PATHWAYS OF CHILDREN AND ADOLESCENTS WITH TUBERCULOSIS IN HEALTH SERVICES

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ABSTRACT
Objective: to know the pathways people under the age of 15 follow in search of the diagnosis and treatment of tuberculosis.
Method: an exploratory, descriptive study with a qualitative approach, carried out from March to July 2015 in priority cities for tuberculosis control. In this research, 11 caregivers of tuberculosis patients under the age of 15 years and 11 nurses from the primary health care units participated, selected in an intentional way. For data collection, semi-structured interviews were recorded and transcribed, organized in Atlas.ti software, analyzed using thematic content analysis.
Result: construction of two categories, namely: In search of the diagnosis in the different gateways to the health system, presenting the services the caregivers use and the aspects that involved the care of these people in those places; Pathways towards tuberculosis treatment, showing the accessibility to the Health Care Network in these people’s search for the diagnosis and treatment of tuberculosis.
Conclusion: the entrance door through the emergency services, the diagnosis at higher complexity levels in the network and the concomitant follow-up by nurses and physicians of two services show the fragility of the family’s bond with primary care. In addition, the need to strengthen the family health strategy in tuberculosis control actions is highlighted, as well as the need to disseminate in the health services what care points exist in the network for the appropriate referral of persons under 15 years of age with tuberculosis.
INTRODUCTION

In the world, the actual situation of Tuberculosis (TB) in children is unknown. It is considered to be related to the low capacity of services to diagnose the disease, the different diagnostic methods in each country; underreporting or incomplete reporting of data or use of different methods to analyze estimates.1

By 2014, there were an estimated 9.6 million new cases of the disease worldwide and, of these, 1.0 million were children. There were also 1.5 million deaths from tuberculosis during this period, of which approximately 140,000 happened in children.1 In Brazil, despite a decline in the number of cases of tuberculosis in the last 20 years, 2,368 cases were reported in children, which corresponds to about 3% of the total cases reported in the country.1

To improve the access of the general population and the most vulnerable populations to TB in Brazil, the National Program for Tuberculosis Control guides the decentralization of actions to Primary Health Care (PHC), making it the system’s main gateway.2 Through a coordinated set of health care points, with different technological densities, this care level is expected to communicate with others, aiming for continuous and comprehensive care.3

With regard to families who are vulnerable to TB, the majority lives in poverty and knows little about the disease and access to health services.4 From this perspective, developing studies on the access of people under 15 with TB to the Health Care Network (HCN), from the beginning of the symptoms to the closure of the cases, becomes relevant to identify the gaps that involve families and health services in this age group. And also to contribute to scientific production on this subject, given the existence of few Brazilian3 and international studies6 involving this age group, which address biological issues of TB (new forms of treatment and diagnostic means), as well as profiles and meanings of the disease for the family.

The choice of persons under fifteen years of age was due to the importance of the epidemiological aspects of the disease in this age group, related to negligence in the diagnosis and/or treatment, immunological and vaccination status, increased risk of developing severe forms of TB and to social vulnerability where there may be a lack of access to health services.4

Knowing the paths covered involves the understanding of the terms accessibility, which is used as the possibility of people getting to the services; and access, which is how people experience this characteristic of their health service. Accessibility is a structural element necessary for the first health care and, in order to offer it, the point of care needs to be accessible and available.7

The objective of this study is to know the pathways taken by people under the age of 15 for the diagnosis and treatment of TB in the health system, according to caregivers and professionals.

METHOD

This is an exploratory and descriptive study with a qualitative approach, carried out in two priority cities for TB control actions in the State of Rio Grande do Norte. The selection of participants was intentional, through the choice of cases of TB in
people under 15 years of age. Initially, access was obtained to the database of the State Disease Notification System (SINAN), in which the inclusion criteria were: being a case of TB in persons under 15 years of age living in the two priority cities for the control of the disease in the State, in the period between January and December 2014. Nineteen cases were identified, eight of which were excluded because they figured in an Institutional Welcoming system (halfway houses), with duplicate files in SINAN.

Considering the 11 valid cases, the Primary Health Care Units (PHCU) were identified where people under the age of 15 were followed up. From then on, the nurses were selected according to the following inclusion criteria: developing activities at the PHCU for a minimum period of three months and accompanying children and adolescents with TB. Subsequently, caregivers of persons under the age of 15 were selected who met the following inclusion criteria: they provided direct care to these people during the diagnosis and treatment of the disease and were residents of the two priority cities for the control of the disease. In total, 11 caregivers and 11 nurses were eligible for the study, without any refusal of the selected individuals.

