

Caring of People Affected by Tuberculosis: Grounded Theory

ORIGINAL

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Abstract

Objective: To understand how nurses in basic health care have dealt with the situations arising from the process of caring for the person affected by tuberculosis.

Method: Qualitative research following the methodological assumptions of the Grounded Theory. Nineteen nurses participated in the study. It was used the in-depth interview. Data analysis was performed using open, axial and selective coding using the Atlas ti software.

Results: It has been shown that in order to be effective in the treatment, the actions of the nurses and the ways of dealing with the circumstances of the care stem from their concern with the person affected by tuberculosis. In addition, it is also considered the situations that permeate the life of this person, so that it can achieve healing and the restoration of their health.

Conclusion: Concerns and ways of dealing with people affected by tuberculosis should be reflected in the planning of care practices for these citizens. With this it is possible to draw confrontations and conduits for successful actions.

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Introduction

Tuberculosis remains a major global health problem, even in the face of remarkable scientific achievements, with the discovery and treatment of people as the main forms of control [1, 2].

Several studies point to the difficulties and challenges that must be overcome in order to guarantee an early diagnosis and a quality assistance to the person affected by tuberculosis. Overcoming the challenges is necessary for disease control and improvements in incidence, mortality, and cure rates [1, 3, 4, 5, 6, 7].

Other studies have demonstrated the existence of several obstacles to effective action in disease control programs, such as: scarcity of material resources; Poor infrastructure; Problems with the supply of medicines; And adherence of people to treatment. In addition, there are obstacles in managing the care of people affected by tuberculosis and their political commitment to ensure quality care in health services [8, 9]. It is still addressed in the studies that attention to the person affected by tuberculosis must go beyond clinical and pharmacological care. Thus, it is possible to comprehend the integral, social and cultural care approach, considering the social inequities of the complex context that involves tuberculosis [10, 11].

In this perspective, health professionals have the potential to act in the control of tuberculosis and in the promotion of a care that favors well-being in the face of the disease, making them important actors within the context of combating it. Nursing, at this juncture, has a very representative historical performance and great credibility in public health, being under its competence several activities of the tuberculosis control program [5, 12, 13, 14].

The importance of nursing practice and the need to establish comprehensive care are issues that have been portrayed in several researches on tuberculosis. Because nursing plays the role of supervising the entire treatment and avoiding the complications that lead to abandonment, relapse and resistant tuberculosis [5, 12, 13, 14].

It is necessary to approach the day-to-day care, taking ownership of its process, as the recommendations and policies of care often do not elucidate the difficulties faced by health professionals in all

the follow-up that is developed to offer a care that achieves satisfactory results and desired [15, 16].

Therefore, it is necessary to reflect and understand the relationships with people and situations arising from this care, which involves singularities of the life context of everyone involved in their process.

The existence of a protocol of the Ministry of Health in Brazil [5], which recommends nursing behaviors in the Directly Observed Treatment of tuberculosis in Primary Care, requires a more timely evaluation to know how actions are taking place from the perspective of nurses and how they have dealt with the situations and contexts existing in the caring process.

Method

It is a qualitative research that followed the methodological assumptions of the Grounded Theory [17]. The scenario was constituted by eight basic health units of a municipality of the state of Northeastern Brazil. The units were chosen because they were located in the sanitary district that had the highest incidence of the disease.

The study included 19 (nineteen) nurses from primary health care, selected for their experience in caring for people affected by tuberculosis, and are working in these health units. Other nurses were not included in the study because of vacations, leave-gestation, server strike or because they did not accept to participate in the research.

Data collection took place between the months of September 2013 and February 2014, using the in-depth interview conducted by the researcher, from a main question: Talk about care to the person affected by tuberculosis. Based on this initial question, it was explored the concepts that emerged, in order to broaden the understanding about the phenomenon investigated, in order to describe the situations and elucidate details about it.

The contact with the participants occurred, initially, by telephone, to mark the meeting for the

interviews. The approach with the nurses occurred in the health units where they worked, at the most convenient time for them. Excepted one nurse because she chose to do her interview at the Federal University due to the strike of municipal servers.

All interviews were conducted in a closed room, with a mean duration of 43 minutes. The interviews were recorded in digital audio and, after transcription, the comparative analysis was started.

