REUFSM
REVISTA DE ENFERMAGEM DA UFSM

UFSM
Rev. Enferm. UFSM - REUFSM
Santa Maria, RS, v. 10, e37, p. 1-18, 2020
DOI: 10.5902/2179769239456
ISSN 2179-7692

Original Article Submission: 09/08/2018 Acceptance: 16/04/2020 Publication: 29/05/2020

Perception of the Nursing team on the adherence and abandonment of tuberculosis treatment

Percepção da enfermagem sobre a adesão e o abandono do tratamento da tuberculose

Percepción de la enfermería sobre la adherencia y el abandono del tratamiento de la tuberculosis

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Abstract: Objective: to know the perception of the nursing team about the factors involved in adherence and abandonment of tuberculosis treatment. **Method:** qualitative, descriptive-exploratory study carried out at the Tuberculosis Reference Center in the city of Porto Alegre, in Rio Grande do Sul. Nine nursing professionals responded to the semi-structured interview and Bardin's content analysis was carried out. **Results:** four thematic categories were identified: the organization of the service and the role of the nursing team in the work process; the social root of tuberculosis; nursing consultation as a device for strengthening treatment adherence; service network as a strategy to reduce treatment abandonment. **Conclusion:** nursing professionals recognize their responsibility in the adherence to the treatment of tuberculosis and perceive the factors that influence abandonment in their daily work. They recognize the need for a networked, intersectoral, and of social protection effort to control the disease.
Descriptors: Tuberculosis; Nursing; Pharmacological treatment; Patient's refusal of treatment; Adherence to medication

Resumo: Objetivo: conhecer a percepção da enfermagem sobre os fatores envolvidos na adesão e no abandono do tratamento da tuberculose. **Método:** estudo qualitativo, descritivo-exploratório realizado no Centro de Referência em Tuberculose no município de Porto Alegre no Rio Grande do Sul. Nove profissionais da enfermagem responderam à entrevista semiestruturada e foi realizada a análise de conteúdo de Bardin. **Resultados:** identificou-se quatro categorias temáticas: a organização do serviço e o papel da enfermagem no processo de trabalho; a raiz social da tuberculose; a consulta de enfermagem como artifício para o fortalecimento da adesão ao tratamento; rede de serviços como estratégia para reduzir o abandono do tratamento. **Conclusão:** os profissionais de enfermagem reconhecem sua responsabilidade na adesão ao

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tratamento da tuberculose e percebem no cotidiano de trabalho os fatores que influenciam o abandono. Reconhecem a necessidade de um trabalho em rede, intersetorial e de proteção social para o controle da doença.
Descritores: Tuberculose; Enfermagem; Tratamento farmacológico; Recusa do paciente ao tratamento; Adesão à medicação

Resumen: **Objetivo:** conocer la percepción de la enfermería sobre los factores implicados en el cumplimiento y abandono del tratamiento antituberculoso. **Método:** estudio cualitativo, descriptivo-exploratorio realizado en el Centro de Referencia de Tuberculosis en la ciudad de Porto Alegre, Rio Grande do Sul. Nueve profesionales de enfermería respondieron a la entrevista semiestructurada y se realizó el análisis de contenido de Bardin. **Resultados:** se identificaron cuatro categorías temáticas: la organización del servicio y el papel de la enfermería en el proceso de trabajo; la raíz social de la tuberculosis; consulta de enfermería como dispositivo para fortalecer la adherencia al tratamiento; red de servicios como estrategia para reducir el abandono del tratamiento. **Conclusión:** los profesionales de enfermería reconocen su responsabilidad de adherirse al tratamiento de la tuberculosis y perciben los factores que influyen en el abandono en su trabajo diario. Reconocen la necesidad de redes, protección intersectorial y social para controlar la enfermedad.
Descriptores: Tuberculosis; Enfermería; Tratamiento farmacológico; Rechazo del tratamiento por parte del paciente; Adherencia a la medicación