Data collection was carried out from March to July 2015, by a researcher, nurse and teacher, holding a master’s degree and experienced in qualitative research. Participants did not know the researcher; the contact occurred personally with visits to the PHCU where the nurses worked and the caregivers’ homes. During this first contact, the reason for the visit was explained, as well as the invitation to participate in the research. In case of acceptance, the place and time of the interviews were defined: 13 took place at the PHCU, seven at the homes and two at the caregivers’ workplace; all in the daytime period.

Interviews were conducted based on a road map with the participants’ identification data and guiding questions. For the caregivers, the interview was started with the following question: tell me about the pathway/itinerary that you have taken from the first symptoms of TB in the child to the closure of the case. For the nurses, the guiding question was: tell me how the Tuberculosis Control Program (TCP) works at the PHCU where you work. As the answers arose, new questions were asked in order to cover the research problem in greater depth. The interviews were recorded, held during a single meeting, with an average length of 40 minutes.

In order to systematize and analyze the data, the thematic content analysis technique was used, comprising three stages, namely: pre-analysis, material exploration, treatment of results, inference and interpretation. In the exploration phase of the material, we used the scientific software Atlas.ti, version 7.5.6, under the license 76433-7A304-9CE81-4Z4F1-0024L, based on which the interviews were organized and coded phrase by phrase, by two researchers. After coding, a comparison was made around the common subject, the families (subcategories) of the study. In the comparative analysis of the families, two categories emerged in the results.

To guarantee the participants’ anonymity, the letter C was used to identify caregivers; and the letter N to identify the nurses, followed by Arabic numerals according to the order of participation in the interviews, i.e. caregiver 1 (C1), nurse 1 (N1), and so on. All the ethical precepts of Resolution 466/12 were followed. The study received approval from the Research Ethics Committee, in accordance with Opinion 978.361 and CAAE 38465414.2.0000.5292.

RESULTS

The 11 caregivers participating in this study were between 31 and 40 years of age. Most were female, married, with finished secondary education, family income of less than a minimum wage plus family allowance and working as a day laborer and/or street vendor. The 11 nurses, all female, were between 30 and 40 years of age. Most of them worked in the Family Health Strategy (FHS) with 21 to 30 years of experience in the TCP. Of the 11 people under the age of 15, the majority was female, under the age of ten, and did not go to school. The majority had an x-ray examination that was considered suspect and had a pulmonary form of TB. All of them underwent treatment for the disease.

From the analysis of the study participants’ narratives, two categories emerged: In search of the diagnosis in the various gateways to the health system and Pathways to treat tuberculosis. They were described and exemplified with excerpts from the participants’ discourse.

In search of the diagnosis in the different gateways to the health system

As a gateway to the health system, the caregivers turned to the emergency services of public or private clinics and hospitals; followed by specialized services and private practices. In this case, the PHCU was the gateway for only one child/adolescent diagnosed with TB. The reasons the caregivers reported for not attending the PHCU include: hav-
ing a health insurance; organization and provision of pediatric services; and the perceived severity of the child’s health condition, which made them visit emergency services.

*My son has a health insurance, so I took him to the emergency service of a hospital (C5). The unit here [...] ‘only God’s mercy.’ And as we did not know what the boy had and his condition was getting worse, I took him to the ER (C10).

[...] I thought like, if I go to the doctor first, he’s going to have me go to the emergency room, so I went straight to the emergency room (C9).

As for the gateway through specialized children’s services, it was observed that these served the referenced population and also responded to the spontaneous demand, which facilitated the access to care. On the other hand, the door of the private clinics was directly related to the patients’ socioeconomic status, as four caregivers had a health insurance.

A relevant aspect for the diagnosis of TB in people under 15 years of age in this study was the caregivers’ difficult pathway, caused by the round trips to health services due to uncertainty on the diagnosis of the disease and the non-specificity of the laboratory tests.

*I took him [son] several times to the ER, did all the exams and x-ray. At first the doctor told me that it could be pneumonia, she passed the medication and I did not see any improvement, eight days later he woke up coughing a lot and bleeding, so I panicked (C7). I said, my God, how can anybody find out what this girl has. Nobody thought of this disease. At that time, I walked a lot. Wow, you have no idea. I have a card of all the places [...] she has records at all pediatricians’ offices, I have everything, all this because of the history of tuberculosis (C3).

