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Barriers in the treatment of latent tuberculosis infection (LTBI) in children: a case study

Barreiras no tratamento da infecção latente por tuberculose (ILTB) na criança: um estudo de caso

Obstáculos en el tratamiento de la infección latente por tuberculosis (ILTB) en el niño: un estudio de caso

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Abstract

Objective: Analyze the barriers the families face in the treatment of latent TB infection (LTBI) in children. **Methods:** Descriptive study, in two stages. In the first, the medical records of 0 to 11 year-old children treated for LTBI at a municipal healthcare center in the city of Rio de Janeiro, Brazil, were analyzed. At the second, an interview with the families. In both stages, the personal, family, economic, social and healthcare service barriers were identified. **Results:** In the first stage; there were barriers in (47/228): the service - 4 (8.5%); personal - 4 (8.5%); family - 21 (44.7%); physiological - 12 (25.5%). At the second; the barriers at (50/85): economical - 19 (38%); social - 13 (26%); personal and family - 18(36%). **Conclusion:** Unfavorable socioeconomic factors affected the care of child in both stages of study. Rethinking the way of dealing with the social determinants associated with tuberculosis may be the way to avoid abandonment and the disruption of LTBI treatment.

Keywords: Tuberculosis; Latent tuberculosis; Child; Primary Health Care; Public Health.

Resumo

Objetivo: Analisar as barreiras enfrentadas pelo familiar no tratamento da infecção latente por tuberculose (ILTB) na criança. **Métodos:** Estudo descritivo, em duas etapas. Na primeira, analisados prontuários de crianças de 0 a 11 anos tratadas para ILTB em um centro municipal de saúde no Município do Rio de Janeiro. Na segunda, entrevista com os familiares. Nas duas etapas buscou-se identificar barreiras pessoais, familiares, econômicas, sociais e do serviço. **Resultados:** Primeira etapa; houve barreiras (47/228): no serviço - 4 (8,5%); pessoais - 4 (8,5%); familiares - 21 (44,7%); fisiológicas - 12 (25,5%). Na segunda; houve barreiras (50/85): econômicas - 19 (38%); sociais - 13 (26%); pessoais e familiares - 18 (36%). **Conclusão:** Fatores socioeconômicos desfavoráveis afetaram o cuidado da criança nas duas etapas do estudo. Repensar na forma de lidar com os determinantes sociais associados à tuberculose pode ser o caminho para evitar abandono e interrupções deste tratamento.

Palavras-chave: Tuberculose; Tuberculose latente; Criança; Atenção Primária à Saúde; Saúde Pública.

Resumen

Objetivo: Analizar las barreras enfrentadas por el familiar en el Tratamiento de la Infección Tuberculosa Latente (ILTB) del niño. **Métodos:** Estudio descriptivo compuesto por dos etapas. 1) Análisis de prontuarios de niños de 0 a 11 años sometidos al ILTB en un centro municipal de salud en Rio de Janeiro, Brasil. 2) Se realizaron entrevistas con los familiares. En las dos etapas se buscó identificar barreras personales, familiares, económicas, sociales y del servicio. **Resultados:** En la primera, hubo obstáculos (47/228): en el servicio 4 (8,5%); personales 4 (8,5%); familiares 21 (44,7%); fisiológicas 12 (25,5%). En la segunda (50/85): económicos 19 (38%); sociales 13 (26%); personales y de familia 18 (36%). **Conclusión:** Factores socioeconómicos desfavorables afectaron la atención de los niños en las dos etapas. Repensar la manera de lidiar con los determinantes sociales asociados a la tuberculosis puede ser el camino para evitar el abandono y las interrupciones del tratamiento.

Palabras-clave: Tuberculosis; Tuberculosis latente; Niño; Atención Primaria de Salud; Salud Pública.

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INTRODUCTION

Contact control is an important tool to prevent illness in individuals infected with tuberculosis (TB)[1,2,3]. Efforts should be made to guarantee medication access and conditions to appropriately monitor these individuals, including the management of the adverse effects and surveillance of missing patients[1,3].

As TB is mainly linked to poverty, despite the whole progress achieved to control this disease, such as directly observed treatment (DOT) and improved access to treatment and medication, the economically and socially disadvantaged population is a risk group for the disease and later for treatment abandonment[4,5,6].

Countless adverse and precarious situations this group normally experiences, mainly in the community and in the home environment, can negatively influence the adherence. Measures to identify possible barriers they face while still in the welcoming phase can contribute to early interventions, so as not to compromise the entire operational schedule established in this control and, consequently, their health.