Introduction

The upsurge of tuberculosis (TB), an infectious airborne disease caused by the *Mycobacterium Tuberculosis Complex*, remains a serious public health problem. The great challenge is to break the chain of transmission of the disease, whose source is people with bacilliferous pulmonary TB, who when talking, coughing or sneezing eliminate the bacilli in ambient air.[1] In 2017, of the approximately 10 million people who were affected by the disease in the world, 1.3 million died.[2] And although 60% of new TB cases worldwide are concentrated in countries in Asia and Africa, Brazil concentrates 33% of the TB burden in the Americas.[1] In 2018, the incidence coefficient, referring to the national average of cases, was 34.8/100,000 inhabitants and mortality from the disease reached 2.2/100,000 inhabitants in 2017. In the same year, Rio Grande do Sul (RS) occupied the fourth place in incidence of cases, with a coefficient of 40/100,000 inhabitants among the federated units.[2] This high incidence of the disease associated with the high rates of treatment abandonment places Brazil among the priority countries for the control of TB. Such unsatisfactory national epidemiological scenario is aggravated by the concentration of cases of the disease in vulnerable populations: people

living on the streets (PLS), people deprived of their freedom (PDF), people living with HIV/AIDS (PLHIV) and indigenous people.[1]

To cope with this scenario, the Ministry of Health (MH), together with the other governmental bodies, has directed the actions to fight TB in accordance with the current strategy for the end of TB (End TB Strategy), which aims to end the global epidemic of the disease.[3] In this perspective, and in line with the National Plan for the End of TB as a public health problem, the Programa Nacional de Controle da TB – PNCT (National TB Control Program, in free translation) recommends actions based on three pillars: prevention and integrated care centered in the patient; bold policies and support systems and; intensification of research and innovation. These pillars form the basis for the urgency to develop and qualify strategies for strengthening therapeutic adherence. Among which, the reception, the Directly Observed Treatment (DOT) and the Singular Therapeutic Project (STP) stand out[1].

Regarding the organization and implementation of the main strategies for strengthening adherence, the current recommendations for TB control highlight the role of nursing actions. This professional category continues to be active both in the national territory and in poor countries with a high load of drug-resistant TB.[4-5] Currently, the challenge that arises for these professionals goes beyond aspects of assistance, management and organization of services. In this sense, strategies to strengthen adherence to treatment require health actions through intersectoral articulation and the coping with situations of vulnerability that affect most people with TB.[6]

In view of the above, this study seeks to know the perception of nursing about the factors involved in adherence and abandonment of tuberculosis treatment.

Method

This is a descriptive and exploratory study with a qualitative approach, carried out in a secondary and tertiary reference service for the treatment of TB in the city of Porto Alegre, Rio Grande do Sul, Brazil. The participants were nursing professionals involved in the care and treatment

of users with TB. The inclusion criteria were the performance of the nursing professional in the service during data collection and having experience of more than six months in the treatment of the disease. The exclusion criteria were not being part of the permanent staff of the service or being away from their duties due to vacation or leave during the period of data collection. Thus, after applying the exposed criteria, of the total of 12 nursing professionals, nine participants remained included in this research.

Data collection took place in May 2018. The researcher contacted the service coordination to present the research and schedule a face-to-face meeting with each of the nursing professionals. At this meeting, the invitation to participate in the research was made, as well as the Free and Informed Consent Term was signed to those who agreed to participate. Afterwards, in a reserved room in order to guarantee the participants' privacy, the researcher conducted the interview. First, information was collected to characterize the participants, such as professional category registration, sex, age and length of experience in TB care. To assess the perception of nursing professionals regarding factors related to adherence and treatment abandonment, a semi-structured interview script was used, with the following open questions: How is the nursing team involved in the process of guiding users about the treatment of TB? In your opinion, what are the reasons that lead users to abandon TB treatment? Do the strategies used to avoid abandoning TB treatment require changes? If so, what would these changes be? How could nursing work collaborate to encourage users not to abandon TB treatment? All interviews were recorded in full.

Regarding the analysis of the material, Bardin's Content Analysis method was applied.[7] To this end, the organization of the analysis, coding, categorization and treatment of results through inferences was performed. After data collection, the researcher transcribed all the interviews in full and coded this material. Subsequently, it was possible to make inferences about the findings. For the differentiation and preservation of the participants' identity, codes with the following letters (followed by the order number of the interviews) were used: N for the nursing professionals, NT for

the nursing technicians and NA for the nursing assistant. For example: NT 1, NT 2, N3, N4, NA5, NT 6, NT 7, NT 8 and N9.