For people younger than 15 years, exclusively attended by the public system and who needed specialists to elucidate the diagnosis, in both cities, the professionals referred to the clinical centers or the municipal polyclinics. In cases of need for hospitalization, the reference was a philanthropic hospital for children and private hospitals serving people under the age of 15, located in the capital. Inpatient services performed most of the diagnoses of TB in people under 15 years of age, perhaps due to the difficulty for emergency care professionals to suspect the disease, either in hospitals or Emergency Care Units (ECU).

*I took him to the emergency room and the doctors looked at the x-ray and did not know if it was pneumonia or tuberculosis, they said that he was going to get hospitalized [...]. At the hospital he did the CT scan and the doctor said, ‘Mom, the infectious disease specialist had TB treatment started because he said that he is sure that his case is not pneumonia, it’s tuberculosis, based on the symptoms and x-ray’ (C9).

It should be noted that children’s hospitals with specialized outpatient clinics received the greatest demand for suspected cases of TB, an aspect that is of concern to PHC professionals, as TB actions in the health system are decentralized to PHC.

The epidemiological surveillance coordination thinks it is way out of line when a patient begins tuberculosis treatment through the hospital, which should not happen. these cases have to be diagnosed and treated at the unit, in the neighborhood where they live (N1).

As for the laboratory tests, these were done at the hospital, while the x-rays for the people under 15 years investigated were taken at the emergency services, private clinics, at a referral center in the city and at the hospitals.

In view of the delay to elaborate their children’s diagnosis of TB, some caregivers expressed feelings of anger, anguish, revolt and denial of the disease.

What went through my head when the doctor said it was tuberculosis was rage, because this disease could have been discovered earlier [...]. We all felt great anguish due to the delay in the diagnosis (C8). Concerning the tuberculosis or not in my daughter, ah, I didn’t accept it! Until today I think it wasn’t tuberculosis (C6).

### Pathways towards tuberculosis treatment

In view of the diagnosis of TB, all caregivers were advised to go to the nearest PHCU to start treatment or to continue the treatment initiated at the hospital. Most caregivers mentioned that they were received well at the service and had the appointment with the nurse on the same day and time as they visited the service.

*At the patient’s first contact with the service, we collect the history, do the nursing consultation, the rapid syphilis and HIV test, counseling on the medication and how the treatment will be, we request the exams for the whole family and we schedule the next appointments (N7).*

The investigation of contacts was done through consultation and request of laboratory and imaging exams. Nevertheless, some family members refused to do the TB research.

*The nurse delivered the x-ray requests of the entire family that had contact. I did not because I really did not want to. But I gave [the request] to his father, who has
contact with the boy at weekends, he did it. His grandmother did not want to, nor his current grandfather, none of them wanted to take care of this disease, the uncle who already had this disease and uses drugs, he did not want to have the x-ray taken [...] (C10).

A nurse reported that, in cases when the service does not have the FHS or the patients have a health insurance, contact evaluation was not scheduled and the professionals did not visit these families’ homes, which interferes in the identification of the adult source of TB and contribute to the spread of the disease.

Regarding the start of the treatment, the nurses reported that, initially, a small amount of medication was distributed while awaiting the drugs requested. [...] Usually we take medication from another patient to start treatment while his medication does not arrive. I have to deliver the medication on the first day, deliver it soon, for him to start treatment the next day (N10).

Despite the availability of medications, caregivers reported that compliance with TB treatment was initially impaired by the children’s difficulty in accepting the palatability of the drugs and ingesting them as tablets and, later, considering a significant improvement of the signs and symptoms, which made them forget about the daily administration of the dose.

At first I diluted the tablet in the water, even so he vomited and I tried again. It was not easy, because the treatment was very heavy for him, sometimes he vomited, did not feel well, did not eat, it was very difficult (C10).

PHC should be responsible for monitoring persons under 15 years of age with TB. Nevertheless, factors such as: condominums with restricted access to Community Health Agents; areas of urban violence; and lack of interaction with PHCU professionals made it difficult to perform the home visit and collaborated to weaken the bond between the families and the team.

In addition, the professional who had most contact with the family was the nurse and, according to some caregivers, she knew the history of the current illness, called the TB patients by name and facilitated communication by providing her personal telephone number.