Brazilian publications about the barriers or difficulties the relatives face for childcare in the home context remain scarce when considering the treatment of latent tuberculosis infections (LTBI). These are focused on adult patients under treatment for TB. One of the service-related obstacles in many countries is the absence of data notification about the baseline and the monitoring of LTBI, or data that are only filed at the units where the individual was treated, which does not permit evaluations and studies about possible adverse effects, interruptions and treatment outcomes[7].

Due to the greater contact and dependence on the parents, mainly until the pre-school phase, the children used to be contaminated at home, that is, the relatives themselves are the transmission source[8]. It is probable that, when barriers exist for adults, the same is the case for children and, without interventions, these can influence the treatment adherence of both.

As this study involved individuals who used a primary public health service, the results aim to encourage the professionals to heed the identification of possible barriers or difficulties during the treatment of LTBI, especially those responsible for treating the children.

METHOD

This descriptive and exploratory study is part of a master's thesis. It was undertaken in two phases, in Planning Area (PA) 2.1 of the city of Rio de Janeiro (RJ).

This PA was chosen because, at that time, it manifested a high incidence rate of TB in the city of Rio de Janeiro, particularly the Rocinha community, an area attended by the Municipal Health Center (CMS) where the study was developed. In 2002, this community showed one of the highest TB incidence rates, four times higher than the city's average[9]. In 2009, the incidence rate corresponded to 380/100,000 inhabitants[10]. According to Census data, in 2010, the community consisted of 69,000 inhabitants, although about 180 thousand people lived packed in its back streets and alleys according to the inhabitants of the community[11].

The community presents architectonic characteristics, basic sanitation problems and disordered growth of the neighborhood, contributing to the dissemination of TB[11,12].

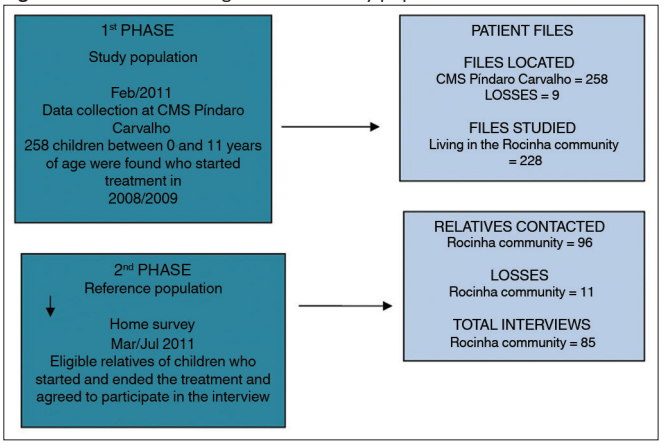
The study population included all users of the CMS who attended the pediatric sector of tuberculosis control. This Municipal Center, located in the South of the city of Rio de Janeiro, was selected because it works with a tuberculosis control program and this study was focused on TB contacts.

The reference population were the family members responsible for children submitted to LTBI treatment who were between 0 and 11 years old, contacts of pulmonary TB cases, whose children started the LTBI treatment between January 1st 2008 and December 31st 2009, corresponding to 258 people.

The inclusion criteria used in the first phase were: children between 0 and 11 years old registered for LTBI treatment in 2008 and 2009 who lived in the community. The exclusion criteria were: situations in which the patient history could not be found; children whose address was not registered in their patient history.

A convenience sample was used. The home survey was only applied to the family members of the children who lived in Planning Area 2.1, in accordance with the inclusion and exclusion criteria. Figure 1 illustrates the constitution of the study population.

Figure 1. Constitution diagram of the study population.



A script was used to collect data from the patient histories, regarding difficulties and barriers the family members faced or were related to the child during this period with regard to the LTBI treatment. The reasons for the interruptions were included, as some also served as barriers for the child's treatment adherence. Besides this information, data were collected about: the children's gender and age, address and telephone number needed for the second study phase. Four age ranges were considered: under one year of age; 1 to 5 years; 6 to 10 years and 11 years, similar to David et al. (2000)[8].

In the second study phase, a home survey was applied to the responsible caregivers of the children who accepted to participate in the study. The inclusion criteria were: family member or caregiver responsible for most of the child's treatment during the study period and living in the same community. Exclusion criteria: deceased family member or responsible caregiver; or who could not be contacted by telephone or in person, family members who did not accept to sign the free and informed consent form (ICF).

