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Therapeutic itinerary of people with tuberculosis in face with their health needs[a]

Itinerário terapêutico de pessoas com tuberculose diante de suas necessidades de saúde

Itinerario terapéutico de personas con tuberculosis ante sus necesidades de salud

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Abstract

Objective: To describe the therapeutic itinerary of people with tuberculosis in face of their health needs. **Method:** Descriptive, qualitative study. Semi-structured interviews were carried out with ten patients. Hermeneutic-dialectic method of analysis and concept of therapeutic itinerary as driver of the analysis. **Results:** Most had classic symptoms at the beginning, however there was a case with coughing for more than one year. Entrance door, access to diagnosis and treatment were predominant in Primary Care, through smear microscopy and X-ray; patients had to pay for exams. Decentralization of treatment for other services when necessary or by link with the professional. The patient followed the decisions of the professionals and the support of relatives; prejudice regarding the disease was noted. **Conclusions and implications for practice:** Fragility in disease management, importance of bonding and family. It should be considered the impact of the disease and the need to support patients to ensure continuity of care.

Keywords: Tuberculosis; Health Services Accessibility; Health Care.

Resumo

Objetivo: Descrever o itinerário terapêutico de pessoas com tuberculose diante de suas necessidades de saúde. **Método:** Estudo descritivo, qualitativo. Realizadas entrevistas semiestruturadas com dez pacientes. Método de análise hermenêutica-dialética e conceito de itinerário terapêutico como condutor da análise. **Resultados:** A maioria apresentou sintomas clássicos no início da doença, mas houve caso com tosse por mais de um ano. Porta de entrada, acesso ao diagnóstico e tratamento foram predominantes na Atenção Primária, através de baciloscopia e raio-X; houve custeio de exames pelos pacientes. Descentralização do tratamento para outros serviços quando necessário ou por vínculo com o profissional. O paciente seguiu as decisões dos profissionais e do apoio de familiares; constatou-se preconceito relativo à doença. **Conclusões e implicações para a prática:** Fragilidade no manejo da doença, importância do vínculo e da família. Deve-se considerar o impacto da doença e a necessidade de apoio aos pacientes para garantir a continuidade da atenção.

Palavras-chave: Tuberculose; Acesso aos Serviços de Saúde; Atenção à Saúde.

Resumen

Objetivo: Describir el itinerario terapéutico de personas con tuberculosis ante sus necesidades de salud. **Método:** Estudio descriptivo, cualitativo. Se realizaron entrevistas semiestructuradas con diez pacientes. Método de análisis hermenéutico-dialéctico y concepto de itinerario terapéutico como conductor del análisis. **Resultados:** La mayoría presentó síntomas clásicos al inicio, pero hubo un caso con tos durante más de un año. Puerta de entrada, acceso al diagnóstico y tratamiento fueron predominantes en la Atención Primaria, a través de baciloscopía y radiografía; se realizó un seguimiento de los exámenes por los pacientes. Descentralización del tratamiento para otros servicios cuando necesario o por vínculo con el profesional. Paciente siguió las decisiones de los profesionales y del apoyo de familiares; prejuicio con la enfermedad. **Conclusiones e implicaciones para la práctica:** Fragilidad en el manejo de la enfermedad, importancia del vínculo y de la familia. Se debe considerar el impacto de la enfermedad y la necesidad de apoyo a los pacientes para garantizar la continuidad de la atención.

Palabras clave: Tuberculosis; Accesibilidad a los Servicios de Salud; Atención de Salud.

