuberculose.
Métodos: Pesquisa qualitativa com referencial na Teoria das Representações Sociais. Para produção dos dados utilizou-se a técnica de entrevista individual, com 52 enfermeiros, utilizando um roteiro com questões fechadas sobre o perfil pessoal e profissional e outro com 27 questões abertas que exploraram saberes e fazeres em seu cotidiano com os doentes. Para análise utilizou-se a de conteúdo temática.
Resultados: Os enfermeiros constroem representações sociais baseadas no estereótipo do doente, os associam à ideia de receptáculos da doença, além de associar a vulnerabilidade ao adoecimento à condição social.
Conclusão: As representações sociais sobre o doente com tuberculose se organizam a partir do medo amparado em características físicas, psicológicas e sociais que ajudam os enfermeiros a delinear a figura-tipo do doente como perigoso.

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Introduction

Tuberculosis has reached the 21st century as one of the main morbidity and mortality causes around the world. Its epidemiological importance is illustrated by World Health Organization data, showing that two billion people have been infected by the *Micobacteriumtuberculosis* around the world, leading to eight million new cases/year and the death of approximately two million people.[1]

In global terms, Brazil figures among the 22 countries with the highest disease burden, ranking 19th, with considerable incidence levels. In 2011, 69,000 new cases were notified in the country, corresponding to an incidence rate of 36.0/100,000 inhabitants.[2]

In the North of Brazil, in the state of Pará, with a population of 7,581,051 inhabitants, distributed across 144 cities, the state capital Belém stands out because it notifies approximately 40% of cases in the state. In 2011, 1,497 new cases were counted, with an incidence rate of 100.0/100,000 inhabitants".[2]

Tuberculosis is historically considered metaphorical and, since its emergence in human history, the disease has appealed to the imaginary of those who have contact with it, whether they are patients, relatives or health professionals.[3] For several decades, contact with the disease and patients brought no logical explanations for contamination. As a result, the social imaginary received constant information that circulated in the scientific universe as well as in common sense, with phantasized and/or stigmatizing explanations that entailed social and biological consequences, often necessarily in that order as, due to the lack of scientific knowledge about the casuses and the lack of effective treatment, the patients had nothing left but harmless or harmful palliative treatments, with consequent lethal outcomes. Because of the stigma surrounding these patients, physical death was preceded by social death.[4]

Today, advances in pneumology permit an early diagnosis, immediate treatment and cure. Diagnosis and treatment are available in the public healthcare network, where patients receive care from a multiprofessional team.[5] Despite this favorable modern scenario, tuberculosis is still feared, and patients continue being victims of social prejudice.[3]

In the multiprofessional teams, in general, nurses accompany patients in the course of their treatment. That has been the case since the start of tuberculosis control in Brazil, in which patients play an outstanding role.[6,7] With a view to understanding how these professionals deal with patients in the daily reality of health services, the aim in this research is to: describe the social representations of nurses working in primary health care about tuberculosis patients.

Methods

This descriptive and qualitative study was based on the process branch of Social Representations Theory. This Theory is focused on socially relevant objects, in the attempt to unveil meanings and senses social groups attribute to them, in order to explain and act on them.

As common sense theories that link thought and action, the study of social representations grants access to the meanings the subjects give to an object. Considered as practical knowledge, they contribute to understand the positions the subjects take in the contemporaneous world.[8] Its elaboration process involve the personal experiences unique and particular to each subject, as well the social experiences, which are the experiences the subject shares with the group(s) he belongs to, in social life as well as in circulating social discourse.

The study contexts were 23 Primary Health Care Units located in the city of Belém, state of Pará, in the North of Brazil, where tuberculosis control has been implemented for more than five years and which concentrate more than half of the cases in the city. These units were chosen because they further the contact between nurses and patients and support the experience that is to be evidenced, for the professionals active in direct patient care as well as for other professionals who, although they are not involved in direct

care delivery, have permanent contact with the patients at these services, making it important to understand their representations and behavior towards the ill as well.

Participants were 52 nurses, 26 of whom deliver care to tuberculosis patients and 26 are active in other areas at the Units. This number was defined based on how many nurses worked in patient care at the time of data collection, i.e. approximately 38 professionals. As the number of nurses in the other sectors was higher, the researchers aimed for numerical equivalence between the two groups. Professionals who had worked at the Unit for less than one year were excluded, as well as professionals on leave for any reason or who did not accept to participate in the study.

The individual interview technique was applied with the help of a script with closed questions about the personal and professional profile, and another containing 27 open questions, exploring the nurses' knowledge and activities in their daily work with patients, their feelings, affection, motivations, actions and the motives for their responses.

The interviews were fully transcribed and classified based on the questions and respondents, through the application of the thematic content analysis technique. The interviews were analyzed based on the recording units corresponding to each question, from which the words and thematic phases were taken that constituted the thematic categories, in accordance with their occurrence and co-occurrence. These were organized in line with the tuberculosis patients' characteristics, in view of the images the nurses outlined in their statements.