The content of the questionnaire included two open questions, one of which was used for this study. Did you experience any personal difficulty, at home or at the health service, during the child's treatment, due to which you had to interrupt the treatment for some time? In this case, family members who indicated some kind of difficulty during the child's treatment were considered as barriers, related to: access to the health service, personal, family or economic difficulties, and to the child (due to which the treatment had to be interrupted at some time). In this phase, only family members who concluded the child's treatment were selected.

Besides this information, the participants' socioeconomic data were also selected. Education levels were considered low when the responsible caregivers was literate or had not finished primary education; and satisfactory in case of finished primary education or higher. Low income was considered when the interviewees received up to one minimum wage, help from others and were enrolled in the social program of the state government of Rio de Janeiro. Informal employment was considered as family members who gained income without an employment contract or were self-employed.

During this phase, the team from the local Family Clinic and a community health agent assisted to gain access to the community. In Brazil, the family health strategy is considered the guiding axis for the organization of primary health care, aiming for health promotion and disease prevention in the population attended[13].

The data were collected between February and July 2011. For the two phases, a database was created in an Excel worksheet. The software Openepi version 3.0.1 was used. In the first phase, the results were distributed in tables and absolute (N) and relative (%) frequencies were calculated. Next, they were analyzed in combination with the findings of the second phase.

In the second study phase, a table was elaborated to analyze the profile of the interviewees who experienced barriers in the child's treatment during the research period. The following variables were analyzed: age, education, income, illness due to TB and occupation. The results were distributed in tables, absolute (N) and relative (%) frequencies were calculated and then analyzed.

The research project was submitted to the Research Ethics Commission of the *Secretaria Municipal de Saúde e Defesa Civil do Rio de Janeiro* (SMSDC/RJ), under protocol 222/10 (CAAE Nº 0254.0.314.314-10) and received approval on 01/31/2011. In addition, authorization was requested from the Coordination of Planning Area 2.1.

Before the relatives eligible for participation signed the informed consent form (ICF), its content was read, which guaranteed the anonymity and confidentiality of the information.

RESULTS

Initially, 258 children were identified for whom LTBI treatment was indicated. The patient histories of nine of them were not located. Among the 249 histories located, 228 children were identified who lived in the community. In this phase, the cases included 125 (54.8%) girls and 103 (45.2%) boys. The age range: under one year of age 5 (2.2%); 1 to 5 year 85 (37.3%); 6 to 10 years 109 (47.8%); 11 years 29 (12.7%).

Among the patient histories analyzed, 47/228 (20.6%) cases of barriers referred by the children's family members were identified. The main reasons were: 10/47 (21.3%) interrupted the LTBI treatment because the child had some condition that suggested adverse effects and later returned to the treatment; 2/47 (0.4%) because of some condition that suggested adverse effects followed by treatment abandonment; 8/47 (17%) did not attend the consultation and did not receive medicines; 6/47 (12.8%) because the relative or the child forgot, 5/47 (10.6%) due to family problems; 3/47 (6.4%) due to lack of medicines at the pharmacy; 4/47 (8.5%) because of the child's refusal to accept the medication followed by abandonment.

In Table 1, the distribution of the main barriers the children's family members were confronted with is described, identified in the first study phase based on records in the medical histories.

In the second phase, among all children enrolled for LTBI treatment (N = 228), only 96 family members could be contacted due to the establishment timetable: 85/228 (37%) accepted to participate and were interviewed. There were 11 cases of losses due to incompatibility between the interviewee's and the interviewer's schedule.

Most of the interviewees were the children's mothers (N = 49) and were between 18 and 61 years of age. More than half were over 26 years of age. As regards the income, 29/85 interviewees did not want to provide this information;26/56 received up to one minimum wage; 13/56 reported that they received financial help from the government through a family aid program (*Bolsa Família*), besides help from other people (Table 2).

Seventy-one/85 (83.5%) interviewees informed they had TB, seven (9.9%)of whom admitted having abandoned the treatment at least once.