For the process of data organization and analysis, the Atlas ti program version 7.1.8 was used, with the license 710CF-CAB84-3697E-8CQ81-002JY. The analysis of the data allowed to highlight the procedural categories, which made up the substantive theory. The actions and interactions, as one of the categories that explain the phenomenon of nursing care to the person affected by tuberculosis, were highlighted in this article and presented from two categories: Concern with the person affected by tuberculosis and the situations arising from the process of care and Coping with situations in the process of caring for the person affected by tuberculosis.

The study followed the guidelines and norms of research involving human beings of the National Health Council, and was approved by the Committee of Ethics in Research, with the Favorable Opinion no. 20637113.9.0000.0121.

Results

The nurses participating in this study were between 41 and 57 years of age and obtained the title of nurses for more than 20 years. The nurse with more training time was 32 years formed. They had been in the care of the person Affected by tuberculosis for more than 20 years, and only two nurses had less than 10 years of acting in this perspective.

Caring for people affected by tuberculosis has raised concerns for nurses because they recognize that these individuals are experiencing a time of

fragility stemming from a socially discriminated disease that brings temporary limitations to them and their families.

These concerns permeated all caregiving actions, evidencing that the nurse's performance goes beyond the performance of prescribed and recommended procedures. Caregiving actions can be understood as strategic to achieve recovery of the health of people affected by tuberculosis and these actions are developed in an interactive process between nurses and individuals affected by tuberculosis.

This context of care for the person affected by tuberculosis is represented by two dimensions: Concern with the person who has tuberculosis and the situations arising from the care process and Dealing with situations in the process of caring for the person affected by tuberculosis.

Concerning the person affected by tuberculosis and the situations arising from the care process

The situations arising from the care of the person who has tuberculosis have generated different concerns for the nurses. Treatment success was heavily commented as something almost mandatory, so the concerns arose, too, because they have to make it happen healing.

The most worrying situation for nurses was the socioeconomic conditions in which people who has tuberculosis lived. This context of life favored the abandonment of treatment, especially the use of alcohol and drugs, the lack of financial resources due to unemployment, expressed by the lack of adequate food, among other consequences.

Users of drugs and alcohol affected by tuberculosis were those who had more difficulty to follow properly, treatment and care instituted. The precarious conditions of life also worried, because people in these conditions could live in agglomerates or in little airy houses; Could be unemployed and could not guarantee a healthy or dignified diet.

The understanding of the disease by the person affected by tuberculosis was something that worried the nurses because they considered that if the person understands what the disease really is, it can better follow the treatment and the care instituted, eliminating the possibility of abandonment. The nurses highlighted as important the information about what Tuberculosis is; How to treat it; How the transmission occurs; The need to carry out the examinations; The importance of food; What is healing; That it is possible to stay at work with clinical improvement and negative smear microscopy; That there are ways to maintain social life.

In addition, the person's relationship affected by tuberculosis, his/hers family and friends raised concern for the nurses because, without support, they tended to become more fragile to carry on with the necessary care for their recovery. The family, considered the foundation for the person affected by tuberculosis, allows the support and care necessary to face the treatment instituted. However, families did not always collaborate in this care. On the other hand, when there was positive family participation, the person's recovery process was greatly facilitated.

Considering the feelings of the person affected by tuberculosis, many nurses sought to treat the person affected by tuberculosis by stimulating his/hers autonomy, encouraging him/her to follow their therapeutic plan.

Professionals needed to get them to realize that tuberculosis occurs with many people, not bragging about the severity of tuberculosis and especially talking in a friendly way. Nurses treated people with respect, caring about the continuity of treatment, and encouraging them to continue to do what was right, in order to recognize advances in clinical condition.

In this sense, the dialogue and attentive listening were relevant strategies that permeated the whole treatment. This process was often individualized and involved, in addition to the disease guidelines, a space for the person to express his/hers doubts.

The continuity and regularity of the treatment were of great concern to the nurses because they knew that this would lead to healing. They reported that the person's non-attendance at the health facility, the person's disappearance from his/hers residence, the lack of examinations or other situation was very disturbing due to the possibility of abandonment. They were always seeking to get in touch and looking for new strategies to maintain treatment.