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INTRODUCTION

Tuberculosis (TB) remains a public health problem in the global context. Brazil is among the 30 countries with high disease burden and among the 20 countries with the highest estimated number of TB and TB/HIV, for the period of 2016-2020. Even in the face of this incidence, the country has made progress regarding the high rate of treatment coverage, which was higher than 80.0% and with a higher service coverage of above 70.0% in 2017.[1]

In the search for TB control, national and international groups have developed plans and strategies, considering as the main tools the early diagnosis and the beginning of treatment.[1] In the search to respond to access and monitoring of cases, in Brazil the control actions were decentralized to primary health care (PHC), in accordance with the recommendations of the Ministry of Health. Although they have occurred vertically and with fragilities in the process, among them the need for articulation between the points of attention and monitoring.[2]

In this context, it is recognized the importance of the work of the Family Health Strategy (FHS) teams, which is taken as a legitimate space for implementation of surveillance actions, prevention and control of the disease. As for the actions of flow regulation, there is still little resolution, since the investigation, diagnosis and treatment of the cases of the disease are redirected to specialized care.[3]

In addition to this scenario, launched to the structuring of the care network and responsibility of the Tuberculosis Control Program, requires clarity on the aspects related to the context and the services that the patients went through during their therapeutic itinerary. Thus, it is essential to contribute to the reorganization of health services that provide assistance to people with TB in order to address their health needs.[4]

The resources available in health services for TB care cannot be limited to access to diagnosis, availability of the drug and supervision of its ingest. These strategies are insufficient because, given the health needs and vulnerabilities of individuals facing illness, priority should be given to the access to treatment, guaranteed through bonding and the support of the health team.[4,5]

In this context, the programmatic assistance flows are intended to guide the citizens' path through the health system, which does not always correspond to that achieved or desired by the people, resulting in unsuccessful pilgrimages by different health services.

The concepts of therapeutic itineraries have been explored from different perspectives, but most often this is done in a fragmented and circumscribed way to the description of routes or flows, or to the search and offer in formal or informal services of the Health Care Network (HCN).[6] Investigating therapeutic itineraries is a potentially revealing and effective practice for understanding the complexity of the search for care. Moreover, the studies of the therapeutic itineraries make it possible to evaluate the HCN, considering the subjective dimensions, and not only performance indicators, that hardly account for the complexity of daily life and its repercussions on the health of the patients.[7]

Faced with a lack of study on the subject, it is essential to know the therapeutic itinerary of people with TB in the care network, because it is essential that the health services offered guarantees universality, equity and integrality and care networks. Thus, the objective of this research was to describe the therapeutic itinerary of people with TB, in face of their health needs.

METHOD

Descriptive study of a qualitative approach, carried out in a municipality located in the mesoregion of southern Ceará. It was used the theoretical concept of Therapeutic Itinerary, considered one of the central concepts in socio-anthropological studies of health. Used to designate activities developed by the person in the search for treatment for illness or distress.[8]

The Therapeutic Itinerary presents two great orders of explanations that are cognitive and socioeconomic. Through these, one can analyze four major themes related to their meaning that crisscross: a) identification of strategies developed to solve health problems; b) characterization of models or patterns in the pathways of treatment or cure; c) patient transit in the different subsystems of health care; and d) functioning and organization of health care services.[8]

The study population consisted of ten people in treatment for TB, seven of them in urban areas and three in rural areas. These met the following eligibility criteria: be enrolled in the Municipal TB Program; be over 18 and be accompanied by the Family Health Team or referral center for TB treatment.

For the access to the participants, contact was made with the coordination of the epidemiological surveillance of the municipality, which authorized the search for registered TB cases in the Notification of Injury Information System ("SINAN"). Twenty-seven people were localized in treating for the disease, of these, five were discharged from the hospital, four were discharged from treatment, two refused to participate in the study, two were not found, one had a diagnosis change and three did not meet the inclusion criteria.

The semi-structured interview was used as a technique for collecting the data, composed of the following guiding questions: What symptoms did you present and how long did it take to perform your care? What health service have you used, which units have you been through to complete the diagnosis and perform TB treatment? Where did you carry out your treatment and for which services were you referred? Have you chosen how and where to carry out your TB treatment together with the health team? How did your family participate in the decision of your treatment?