The project of the present research was approved by the Ethics Committee of the School of Public Health/CES/RS, on May 9th, 2018, under the opinion number 2,646,027, CAAE 79992817.4.3002.5312, by the Ethics and Research Committee of the Centro Universitário Metodista IPA, under opinion No. 2,560,294, CAAE 79992817.4.0000.5308 and by the Technical and Scientific Commission of the place where the research was carried out. This study met the technical and scientific requirements that regulate the ethical precepts determined by Resolution No. 466/2012, of the National Health Council, which provides for research ethics involving human beings.

Results and discussion

Of the nine nursing professionals interviewed, three were nurses, five nursing technicians and one a nursing assistant. Eight females and one male. The age ranged from 34 to 65 years. The average time in professional practice in TB care was 14 years.

Regarding the analysis, it was possible to identify four thematic categories: the organization of the service and the role of the nursing team in the work process; the social root of tuberculosis; nursing consultation as an artifice for strengthening treatment adherence; health services network as a strategy to reduce treatment abandonment.

The organization of the service and the role of the nursing team in the work process

Professionals realize that they perform activities in the different stages of TB care, they feel co-responsible for the success of the treatment. They identify that they exercise care ranging from the reception of users and the provision of guidance to the completion of treatment.

> *The nursing team is at the frontline, gives all the guidance* [...] *but we always try to encourage them* [users]. (NT2)

> *The nursing team must address the issues of the disease itself and the way of transmission, treatment, duration, the medications that are used by the patient and their effects.* (N4)

> *I try to get involved as much as possible to make the patient understand the treatment.* (N3)

The performance of nursing professionals in various stages of TB care reinforces the role of this category in coping with the disease. They are responsible for territorial based vigilance actions such as the search for suspected cases of the disease in the community for early detection of the disease. In addition, they are responsible for providing direct assistance to people undergoing treatment by providing guidance on the disease to answer questions from the user and family. Still, the identification of possible contacts of the individual with TB and the supervision of taking medication through the DOT, are part of the care provided.[8] In addition, it is important to emphasize that the individual's involvement and protagonism in the conduct of his/her treatment, clearly perceived by professionals, is in line with the recommendations of the current national TB control plan.[3]

Regarding the involvement of the nursing team in therapeutic adherence, the professionals interviewed perceive welcoming as one of the main elements for the success of treatments. They understand that welcoming reflects positively on the therapeutic relationship.

> *The fundamental thing is the reception of the patient* [...] *we had a patient who was very rebellious and she stopped missing the appointment, because every time she was absent the doctor would pick up the phone and call* [...] *and she found that to be amazing. She felt herself important* [...] *the moment you show an interest in their treatment, it's important.* (NT6)

> *At first, we welcome.* (NT7)

The perception of embracement as paramount in adherence meets what is recommended by the first pillar, which supports the current strategy for the end of TB, prevention and integrated and patient-centered care.[3] The intention is to carry out integrated and centered in the patient care, through a good interpersonal relationship, to trigger unique therapeutic bonds[9-10] potentially capable of improving adherence to TB treatment. In the current scenario of confronting TB, the Ministry of Health recommends the treatment of vulnerable populations as a priority. In this sense, embracing becomes an important technology to be used by nursing professionals to strengthen adherence.[1] Active and welcoming listening facilitates the understanding of the main subjective components that influence the behavior of people with TB. Among them, the different meanings that the person holds about the disease, the degree of involvement and expectations in relation to the prescribed treatment are important for planning a care shared by the nurse.[11-12] Nursing professionals also understand that the user is co-responsible for their state of health.

> *I try to get involved as much as possible to make the patient understand the treatment.* (N3)

> *I usually joke with patients that the treatment is 50% us, the institution, the medication, the service, the exams and 50% is him/herself with the treatment.* [...] *if he/she takes the role of protagonist of his/her treatment, we have a greater chance of achieving success.* (NT6)

The perception of nursing professionals as to the understanding that part of the responsibility for treatment lies with the individual with TB is in accordance with the current definition of adherence used by the MH. It is configured as a collaborative process in which the person undergoing treatment must accept the institution of a certain therapeutic regime.[3] This collaborative posture can be observed in cases in which treatment is given by the DOT, a mode in which the user is responsible and committed to go to the Health Unit five or three times a week to take the medication in a supervised manner by health professionals.[8] However, without disregarding that the individual has part of the responsibility for the treatment.