The family members referred barriers in 50/85 (58.8%) cases, which were:13/50 (26%) mentioned lack of money for the transportation; 7/50 (14%) distance from their place of residence (lived in the highest part of the community); 6/50 (12%) deficient public transportation (motorcycle taxi only); and 24/50 (48%) mentioned some personal, economic difficulty or in the home environment. They needed to interrupt the child's treatment at some time because: they did not have money to give good food together with the medicine to the child (on doctor's orders); they had to work and the sibling forgot to give the medicine; when the

Table 1. Distribution of main barriers identified in the first study phase

Motives	Barriers (n = 47)	n	%
Physiological	Collateral reactions	12	(25.5%)
	Total (n = 21)		
Family	• Non-attendance to consultation and did not receive drugs	8	(17%)
	• Forgetting by relative or child	6	(12.8%)
	• Family problems	6	(12.8%)
	• Loss of drugs	1	(0.2%)
Health service related	Lack of drugs at pharmacy	4	(8.5%)
Personal	Refusal by child	4	(8.5%)
Social	Did not attend the consult due to shooting in the community	1	(0.2%)
Non-registered motives	Non-registered motives	5	(10.6%)

Table 2. Profile of relatives and main barriers reported in the second study phase. Rocinha Community, Rio de Janeiro, 2008-2009

Variable	Barriers found (n = 50)	
	Yes (%)	No (%)
Family relation with the child (n = 85)		
Mother (n = 49)	37 (74)	12 (24)
Others (n = 36)	13 (26)	23 (46)
Age of interviewees		
18 to 35 (35/85)	23 (46)	12 (24)
36 to 61 (50/85)	27 (54)	23 (46)
Education		
Low education (71/85)	39 (78)	32 (64)
Satisfactory education (14/85)	11 (22)	3 (0.6)
*Income of interviewed relatives (56/85)		
Up to 1 minimum wage + Family aid + help from relatives (n = 39)	22 (39.3)	21 (37.5)
2 to 3 wages (n = 17)	12 (21.4)	5 (0.9)
Illness due to TB (n = 71)	50 (100)	21 (42)
Occupation		
Unemployed (20)	14 (28)	6 (12)
Formally employed (29)	8 (16)	21 (42)
Informally employed (24)	21 (42)	3 (6)
Housewife (6)	6 (12)	0 (0)
Retired (5)	0 (0)	5 (10)
Pensioner (1)	1 (2)	0 (0)

* As some relatives refused to provide the information, they were not calculated in the table.

child stayed at the father's house he did not give the medicine; due to fights with the husband she had to leave home sometimes; left to work and forgot to administer the medicine sometimes; the child stayed alone and did not take the medicine; lack of time to pick up the medicine because she worked (although the community health agents (CHA) brought the medicine sometimes). Sixteen/50 (32%) family members cited more than one barrier during the child's treatment.

Table 2 displays the interviewed family members' profile and the main barriers experienced in the second study phase.

DISCUSSION

In this study, whether based on records in the patient histories or during the interviews, the family members reported barriers during the treatment of the children with LTBI, similar to those of patients under treatment for active TB. These included absence from doctor's appointments, family problems, side effects of the medicines, irregular medication use due to extra doses and forgetting, refusal to take the medicines, lack of supply at the health service pharmacy, difficulty to get access to transportation due to disadvantaged economic conditions and urban violence. On the other hand, in this group, the LTBI treatment was not permanently suspended in any case.

In addition, the inaccessible location of the health services and the functioning hours different from the users' needs could be considered as barriers[14].

Female interviewees were predominant, probably due to the different profiles of paid work in the male and female population. Also, as the interview was only held on weekdays, more women than men may have been selected.

In the second phase of the research, it was identified that more than half of the interviewees reported some kind of barriers during the child's treatment. As regards the interviewees' profile, no significant differences were found in terms of age, as middle-aged people and older experienced some difficulty.

Most of the interviewees showed low education and income levels. Even though one third of the interviewees (29/85) felt uncomfortable to inform their monthly income, considering most of the interviewees' profile, and the incidence of TB was higher in poor areas, the low income should be considered[4,5,6,15].

It was verified that 70% of all participants had an informal job or were unemployed. As regards informal employment, many gained their income through some kind of trade at their place of residence, using spaces like garages, back yards and terraces to organize children's parties, sell products in magazines, or inside their home as child caregivers or through improvised beauty parlors.

In accordance with the present findings, Lopes[12] emphasizes that, although this community is characterized by absences and shortages, the intense population density led to the proliferation of a stable and dynamic economy, with a concentration of micro and small companies that create jobs. This serves as a survival strategy for many individuals.