The production of the empirical material occurred in the period between March and July 2015. For that, the interviews were previously scheduled. The Community Health Agent mediated the first contact of the researcher with the participants at home and, in this context, the objective, risks and benefits of the research were presented. After clarifying the doubts and signing the Term of Free and Informed Consent. The interviews were recorded on a digital recorder with a chip and had an average duration of 35 minutes. Subsequently, they were transcribed in full, composing an authentic material for the analysis.

In order to analyze the data, Minayo's Hermeneutic-Dialectic was used, which approximates the studied object to reality, through the interpretation of the meanings, subjectivity and relations of the individual, contrasting their individual and social practices.[9] Such technique was performed in stages, namely: data ordering; data classification; cross-reading and; final analysis. In the assurance of abiding to confidentiality and anonymity of study participants, they were identified by the letter "S" and by the number of respondents (S_1, S_2 ... S_{10}).

The study complied with Resolution 466/2012, respecting the ethical principles of autonomy, beneficence, non-maleficence and justice.[10] It was approved by the Ethics and Research Committee of the Regional University of Cariri, with the opinion number: 974.841.

RESULTS

Respondents were aged 20 to over 65 years. Six people had less than four years of education, and seven of the respondents had monthly income of up to one minimum wage (R$ 788.00).

In the analysis of the itinerary of each individual under treatment for TB, the following categories emerged: Onset of symptoms and diagnosis of tuberculosis; Gateway and access to diagnosis; Decentralization of treatment and referrals to other services and; Conduct of patients and family members regarding treatment.

Onset of symptoms and diagnosis of tuberculosis

As for the symptoms related to TB, study participants reported the presence of classic signs and symptoms such as fever, cough, tiredness and even hemoptysis.

> *In the beginning I had fever all the time, I used to cough a lot, I was very tired* [...]*, I lost a lot of weight* [...] (S_1).
>
> *I coughed blood and the doctors suspected, but the doctor said that that blood was too much to be from tuberculosis, because it was too much, when I coughed (thrilled) that I know the cough. First came that bunch of curdled blood, then the blood comes and coughing and coughing* (S_4).

In most reports, the diagnosis of TB occurred in a timely manner, since the participants presented cough in less than one month. In disagreement, the inopportune time of the diagnosis occurred for those who reported coughing for more than one year, and the interviewees stated that there was a delay in the decision of the diagnosis and treatment, despite the user's insistence on the search for the resolution of the problem.

> *It took 15 to 20 days to figure out the disease, about that* (S_8).
>
> [...] *It's already three years now in June that I find myself struggling to figure out what it was that I felt. Because it was like this: when I went up any ramp, I would soon get tired, if I got altered or walked fast, I would get tired, so I wanted to find out what it was* (S_9).

For cases in which the diagnosis was late, the difficulty was identified in each report, because even with initial and classic symptoms of the disease, errors occurred in the diagnoses and, consequently, in the medical prescriptions and even in hospitalization. This was reported because of a misconception by the hospital health professional regarding the differential diagnosis of TB between pneumonia and asthma, even with the support of complementary tests (X-rays) in the Secondary Attention environment.

> *First I went to the hospital, I was tired, he (doctor on duty) said that I had asthma onset, then I took three sprays, I took three injections and I came home* (S_3).
>
> *At first I lived with a lot of fever, was coughing a lot, was very tired, I went to the hospital, consulted, had an X-ray, and the doctor said it was pneumonia. Would be hospitalized, take medication for eight days, and leave. They only said that until I was just doing this treatment, thinking it was pneumonia and nothing. When I did the examination of this disease, it was accused this serious illness* (S_1).

Gateway and access to diagnosis

Participants pointed out that the entrance to the health service was preferably the FHS, which facilitated access to diagnosis and exams such as bacilloscopy and X-ray. Monitoring and treatment were also facilitated, as they were performed by the FHS itself, without the patient going to other places.

> *It started with a very loud cough and the days were passing by and nothing was happening. I looked for the health center (FHS) and the doctor passed the examination for me to do. I did the X-ray and it was discovered. I did the other sputum culture tests, and then it was proven. I started the treatment and so far it did not need me to go anywhere else* (S_8).