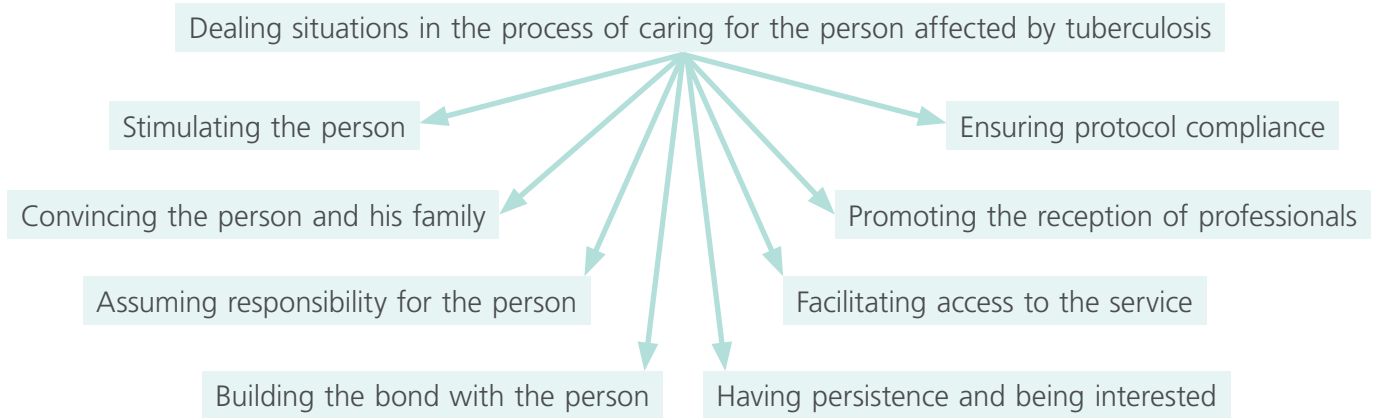
The social chronicity of the disease concerned the social exposure of people affected by tuberculosis. The nurses listened that the person affected by the disease and carried it for life, being able to transmit it to other people and be recognized in every environment they attended. In this sense, the nurses were committed to changing this image of a stigmatized disease and that, socially, they would be recognized as "tuberculosis people".

The professionals realized that there was a change in the profile of those who acquired the disease, since people with good living conditions were suffering from tuberculosis. These people had jobs, paid for private health insurance, and had good food. What disturbed the nurses was that they did not know the causes of these changes and thus had no more preventive action or how to explain to the people why they had acquired the disease.

The issue of the transmissibility of the disease in the workplace was highlighted as a cause for concern, since workers living with the bacilliferous person were at increased risk of acquiring the disease. Sometimes nurses suspected that there were more people affected by tuberculosis in certain companies because several people with the same occupation were getting sick.

Nevertheless, the prejudice that the person could suffer in these spaces generated afflictions. There was still the possibility that the company did not want the person to go back to work, especially when it came to informal work. There were people

Figure 1: Strategies arising from dealing with situations in the process of caring for the person affected by tuberculosis, 2014.



Source: Own authorship, used Atlas ti software.

affected by tuberculosis whose work required the undertaking of great physical efforts, which should be avoided during treatment.

There was also a concern with bacterial resistance resulting from the inadequate use of medications and abandonment of treatment. Nurses became more apprehensive when a person had the resistant form of the disease. This is grounded in the fear that other people will acquire this form because the nurses know that the treatment would require other medical care and the completion of complementary tests.

Dealing with situations in the process of caring for the person affected by tuberculosis

Nurses' care in the care of the person affected by tuberculosis ran through several situations that required some form of intervention, whether it was a specific procedure, a conversation, or an attitude of safety and trust. **Figure 1** presents the strategies of dealing with situations in the process of caring for the person affected by tuberculosis.

Nurses developed different ways of approaching the person affected by tuberculosis, stimulating him/her through more effective communication. Nurses also felt that these strategies helped persuade and motivate them to follow treatment. Its argumentati-

ve resources were different, always considering the different situations encountered.

The conviction was highlighted as an important skill of the professional and involved: persuading the person to perform the treatment; Convince him/her to accept another professional; To convince communicants with Latent tuberculosis Infection to be treated; Help to accept Directly Observed Treatment; Convince the person to continue with the treatment, when the clinical improvement occurred; The frustrations arising from the logistics problems of the health care network.

The nurses emphasized that they took responsibility for the treatment of tuberculosis and the care of the people affected by this disease, and they were proactive in order to keep the treatment going, thus avoiding the possibility of abandonment. For this, they used strategies considered effective, such as building link.

This relationship began in the first host, usually to be made the diagnosis. At such times, the nurses' persistence proved to be a tool to keep the person in his/hers treatment to completion. One of the strategies used by the nurses was the interest in the person and the therapy, since the nurses believe that this particularity motivated the person to continue the treatment.