The study development complied with Brazilian and international ethical standards for research involving human beings.

Results

About the nurses who participated in the research, 50 are women and two men, in the predominant age range superior to 45 years (46.1%). 61.5% graduated more than 20 years earlier, 88.5% hold a specialization degree, 73% have a stable employment situation and 77% have more than one job. Half of the participants gain a monthly income between six and ten Brazilian minimum wages. Among clinical professionals, 100% received specific training, 38.4% have worked at the Unit between six and ten years and the same period at the tuberculosis sector. Among professionals active in other function, 69% have worked at the Unit between one and five years, and 80.7% have received training.

Concerning the social representations, the stereotype of the tuberculosis patient remains strongly present, with physical, psychological and social characteristics. Although it seems outdated, the conception of fear the nurses described continues strong nowadays. And, despite the whole scientific evolution to diagnose and treat the disease, this fear related to tuberculosis patients is still a spectrum on the loose in society.

The tuberculosis patient: a stereotype

The patients were mainly described based on physical characteristics, whether considering weight loss or another characteristics. In the light of the data, the description involves stereotypes that were constructed and are predominant in the social imaginary. The disease is objectified in the classical figure of "consumption": skinny, pale, bowed and weak.

This stereotype does not only decodify the patient, but also underlies the conception that his physical appearance presupposes a severe illness as, according to the nurses, guided by scientific rationality, the stereotype of "consumption" would only be present in advanced stages of the disease. Thus, according to some testimonies, the stereotype is conditional to this severity.

It is also highlighted that, when talking about their representations, the nurses describe the patients' clinical condition in superlative terms, using words like "highly" and "super", which emphasize the patients' characteristics. When considering tuberculosis, it is insufficient to state that the disease is in an advanced stage or that the patient is downcast, the superlative form is needed, "highly advanced", "super downcast".

Psychological characteristics

As it figures in the sphere of feelings, the psychological condition is objectively captured, based on indicative signs. Hence, the patients' sadness is objectified in the "fallen shoulders", in a somewhat cowering posture, which metaphorically means the social weight of the disease they corry on their shoulders. Similarly, a successful treatment is objectified in perceptible changes in their changes, with important alterations in the patients' behavior and physical appearance.

Social characteristics

In this respect, the characteristics that indicate personal and social vulnerability are predominant, from a socioeconomic perspective, which also involves matters of low education and prejudice.

As regards vulnerability, although scientific knowledge enables them to affirm that the disease depends on contact with the causative agent, they associate this vulnerability with the social groups the disease has affected across history, that is, people who did not receive socioeconomic and social attention. Hence, they demonstrate their estrangement when witnessing, among these patients, people whom they would not consider part of this group, due to their distinguished social position, from a socioeconomic as well as educational viewpoint. Thus, although they seem to demonstrate a certain degree of naturalization, considering that the disease can affect anyone, soon, estrangement appears, indicating that the stereotype of the socially unattended patient remains strongly rooted in these social representations.

Constructing the type figure: The dangerous patient

The nurses classify the patient figure according to what they consider him to be, using practically immanent expressions. They consider that tuberculosis patients are not just any patient, they are distinctive and gain importance because they are, or so as to seem to be, a receptacle of microorganisms, representing a source of contamination and transmission. In the attempt to name the patient, they use expressions like: a danger, transmitter, source of contamination, thus informing their representations.

Discussion

The range of this study stands out when considering the number of scenarios and subjects in the city of Belém, although this is also considered its limitation. Another limiting factor is the impossibility of gender analysis, in view of the restricted number of male nurses. Nevertheless, in view of the sample, the study objective was achieved, showing that the representations the nurses expressed about the tuberculosis patients seem to have undergone little redimensioning over time. While, in the past, patients needed to show determination to cope with social prejudice and were captives of palliative treatment, today, they are encouraged to be equally determined in order to face similar prejudices and the strictness of modern chemotherapy.

The Social Representations Theory showed to be a pertinent theoretical-methodological reference framework in this research, revealing social representations about the patients, so as to understand how the nurses act, through they meanings they construct about them. Understanding their thoughts and actions permits understanding why they often choose not to attend to these patients. Without this possibility, they end up providing assistance void of care and lacking quality, as it rests on fears and prejudices referent to the patients and their disease.

By unveiling these aspects, this study contributes to the quality of care delivery to tuberculosis patients. This is relevant when considering that the way they receive care at health services can make a difference in their adherence or not to long-term treatments like that against tuberculosis.