Participants also gained access to diagnosis in a hospital and medical specialty center, specifically with pulmonologists. At these places, they performed complementary exams such as the "PPD" (Tuberculin Test) and others, which although not

specified, were not available by the public service and were paid by the own patient.

> *I went to the hospital with a cough and tiredness and got admitted. After I left, he sent me to the "grota's" health center (medical specialties center) and the doctor (pulmonologist) asked me for the exams and I showed the doctor of the health center (doctor of the FHS) which sent me to the "grota's" health center again because he said: No, the doctor (pulmonologist) has to see, because he was the one who asked for it.* (S_{10}).

> *The doctor asked for an X-ray of the chest, I did and it pointed an injury. I treat with a bone doctor (rheumatologist), and I went to him to show the X-ray. He looked up and said: "Let's go deeper and find out what it is", and asked for a CT scan. When I did it, it showed an extensive injury and tuberculosis. He directed me to the pulmonologist, who asked for many exams. The exams were very expensive and I had no way to pay. I went to the hospital that I had to make one of the nodule, I paid R$ 200.00, then when I received it, it was tuberculosis* (S_9).

> *First, I went to the "grota's" health center and the doctor (pulmonologist) asked for the exams of the sputum culture, the blood, the X-ray, and the one of here (shows the left arm, Tuberculinal Test - "PPD"). Then, I went to show the doctor (pulmonologist of the medical specialties center),* [...] it *was 20 (20mm) and the sputum had not given anything. I know that this one of the arm was the suspicion ("PPD"). He passed a nose exam (bronchoscopy), where it showed the bacteria that were being generated* (S_4).

Decentralization of treatment and referrals to other services

The treatment of most of the respondents was performed in a decentralized manner, in the FHS of their locality, close to their home, such as the monitoring of smear exams, which were facilitated and performed at home or at the Basic Health Unit.

> *I do my treatment at the health clinic right here. I do the smear microscopy,* [...] *I do at home and I send to nurse doctor* (S_2).

In contrast to the decentralized treatment in the FHS, it was possible to meet participants who performed their treatment at the Center of Medical Specialties of the Municipality. The choice of this health service was due to the link established with the health professional or the absence of FHS near their home.

> *I went to the doctor at the "grota's" health center* (medical specialties center)*, because he's always been the one who listened to me the most, since when I had the first pneumonia, got it? I didn't go to the other health center (FHS of their locality), because I don't like the doctor there* (S_4).

> *I go to the "grota's" center because here in the neighborhood there is no health center* (S_6).

Most of the respondents were referred to the Secondary Care level, in this case, the specialty center, because it offered assistance with pulmonologist doctors. The reason for the referral was due to the need to confirm the diagnosis, in case of doubts, or to investigate the disease, in atypical cases.

> *I went here to the post (FHS) and I told the doctor about that cough and the tiredness I was feeling. There, the doctor immediately asked for the tests for this disease, before receiving the results he already suspected that it was tuberculosis. Then he sent me to the "grota's" center (medical specialty center) just to confirm (S_7).*

> *Only now, for pulmonologist. The doctor sent me to the "grota's" health center (S_9).*

Conduct of patients and family members regarding treatment

The participant's role was also examined when questioned about the choice of how and where he underwent treatment with the FHS team and whether his family participated in the decision to treat it. Accordingly, what converged in the speeches was a certain submission, in which the participants reported certain passivity in the decision-making moment of the treatment, complying with the referrals and obeying the commands given by the health professionals. Highlighted in the speeches:

> *The doctor (nurse) from the post near my mother's house, who put me to do the treatment near where I live, but I liked it, I do not like to walk much.* (S_3)

Divergent from the above it can be observed that only one of the interviewees had freedom of choice, since they chose where and how to carry out their treatment. The choice for follow-up at the specialty center was due to the relationship with the health professional of the service, while in the FHS the distancing was due to the lack of trust in the service.