The facilitated access to care was also evidenced as a strategy to keep the person affected by tuberculosis linked to the service. Such conduct within the basic health unit was a means of ensuring care for the person affected by tuberculosis and not causing dissatisfaction with a service that the person would routinely attend.

The nurses participating in the study reported that they were trying to promote a better reception by the other professionals involved in the treatment. The nurses attempted to insert other professionals into this care as much as possible and made it clear that when the person arrived at the unit, the person could be promptly referred to the nurse's office.

To ensure compliance with the tuberculosis protocol, the nurses developed a set of care activities prescribed by the Ministry of Health of Brazil. The nurses understood that it was essential to leave the person linked to the health service and in that context allow him/her to live normally within the possibilities of her life context.

Dealing with people and situations in the context of tuberculosis involved dealing with many different events. Talking about these often dramatic events, led some nurses to get emotional. Others took a position of emotional defense with rather harsh faces and lines, and others showed great reflection of what they were saying, admitting that they did not stop to think about it and that participating in the study was promoting this opportunity.

Discussion

Caring for the person affected by tuberculosis has enabled nurses to experience various situations and contexts of health and illness, sometimes satisfactory, others sad or difficult. In these experiences, the dimensions of care were clinical, managerial or educational.

The concern with the socioeconomic conditions comes from the fact that the participating nurses know that the majority of people affected by tuber-

culosis live in situations of personal and social vulnerability. This puts people affected by tuberculosis at risk for adherence to treatment.

This condition of economic and social deprivation, observed in other studies, begins to weaken the person, mentally and physically. With the disease, it even reveals himself/herself in the difficulty of accessing the diagnosis, resulting from the need for incentives and benefits that this person needs to follow his/hers treatment properly [18, 19, 20].

The understanding of tuberculosis by the patient, their families and the community is a relevant factor to minimize the stigma attached to the disease. Therefore, it is necessary to raise awareness and recognition of professionals that society has an influence on the health of the population. Thus, it is important to promote the articulation between the various local social equipment that can contribute both to promoting disease control and to understanding what this disease is. This avoids the prejudice and isolation of these people [21].

Concern over the suffering and feelings that tuberculosis can cause is highlighted by MH and other studies. The findings recommend that nurses attend to the suffering coming from the diagnosis, due to situations of social discrimination that can be experienced, making treatment difficult. Thus, the nurses' concern with the context of the person affected by tuberculosis can be understood. For these professionals understand that a person without support is more vulnerable to failure in coping with the disease [5, 18].

The suffering caused by the disease is not only cured with medicines, since the disease requires more than technical solutions, not only to reach the physical body, but to have implications in the psychosocial scope.

The return to normal life of the person affected by tuberculosis is a challenge, since the experience of having an infectious contagious disease loaded with prejudices and stigmas modifies daily life. Thus, it is important for the professional to value clinical

improvement, as a possibility for the person to return to his/her routine [18].

tuberculosis, when affecting people with good living conditions, raised concern in the nurses of this study, due to the sensation of uncontrolled spread of the disease. This concern, also present in another study, may demonstrate a stereotype of the person affected by tuberculosis in being socially unassisted. Because the transmissibility of the disease and spread is worrying, the reality is that other people may become ill due to contact with individuals affected by tuberculosis in their transmission period. This individual would then be a source of contamination, which raised concerns in the participating nurses [18].

Inadequate treatment, in turn, can generate bacterial resistance, which was pointed out as something disturbing by the nurses of the present study. International publications on tuberculosis have alerted the presence of the resistant form of bacillus to the drugs used to treat the infection and the difficulty in diagnosing the disease and resistance of the bacillus early [22, 23].

This context of concern for tuberculosis is consistent with epidemiological data on tuberculosis worldwide. The rate of decline in tuberculosis incidence has remained only 1.5% from 2014 to 2015. There is an urgent need to accelerate to a 4-5% annual decline by 2020 to meet the goals of the Final tuberculosis Strategy. In 2015, an estimated 480, 000 new cases of multidrug-resistant tuberculosis and an additional 100, 000 people affected by rifampicin-resistant tuberculosis were estimated [24].

Countries such as India, China and the Russian Federation accounted for 45% of the combined total of 580, 000 cases. It occurred an estimated 1.4 million deaths from tuberculosis in 2015, and although the number of deaths from tuberculosis declined by 22% between 2000 and 2015, the disease remained among the 10 largest Causes of death worldwide in 2015. Treatment of tuberculosis prevented 49 million deaths worldwide between

2000 and 2015, although there are still major gaps in diagnosis and treatment [24].