It should be noted that, in the case of vulnerable populations, it is necessary to exercise caution in exalting individual responsibility in the treatment of a disease. This is because these populations are often without basic living conditions resulting from human rights violations that prevent them from "collaborating on their own" with treatment. A fact that requires greater attention from social protection actions carried out by the government, since income transfer programs, such as the Bolsa Família (a social welfare program of the Government of Brazil), had a positive effect on the treatment of the disease.[13]

Education actions are also perceived by the team as fundamental to the success of the treatment.

> *I think the first issue is information. Tuberculosis has to make sense to them. The treatment has to make sense. What is this disease? Why should I treat? Why shouldn't I abandon? And I think it is very important for the nursing team to work on these educational issues with the patient. In the disease making sense initially, it is already a major breakthrough in treatment, because the patient will understand the reasons why he/she cannot abandon treatment.* (N4)

Although health education actions are recognized by the nursing team in strengthening adherence to TB treatment, research reinforces that, sometimes, they are still punctual and not very expressive in the work process of Primary Care teams.[14] This is because approaches that disregard dialogue tend to delegate to individuals the full responsibility for their health status. Which in turn, contributes to the victim blaming for non-adherence to treatment. Therefore, it is understood that health education actions, in the context of TB, can be more effective the more they consider the interaction between the technical knowledge of the professionals and the popular knowledge of the people being treated.

The social root of Tuberculosis

Among the factors related to the abandonment of TB treatment, the socioeconomic conditions of users were the most mentioned by nursing professionals.

> *It is a disease with a deep social root* [...] *The issue of the stigma of tuberculosis is closely linked to treatment abandonment.* (N4)

> [...] *there are several factors. One is their social status. He has nowhere to live, he has nothing to eat, and he has no support from his family. They feel uncomfortable with the disease. There is still prejudice of the disease.* (NA5)

> *There is abandonment due to issues that we can attribute to socioeconomic conditions, drug and alcohol use, issues of vulnerability both individual and social.* (N9)

> *We have patients who abandoned because of the simple fact that they had no way to come because they worked and the hours did not match so that they could take the injectables* [...] *he said: I have to work or I will be evicted.* (NT6)

Although the association between the occurrence of TB and poor socioeconomic conditions is widely known, it is the first time that the need to face the social determinants of health is formalized as a recommendation in the disease control manuals.[3] This fact is partly due to the growing social inequalities in Brazil, one of the countries with the highest concentration of income and inequities in health, conditions that aggravate rates of treatment dropout. Such aspects are even more worrying in the PDF, which live in overpopulated cells that lack health care.[15-18] Despite the understanding of the need to face these social determinants, it is necessary to pay attention not to overestimate the effectiveness of the health sector in solving "macro-structural problems". This is because the actions of nursing professionals will be more effective the more they are added to the actions of other sectors. In this context, it is necessary to value nursing work in involving the family as a support network for users in treatment. A family support network helps to reduce stigma, discrimination and social isolation generated by the disease.[19]

The subjective issues of the person in relation to treatment were also signaled by the interviewed professionals as factors that hinder the adherence process.

> *There also are the subjective issues of the patient. When I see the patient who leaves and returns, I hear a lot: Oh! I stopped taking the medicine because I don't feel sick* [...] *but there is also the other side that I hear a lot: I'm fine, I don't need to take the medicine anymore* [...] *the patient does not identify himself as sick.* (N9)

Such report corroborates the importance of considering the subjective aspects of the user in the treatment of TB, since the unique way in which each individual understands the health-disease process influences treatment adherence.[19] In relation to this, a study that evaluated the subjective factors related to therapeutic adherence in users of a reference center, reinforces the importance of conducting more research with a qualitative approach.[5]

Nursing consultation as an artifice for strengthening treatment adherence

In the professionals' testimonies, it is clear that strengthening therapeutic adherence demands time from the team and, especially, from the nurse during the nursing consultation. However, the reality of the services and the lack of human resources is a reality in the daily work of health services that deal with such a problem.