> *Yes, I chose the specialty center, because of Dr. X, whenever I feel something, I go there. He's the one who attends me the most since I had the first pneumonia. I did not go to the center near my house because the doctor got my prescription wrong. There was this time I went to get my pressure medication and when I was about to buy it the pharmacist said: this is a syrup. After that I got afraid* (S_4)

In this context, the family's participation in the treatment decision prevailed. Observing a fragility of the participants, who relied themselves on the family as a base of emotional support and of assistance in health care in face of the difficulties that appeared.

> *Mother and all my sisters. It was at the health center that I warned the doctor that I was sick and scheduled a visit to see what that cough was. They tell the nurse that I'm not okay, they go after medication so I get better, they help me a lot.* (S_2)
>
> *Participated. My wife and children, who helped me in everything, took me to take exams and everything.* (S_7)

The absence of family participation was observed, especially for one of the participants, which highlights the prejudice of people in relation to TB, appearing to be fragile in face of their health situation.

> *I solved everything myself, without the help of anyone, neither of my family, people here have prejudice with this disease* (S_8)

DISCUSSION

The therapeutic itinerary study sought to identify the organizational dimension of the health system and the care technologies offered to people with TB. Patient transit was verified in the different subsystems of health care to meet the health needs of study participants and to guarantee access to technologies that improve and prolong life.

The early diagnosis of TB is one of the important actions to control and disrupt the transmission chain. In this study, the time elapsed for the diagnosis was from days to years. In Brazilian studies, it was observed a considerable difference in the time for completion of the diagnosis of the disease, which includes fragility of access to the diagnosis related to health services with a median delay time of 15 days,[11] or with median time less than or equal to 30 days.[3] In addition to the influence of individual determinants on delayed TB diagnosis, such as single individuals with up to eight years of schooling and unemployed who delayed from 20 to more than 30 days to seek health services.[12] These findings demonstrate the need to investigate treatment delay, to elaborate planning, research and articulation of health services. As well as the need for more effective performance by health professionals, especially from the PHC, in investigating cases of the disease in its area of coverage.

Two misdiagnoses were identified, especially in the differential diagnosis between TB and pneumonia. These data are in agreement with a survey carried out in municipal public services of three major capitals of the country, according to which the respiratory symptomatic individuals attended routinely have errors in the diagnosis. Thus, they are often treated for flu, cold, allergy and pneumonia. This has occurred because health professionals do not have TB as a diagnostic hypothesis.[13] Then, it is possible to note the patients' long path, between hospitals and health care units, until the late diagnosis of TB is confirmed. In addition to the health professionals making use of more complex tests, to the detriment of the most specific and least costly, to confirm the disease.

Regarding the gateway, participants sought different levels of primary or secondary attention. These results highlight the reality found in other studies,[14,15] which signal as a gateway to PHC, the emergency units, the private health service and the specialized care service. The latter as the best in diagnostic performance for the elderly population.[15] Although, in the analysis of the program to improve access and quality of basic care, the number of confirmed cases of TB and symptomatic respiratory diseases, reached 81.1% in the FHS throughout Brazil.[16]

In theory, they all serve as a gateway to both the diagnosis of the disease and to alleviate more serious symptoms, as well as direct access to medical consultation and/or other services.[17] However, it is necessary to improve primary health care, as organizer of care and guarantee of access to avoid the delay of diagnosis and treatment that have repercussions in the control of the disease.

It stresses that the transit of each patient may occur in different ways in the search for a health subsystem, which are related to cognitive and socioeconomic aspects.[8] The choice of these services was also motivated by the link, the ease of access, the orientation of family members and the search for problem solving, also found in another study.[17]

Comprising the logic of comprehensive care, PHC must be able to diagnose and resolve most of the cases. A study of respiratory symptomatic flows and results achieved in the PHC unit in two municipalities of Rio Grande do Sul, in general, detected fragmentation with low case detection and response to diagnosis in 8.8% and 50.0% in this level of attention between the Municipalities of Pelotas and Sapucaia do Sul, respectively.[18] This data reflects a reversal of the flow in care, since the PHC is a health care provider and a preferential gateway. In particular, it would be up to her to prioritize the care of people with these chronic conditions.