He is attended by the same professionals, the nurse and the doctor, and it has to be, because if you change one of them, I do not want to! (C2).

At the end of the treatment, the cases were closed differently for people under the age of 15 who were accompanied by two health services.

[...] the patients who are accompanied by the hospital do everything there, including the discharge due to cure is given there because they do the x-ray and the exams as well. Then, they go to the service with the discharge papers and I attach a copy in his medical record (N11). The doctor did not ask for a test, he said: ready, he stopped the treatment and told me to lead a normal life (C5).

In one case, the caregiver did not commit to visiting the team to complete the final examination and close off the TB case.

I was able to give the pills for six months, but I did not go to the doctor at the end. I had a lot of problems [...] and time went by and I did not go there any more. I think it’s been a couple of months since he finished. My health care agent always says: go there to close off with the nurse (C10).

DISCUSSION

The path taken by caregivers of persons under the age of 15 years with TB in the search for the diagnosis and treatment involves the availability of access and accessibility to the services, which starts with the first health service they visited. A service is considered a gateway when the population and staff identify it as the first health resource to be pursued when there is a need or a health problem.9

The choice of these services is related to the degree of physical and psychological suffering the family members experience, besides the view of children as more vulnerable beings, who need the care of more accessible health professionals, with more available diagnostic means and without the need to schedule appointments.10

These characteristics are in line with the emergency services, which possess greater problem solving ability and serve people from their homes, with health problems that could be solved at the PHCU. For physicians at these services, releasing a child without care becomes a problem due to the risk of an aggravated health condition on subsequent days, especially if they are younger than one year of age.11

For this reason, caregivers prefer to remain in the unit for hours waiting for care and to overcrowd the emergency services, whether public or private.

This problem can be mitigated by the strengthening of PHC’s attributes of integralty and longitudinality with PHC users, especially those related to child health care, as some of the problems would be identified and solved at this level of care, also for children and adolescents who have access to supplemental/private health services.12 In this study, all caregivers who had health insurances and who
did not use the PHC services before their child’s TB pursued the emergency services. In addition, the emergency services, whether public or private, have weaknesses in their structure and gaps in the identification process of TB cases, especially those involving children, which explains the importance of PHC monitoring.

In this process, factors related to the family - such as the understanding of the children’s health situation and the interactions that permeate the relationships around them - and to the children - such as the presence of signs and symptoms common to other bacterial and viral infections, HIV, malnutrition and especially pneumonia, in addition to radiological manifestations, which are mostly unspecific in children - generate uncertainties in the physician to conclude the diagnosis of TB in children.

For some medical professionals, the low frequency of cases of children with TB in PHC and, as a consequence, the inexperience in diagnosing the disease in this age group generates a difficulty in the management of TB in pediatrics, which makes this event somewhat rare, being an assignment of specialist physicians. This fact may justify the referral of people under the age of 15 by PHC and general hospital professionals to referral hospitals in order to obtain a TB diagnosis and treatment. This demonstrates the need for professional training on child TB at all levels of care and in accordance with TCP protocols. In addition, the large number of patients in hospitals may reflect the lack of awareness on the decentralization of TCP actions to PHC, which has been slowly adapting as the Health Care Network is reorganized, mainly articulated with the expansion of the FHS.

In this scenario, the delay in the diagnosis generates, among other feelings, the denial of TB. In the search for a concrete response, caregivers follow other avenues to confirm their suspicions and continue to deny TB, mainly due to the fear of discrimination of children, resulting from the stigma and prejudice that surrounds the disease. These feelings need to be overcome with the help of trained professionals who are specialized in dealing with people under the age of 15 and their families.

In view of the confirmation of the TB diagnosis and the decentralization of actions to PHC, professionals and managers should provide a welcome that is committed to the new healthcare model, capable of involving users in the unit’s self-care and educational actions.

In addition, involvement in self-care involves the ingestion of anti-TB drugs that are distributed in the country exclusively by the public health service. Both the caregivers and nurses in this study assessed the availability and the gratuity of the drugs positively for the sake of the continuity of TB treatment. Brazil is the only one of the 22 countries with the highest burden of TB not to have a private market for manufacturers and consumers and to follow the World Health Organization guidelines for the treatment of this illness in its entire health system. Which contributes to the demand for PHC, independently of the families’ socioeconomic condition.