> *Sometimes I feel like doing more, but I know that the structures don't help me. We run into the system.* (N3)

> *Here we do the nursing consultation at the beginning of the treatment and when he returns to restart an abandoned treatment. Sometimes I think we should make an adherence nursing consultation, every time the patient comes* [...] *because when he gets there in the 12th month, he still has 6 more months or 1 year of treatment* [in cases of drug resistance]*, but he is doing very well. He should have consults for other demands, in order to reinforce: you are well, but you are not cured. Obviously, we don't means for this.* (N9)

The nursing consultation, a private activity of the nurse, brings with it the potential to strengthen adherence to TB treatment. Such activity is configured as a space for expanding strictly

biomedical approaches, as it includes the plurality of care proposed by collective health.[20] However, despite its importance, nursing consultation is one of the many activities of nurses, who, many times, need to divide their working time in planning and managing health actions in the service.

There is also a certain difficulty for nursing professionals in dealing with users who do not seem to understand the real dimension of the need to follow TB treatment. In this aspect, the nursing consultation is perceived as a welcoming space that must be incorporated periodically in the follow-up of the treatment.

> *And another thing that I also think is the lack of knowledge of the disease. You are not very interested in your health* [...]. (N3)

> *I hear a lot like this: Oh! I stopped taking the medicine because I don't feel sick* [...] *I'm fine, I don't need to take the medicine anymore.* (N9)

> *As he is a patient who has a very long treatment, it is useless to do it only at the beginning of the treatment* [the nursing consultation]*. It is a job that has to be done in every* [medical] *consultation. Will it become a little repetitive? Yes, but it is important to insist on welcoming, on the importance of his commitment to treatment, precisely because it is too long.* (NT6)

Despite the importance of the nursing consultation as a space, care technology and a tool capable of qualifying the management of TB, it is necessary to consider some limitations.[21-22] Such limitations refer to the fragmentation existing between the stages of anamnesis, physical examination, diagnoses, planning, implementation and evaluation of the therapeutic plan. As for these aspects, a study that evaluated the nursing consultation to patients with TB in Primary Health Care, demonstrated that anamnesis and physical examination were performed, but that other steps were not always included in consultations.[23] It is understood that it is up to the professional nurse him/herself, as well as the managers of the health services, the valorization of this private activity, in order to integrate it in a consistent way with the TB control activities.

Health service network as a strategy to reduce treatment abandonment

For the nursing professionals interviewed, the success of the treatment is strongly related to access to the health service network and, consequently, to the involvement of the various professional categories.

> *You need more people in search of these* [absent] *patients when they start treatment, because they don't come. And they stay 3, 4 months* [away from treatment]. (NT1)

> *I believe that we should have a social reinforcement together with the tuberculosis clinic, because we have seen that the health, by itself, has not been able to cope with this disease.* (N4)

> *I believe that a lot is done only within health. So, people who are in health care, have care, have search strategies, have strategies to avoid abandonment, but cannot extrapolate the health field. There is no network that can be directly referred to a follow-up service, a social service in the region* [...] *I think we are very limited in terms of health.* (N9)

The performance of intersectoral actions emerges as an important recommendation for tackling the social determinants related to TB.[12] The current disease control manual highlights that the approximation between the health sector and social assistance helps to reduce the vulnerability situations of most of the people in treatment.[3] However, despite the recognition of the importance of intersectorality, it is necessary to discuss how effective their actions should or could be in solving social problems generated by the very inequalities of the current economic systems.[16] In this sense, it is believed that, to delegate to the intersectoriality the potential to reduce situations of poverty is to overestimate its contributions beyond the qualification of health care. This is because the reduction of inequalities requires macro-structural changes that go beyond the actions of different sectors.[24]

In addition, it is also perceived that, although the reference services have an interdisciplinary team in direct assistance to users, a good part of these individuals with TB have difficulty accessing professionals from psychology, psychiatrists and social workers.