In the context of the nurses' description of these patients according to stereotpyes, it should be kept in min that the definitions of health and disease in society vary according to individual, family, cultural and social characteristics. In Western communities, the definitions of health include physical, psychological and behavioral aspects. Thus, defining

someone as a patient involves different perception spheres; in the individual sphere, people acknowledge themselves as ill; in the collective sphere, they are acknowledged as such by society and two types of perception can articulate. The list of physical or subjective experiences involved in this decoding process of oneself or the other includes perceived changes in organic functions, which take the form of limb functioning, emotional conditions and bodily appearance.[9]

Therefore, by provoking changes in the patients' physique, which clearly marked them when the disease was incurable, tuberculosis makes the nurses objectify patients according to this socially constructed stereotype, which apparently preserves reminiscences. Hence, they start to be acknowledged as patiens in society. When associating the physical weakness with the worsening of the disease, the nurses use the reified knowledge this idea rests on, as the clinical evolution of tuberculosis is slow and, if not diagnosed early, worsens the patients' physical conditions and consequently changes their body image, to the extent that it advances without any medical intervention.

The use of superlatives to describe the patients' clinical conditions underlines the idea that tuberculosis is not just any disease, it is not just one on the list of infectious diseases nurses can deal with in their daily professional or personal life. Despite knowing that infectious conditions weaken patients, when referring to patients with tuberculosis, their description is loaded with symbols, whose explanation lacks superlatives and quantitative gradients.

In the psychological sphere, associating the patients with certain characteristics or feelings is not new. This practice has been frequent in the social sphere across the disease history and has continued for a long time on the patients' trajectory, serving to hide a combination of stigmas fed by patients, their relatives and the medical groups responsible for care delivery. In that context, the patients were fit into their characteristic psychological/behavioral model and did not dare to reject it.[10]

In the sphere of social characteristics, the association between the disease and the subject's social level marks an apparent transition towards the naturalization of the patient's profile, in view of a change the nurses describe, towards "almost" equal conditions and the coexistence of "two types of patients". Nevertheless, the socioeconomic condition seems to be the differential.

In view of the different and frightening, in this case epidemic and incurable diseases, society looks for explanations and people to blame, as well as for justifications and victims. Thus, it socially constructs groups that fit into its explanatory model/justification, in order to accuse or protect them. These projections onto groups can derive from collective memories, scientific theories or even from social chatter.[11] This aspect is identified when observing that the nurses project tuberculosis onto certain groups based on their contact with the ideas about the disease that circulate in common sense and in the scientific context.[12,13] According to them, who rest their representations on stereotype, the disease is a prerogative for socially unattended and physically frail people, while those without these conditions would be less vulnerable to it. In other words, the protection of the group the patients belong to is strong and clearly expressed in their statements.

As a disease that has always been described as a socially relevant phenomenon, the social representations organized about tuberculosis gained new meanings and organizations over time, always accompanying changes in society. In that context, by organizing their thinking based on the idea of patients who represent a social danger as they are bearing the bacillus, the nurses remit to the former social representations of "consumption", when patients carried the mark of death.[4]

At the end of the 19th century, because of the new meanings attributed to the disease in the social context, patients were no longer seen as victims and started to be considered as dangerous, because of their ability to disseminate the disease. This apparently outdated fear, related to disease that aroused/arouse great mystery, still continues despite new perspectives. This thought is valid with regard to tuberculosis, as the entire mystery surrounding its causes is unveiled and effective treatment is available. But what has been described in this study is

that no science about the disease will be capable of dispelling the fears it arouses in common sense.[10,14]

In organizing the components of representations about tuberculosis patients, the discourse mostly remits to the stereotype of "consumption", which was socially constructed for them. When moving the patient figure to the vulnerability axis of social groups, the nurses acknowledge that part of this space belongs to the group that legitimately occupies it: socially unattended people.[14] In that sense, they manifest their estrangement, identifying that, on the same vulnerability axis, another space is occupied by subjects who should not be there, considering their distinguished socioeconomic and educational background. This possibility surpasses their understanding when they report on their experience at the Units, personal and professional information and official statistics about the disease, which show the predominance of the disease in the socially vulnerable group. Therefore, this is a new element in the puzzle that helps to organize the social representations about patients for these nurses. This repertoire includes the idea that they are a source of contamination, giving feedback to the stereotypes, which in turn reconstruct the type figure of the patient as dangerous, reinforcing the professionals' fearful attitude towards him.

This attitude can guide behaviors and practices in the nursing care context. As, essentially, care presupposes the idea of proximity with the other, it is valid to reflect on the conditions it occurs in and the consequences it entails if the nurses are insecure and fearful about it. When these affections are mobilized, the patient-nurse relation tends to weaken and fail, which can result in patients' non-adherence to treatment, as the professional did not adhere either.

Conclusion

The social representations about tuberculosis patients are organized based on fear, which rests on physical, psychological and social characteristics that help the nurses to outline the type-figure of the patient as dangerous.

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Collaborations

Rodrigues ILA; Motta MCS and Ferreira MA participated in the conception of the project, data analysis and interpretation, relevant critical review of the intellectual contents and final approval of the version for publication.

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