Motivation and stimulation were observed in the participating nurses to follow the treatment, also as a strategy used by Japanese nurses to care for the person affected by tuberculosis [16].

In order to strengthen care, counseling people affected by tuberculosis and their relatives about medication use, clarifying doubts and demystifying taboos and stigmas, is an important practice to be developed by nurses, according to Ministry of Health [5].

In this respect, the nurses of this study tried to convince the person affected by tuberculosis and his/her family that the disease was healing and that the treatment given was how to achieve it.

To promote continuity of care for the person affected by tuberculosis and knowledge of his/heir living conditions by the health team, the construction of the bond is of great relevance. The bond is closely related to the practice of effective care, where there is exchange of affection and potentially reconstructive coexistence of autonomy [25].

This bond was also strengthened, according to the nurses in this study, because they accompanied the person affected by tuberculosis until the end of treatment. A similar finding was found in another study carried out in this subject, which pointed out that the follow-up of the individual affected by tuberculosis by the same professional throughout the treatment may be one of the factors favoring the link between them [26].

The long time nurses attending care for people affected by tuberculosis and the professionals' knowledge of the community where they worked were elements that facilitated the quality of care for these people. This element was also highlighted in another study, which indicated that the nurses' time and experience may explain the connection with the people in their care [16].

Having persistence and being interested was a strategy of the nurses in this study to make the

persons affected by tuberculosis remain linked to the treatment instituted. The fact that people affected by tuberculosis perceive that the professionals who care for them have an interest in their recovery causes them to have a commitment to this care [16].

Facilitating access to the unit, professionals and health services was pointed out as a strategic action, developed by the participating nurses. Other studies also pointed to this factor as an important strategy and that guaranteed the construction and strengthening of the link [19, 27].

Therefore, the nurses in this study reported concerns about the reception and relationships of people affected by tuberculosis in health services.

In order to guarantee the follow-up of the Ministry of Health protocol in Brazil, the nurses in this study stated that they performed the actions recommended by the Ministry, following the manuals on tuberculosis. Thus, the care they reported was consistent with what Ministry of Health of Brazil proposes in caring for the person affected by tuberculosis [5].

The participating nurses demonstrated that care for the person affected by tuberculosis goes beyond technical procedures, through understanding the person's way of living, their beliefs and values. These factors interfere and influence the quality of life of those involved and, consequently, their health and illness. Taking care of these perspectives allows to provide the person under his / her care possibilities that favor the reflection and the autonomy for the decision making [28].

Therefore, it should be emphasized that nursing care demands transpersonal efforts of nurses to the persons under their care. Because this nursing profile aims to protect, promote and preserve humanity as a whole, helping people to find meaning, confrontation and strength in the face of illness, suffering and pain [29].

Conclusion

Caring for the person affected by tuberculosis demanded from the nurses participating in this study a professional and personal effort to meet the demands and demands to achieve the restoration of the health of the affected person and to reach the goals proposed by Ministry of Health of Brazil. It was evidenced that nurses' actions for success in treatment stemmed from their concern for the person affected by tuberculosis and the situations that permeated that persons, so that they could achieve healing and the restoration of their health.

However, the concerns and all the effort in performing nurses' practices, while of utmost importance, seemed not to be enough in some cases to achieve better results. Especially when it came to situations involving people who used alcohol, drugs and who were homeless, and with poor living conditions considered at risk for dropping out of treatment.

Given the context of care for the person affected by tuberculosis, it can be seen that the great strategy to maintain the bond and prevent abandonment by the professional nurse was to deal with the different situations that suggest in the care process. In this confrontation the nurse is not limited to the more formal actions indicated in the manuals, but is effectively involved with each person and in the context in which these people were inserted.

Thus, care required a broad approach, with the knowledge of the person affected by tuberculosis in all its dimensions, in order to achieve the cure of the disease and the restoration of the health and life of that person.

The limits of this research are related to the fact that the study presents a situation where the majority of the nurses acted long time in the same place and in the care to the people affected by tuberculosis. Thus, it would be relevant to know how the nurses with less time of action think and execute the actions of care of the person affected by tuberculosis and control of the disease.

This study then enabled an understanding of nurse care to the person affected by tuberculosis, demonstrating that caring concerns and ways of dealing with care are issues that need to be considered in practice planning, making it possible to draw successful actions. It is emphasized that in order of producing this article the authors declare no conflict of interest.

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