> *I think there had to be a closer relationship between health and the network. I think one of the things that makes this difficult is the issue of waiting. We* [reference service] *are state and they* [primary care] *municipality, I think it makes it difficult. But it is as if we* [reference service] *are separated from everything. So, we do our searches, we have a social service that makes contact, that makes the visit, but we were not able to talk, for example, with the professional from the basic care who makes the visits of the Bolsa Família* [Social Welfare Program]*, who could help in the adhering to the treatment, with the community health agent.* (N9)

The complexity involved in adhering to TB treatment makes the participation of several professional categories urgent, reinforcing the importance of organizing a solid and resolute service network for a positive outcome of cases.[21] In this regard, in the current political context, it is necessary to pay attention not only to the need to qualify the services of the Unified Health System (UHS), but also for their own defense and maintenance as a public health service with access for all. This is because the sustainability of these services depends both on the training of the professionals who work in them, and on the formulation of policies that contemplate the inclusion and participation of the various professions.[25]

Still on the service network in TB care, according to reports, professionals identify the desire for integration between the stages of the search for respiratory symptoms (person who coughs for 3 weeks or more), the performing of the diagnosis and, the monitoring of the treatment. Such integration refers both to actions within a single health service and to referral and counter-referral at different levels of health care (Primary Care and Specialized Service).

> *The search in primary care and a better partnership of reference with primary care. I think the teams had to be practically one. Work together.* (N3)

> *We do some referrals, but it is as if sometimes I feel that we are not part of the network as a whole. So, we refer them to the health clinic and the health clinic, from then on, has to refer them to psychology, to social work, and they face the difficulty of lacking these services there too.* (N9)

In Brazil, despite the construction of the Care Line for Tuberculosis, which includes the decentralization of treatment for Primary Care[1], there is still difficulty in communication between the different levels of care. To this end, there is an effort to train professionals who work at the frontline to manage the disease.[20] Such training must take into account that, as it is a condition strongly associated with situations of vulnerability, it is necessary to carry out an integrated and non-fragmented care.[17] In addition, it is emphasized that the lack of support and commitment from managers in the allocation of financial and human resources, may come to compromise the ability of Primary Care to manage TB cases. This in turn will reflect in epidemiological indices below those recommended by the Ministry of Health.

Final considerations

Nursing professionals involved in the care process for individuals with TB recognize the responsibility and importance of the work of guiding and monitoring the treatment of users. They also perceive, in this context, several factors that can influence the adherence and the abandonment of the disease treatment. In this aspect, embracing stood out as an important factor for building a bond with the user, which can be reflected positively not only in the therapeutic relationship, but principally in the control of TB. It should be noted that the nursing team observes the abandonment of treatment as a reflection of the issues related to the social determinants of health and consider this a major challenge to be faced. In this sense, the lack or insufficiency of social protection measures for users tends to compromise the quality of the treatment of a disease which has strong association with contexts of poverty.

It can also be observed that despite the perception of the need for periodic nursing consultation throughout the treatment, there is a limitation placed by the work overload of this professional category. In addition, the provision of network care comes up against difficulties such as the fragility of the

relationship between health and social assistance. Aspect that, if added to the lack of a family support network, may contribute to the abandonment of treatment, making it even more difficult to control TB.

Thus, nursing professionals perceive themselves with attributions beyond biomedical issues, which go beyond the health sector, such as the reduction of situations of social vulnerability (unfavorable socioeconomic conditions, being on the street, being a user of alcohol and other drugs) in which a large number of users with TB are found. Therefore, it is believed that the balance between carrying out the actions of these different sectors and actors is decisive for the control of the disease in different scenarios and social contexts.

As a limiting factor of this research, it is considered the fact that it occurred with a reduced "n", which prevents the data from being generalized. However, the results present relevant information that may guide new studies in order to expand the coverage to other levels of care, in order to corroborate the results found.

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How to cite this article

Freire APVS, Normann KAS, Nakata PT, Cicolella DA. Perception of the Nursing team on the adherence and abandonment of tuberculosis treatment. Rev. Enferm. UFSM. 2020 [Accessed in: Years Month Day]; vol.10 e37: 1-18. DOI: https://doi.org/10.5902/2179769239456