In this study, soon after the first contact, smear microscopy and X-rays were requested to confirm the disease. Similar studies confirm that smear microscopy is the method of choice,[19] especially in the health units.[20] In fact, the aforementioned exams are those recommended for the diagnosis of TB, which should be easily accessible, low cost and offered by the Unify Health System, however the access prints the conduct of the case that can confer delay in the diagnosis and treatment of the disease.

Other more complex diagnostic tests were also requested, such as tomography, bronchoscopy and biopsy, which generated higher costs for some participants and, consequently, delayed diagnosis. To corroborate this reality, the research identified other tests performed in addition to smear microscopy and X-rays, such as the Tuberculin Test (PPD), biopsy and sputum culture.[21] In fact, despite the free TB service, in India, the substantial costs

for the search and treatment incurred in financial burdens for the patient. These costs can be minimized by promoting the early search for care and the decentralization of efficient diagnoses and treatment services.[22]

Complementary exams should be requested when needed, but it is up to the articulation in the network of attention to make them available and facilitate access, at no cost to the user.

Most of the participants were referred to the specialist in the search for definition of diagnosis, specifically in cases of doubt. Referrals to specialized services present better performance in relation to the diagnosis of the disease, since these institutions have specialized teams and offer diagnostic support tests.[23] Although, referrals are strategies used by FHS professionals to support the correct diagnosis, there is a need to qualify and sensitize these professionals about the importance of proper management of the person with TB.

It was found that the role of the person with TB in the choice of their therapeutic itinerary was limited, since they were partly tracked by health professionals. On the other hand, family participation prevailed, mainly performed by the mother, wife, children and sisters. These collaborated in the management of health care through the communication between the professionals of the FHS and the patients. Results identified in a study, carried out in Ribeirão Preto-São Paulo, pointed out the importance of family participation in achieving TB treatment success and in the effectiveness of the strategy to cope with the disease.[24]

Corroborating, a study in India also found the influence of families on TB control, related to the support given in face of the prolonged treatment time and clinical conditions; the need for nutritional and subsistence support, and adherence to treatment.[25]

It is understood that in the practice of care, the analysis of therapeutic itinerary requires qualified professionals capable of carrying out articulated actions, so that they meet the health needs of people with TB. In the search to implement care through a link and a social network of support that groups actors in the practice of processes of illness and treatment directly observed. This set of events differs from the possibility of fragile, uncertain and controversial ties that the therapeutic itinerary makes explicit between the world of practices and practical ontologies.[8] For this, it is necessary the social interaction between health professionals, patient and family to reduce the path, especially of the diagnosis. In addition to the need to promote a consistent approach in public and private health services, making similar the commitment to the targets for the "end of TB".

CONSIDERATIONS AND IMPLICATIONS FOR PRACTICE

The itinerary of people with TB in Primary Care reveals fragilities when the mishaps to obtain the diagnosis and health care, which requires the need to raise awareness among health professionals at all levels of care.

In the management of care, a greater integration of health services, a service flow chart to access the necessary technologies and patient monitoring, should be established in order to ensure supportive and integral care.

The interactive link between patient, family and professionals was potentialized for negotiation of care regarding the condition of the patients. Although a person who did not get support from relatives caused by stigma and prejudice regarding the disease is identified. In addition to other information provided by patients for being in other types of treatment and costs that may be obstacles to the conduct of treatment in accordance with their social context.

The study presents limitations related to the number of participants and the study site, which prevents the generalization of the findings. However, the aspects elucidated by the challenge of the therapeutic itinerary of patients, in their broadest aspect and in more comprehensive investigations, stand out in the face of the need for complementary studies, since there is a lack of research on the practice of patient care with TB.

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