The barriers that most stood out during the two study phases were family and economic barriers. Children were left alone or under the care of an under-age sibling or cousins; single-parent families; family conflicts; loss of structure and disorganization in the family structure. At places where low-income people live, it is very common for children to spend most of the day with a neighbor, while their family members are working. Also, the lack of satisfactory financial conditions to provide appropriate meals and housing at an inaccessible place were the main complaints.

According to Michaelis[16], adherence means the act or effect of adhering; agreement; consent. In this case, it refers to the family member's and even the child's agreement to do the LTBI treatment upon medical recommendation, as they had been infected by the bacillus after preliminary contact with an adult who transmitted TB. In this group, however, the adherence was compromised by different kinds of vulnerabilities. Authors indicate low education, unemployment, housing situations, lack of family union and associated diseases as social vulnerability situations for adherence to TB treatment[17].

The comprehension of how the family understands the disease, besides the coping with social and economic problems, need to be taken into account and go beyond the completion of forms at the health services[17]. Strategies to change these individuals' employment situation and social determinants that can interfere in the complete adherence to the treatment can contribute to achieve the goals of the National Tuberculosis Control Program (NTCP).

The family health strategy works based on the population's individual or collective needs and applies problem-solving actions that go far beyond health care[13]. Concerning child health, the strategy establishes permanent education mechanisms for the team in order to act on child care in the family context[13].

In this case, the strategy is to identify possible barriers imposed in the course of this treatment, in order to forward problems that can be solved, to avoid them from turning into reasons for treatment abandonment or interruptions. This means that getting to know the characteristics of individual, collective and regional problems for the correct distribution of the budget and the treatment services can be the first step.

Due to the social nature of the disease, public entities offer the active TB patients enrolled in the NTCP incentives, aiming to strengthen their treatment adherence, such as snacks, transportation tickets and social support[1]. Authors observe, however, that they need to comply with certain requisites in order to receive these benefits: participating in directly observed treatment (DOT) (the patient is observed during the medication intake at the service or the service visit's the patient's place of residence), not missing any appointment, during the third month of treatment[17].

There is not DOT to treat LTBI. Normally, this is to be carried out by the family members, who are often being treated for active TB, experience difficulties to cope with their own disease and need observation. If active TB patients face barriers, this will certainly also be the case for children treated for LTBI. This reveals the need for operational reorganization for LTBI patients.

One of the barriers mentioned due to which the relative did not attend the health service with the child was a "shooting in the community", which arouses reflections on the peculiarities of the socioeconomic context in this community. The violence expressed through the impositions and rules of drug traffic in communities are barriers the patients and service professionals face[18].

Another barrier found was the interruption of treatment by the relative or child due to side effects of the medication. In the literature, it is considered that there are few restrictions to prevention

in this respect during childhood, as isoniazid (INH) tends to be well tolerated[7]. Reactions like itching, rash and hemolytic anemia are rare, but all individuals under treatment for LTBI should be monitored regularly[3,7].

Many studies indicate that the TB problem is closely linked with social inequalities. These social determinants demand effective policies to respond to these individuals' needs for the control of the disease. Actions that facilitate the patients' lives, such as humanized welcoming, easy attendance, knowledge of patients' needs, forwarding to social services if necessary can be positive measures with a view to treatment adherence.

One of the limitations in this study related to the losses, mainly during the second study phase. During the fieldwork, difficulties were experienced to discover the geographic micro-area of the child or adolescent LTBI patient. In addition, the lack of house numbers, repeated addresses and address changes made it difficult to find the relatives. Also, many LTBI cases no longer lived at the same address registered in the patient history. In addition, there may have been a memory bias among the interviewees, due to the time gap between the LTBI treatment and the interview.

CONCLUSION

In this study, no substantial differences were found between the results of the first and the second phase. The findings are complementary.

The main barrier faced was the disadvantaged socioeconomic condition (evidenced by low income and education), which hampered the child's treatment adherence. Additional barriers included conflicts and lack of organization and structure in the family context.

Due to its greater contact with the community, the primary care strategy through family health can be used to approach these family members, focusing on the children's care in the home environment.

Measures applicable with a view to the appropriate forwarding of these problems, considering the government's financial incentives, include orientations and qualified listening to unveil barriers that can influence the proposed treatment. Also, this interaction can establish a bond of trust between users and professionals, avoiding barriers from turning into reasons for abandonment or LTBI treatment interruptions. The form of coping with the social determinants of health associated with TB should be reviewed in the most vulnerable population, involving the academic sphere as well as the professionals working with these clients. The operational strategy for the treatment of children with LTBI needs to be reconsidered.

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