In relation to the investigation of the contacts, in this study, we can identify problems that are similar to the findings in the literature, such as, for example, not performing the clinical consultation of the contacts as a service routine, not using the tuberculin test as determinant in the identification of latent TB infection and the low adherence of the contacts to the requested tests. As a result of the decentralization of TB control actions to PHC - which coordinates care at the various care levels in the network, this situation is aggravated when there are no FHS and nurses involved in the continuity of the actions towards prevention, control and interruption of the TB transmission chain with the families.

In this sense, part of the problems related to the investigation of the contacts may be related to the fragility of the bond/longitudinality of the users with PHC. Thus, the care level is unable to grant conditions for the development of this attribute, reflecting the caregiver’s merely occasional demand for this care level.

Therefore, the good relationship between user and service is essential for compliance with the Directly Observed Treatment (DOT) strategy, which consists of observing the medication intake and requiring that the PHCU reorganizes the team’s structure and work process. Therefore, the health team needs to closely monitor the family, using a home visit, an FHS work tool, essential for the follow-up of tuberculosis cases in DOT.

Nevertheless, weaknesses were identified in the implementation of this strategy in the two cities studied, which were mainly related to the lack of guidelines on drug administration in children; insufficient staff to control the medication intake, which was the responsibility of the parents; and the difficulty to get access to the residences. In addition, the use of this tool comes with other difficulties, such as the non-systematic planning of actions, relationship problems among professionals, work overload and fear of violence in the territory. Thus, in order
to avoid treatment abandonment, the professional of PHCU should change the structure and work process in order to meet the needs of TB patients.18

The persistence of these aspects, combined with the fragmentation of continuity at other care levels, compromises the integrity and proper coordination between them, requiring that managers use strategies that favor the resolution of health problems. One of these strategies is the hiring of services through the private network21 to perform more complex imaging tests that are not offered in the cities or agreed upon with the public health network.

Regarding the closure of the cases, it could be identified that two caregivers did not visit the UBS to complete the follow-up, a fact that negatively influenced the notes in the medical records and the completeness of the TB investigation forms. In this process, the low completeness of reporting forms limits the analysis of health information systems’ data, and may compromise TB control actions by interfering with care and decision-making processes.22

Despite these problems, the access and accessibility to the service by caregivers of persons under 15 years of age with TB were facilitated by good relationships and communication with the nurses, through spontaneous demand, available schedules and good communication. This demonstrates the creation of a bond with the person and his family, the direct monitoring and the accountability to the municipal managers for the treatments.23

In this perspective, training the team on TB in the children’s age group is a necessary strategy to reduce the problems the caregivers and the nurses experienced regarding the accomplishment of exams and treatment abandonment, which can compromise the cure and the control of the disease.

In addition, TB control actions, with an expanded health focus, require the combination of integrated and specialized activities, so that a care model can be guaranteed that considers the debilitating state of the disease.24 For this to happen, investments in all aspects are needed for the improvement of PHCU’s and specialized health services, as well as the support of PHCU management regarding the organization of actions and the problem-solving ability of TB patients and their families’ needs.25

The limitations of the study were related to: sample size; subjects’ fear of recording interviews; and the risk of violence in the data collection scenarios. The knowledge built can contribute to the discussion and organization of referral protocols and flow for people under 15 with TB within the healthcare network.

CONCLUSION

This study allowed us to discover the pathways people under 15 years of age with TB go through in the health services, according to the caregivers and the nurses of the PHCU. The gateway into the health system was through the emergency services of the hospitals and the emergency care units, and the diagnosis of TB occurred in the hospitalization sector of the children’s hospitals, through imaging tests and pediatric infectious disease specialists. The nurses at the PHCU were responsible for distributing and controlling the drugs and case monitoring happened concomitantly at two health services, as the doctor’s appointments took place at the services where the TB diagnosis had been reached. Some of these aspects highlight the difficulty of emergency service professionals in suspecting and conducting confirmatory tests for TB in this age group and the fragility of the family bond with PHC.

Because TB is difficult to diagnose in people younger than 15 years of age, adults should be investigated, considering that the disease in adults is a sentinel event for TB in children. It is also necessary to strengthen the FHS; to train professionals at the various care levels, particularly the nurses, to increase the suspicion; and to better understand the specific tests for the diagnosis of childhood TB. In addition, the importance of PHC as the gateway to the system needs to be strengthened, including investments to disclose the PHCU to the care points in the network, which is fundamental for the appropriate referencing of TB patients younger than 15 years of age.

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