

ORIGINAL ARTICLE

HIV and childhood tuberculosis: fragmentation of the flow of information in the countryside of the state of São Paulo

HIV e tuberculose infantil: a fragmentação do fluxo de informação no interior paulista
VIH y tuberculosis infantil: la fragmentación del flujo de información en el interior del estado de São Paulo

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ABSTRACT

Background and objectives: children are still affected by HIV and tuberculosis (TB). This study aimed to identify the occurrence of HIV and TB cases in children. **Methods:** this is an epidemiological, non-experimental, retrospective study, in which the population was made up of records of HIV and TB cases in children living in a municipality in the countryside of the state of São Paulo, from 2012 to 2022, in the age group of zero to 13 years old. After data collection, data consistency and validity was checked, followed by categorization of information for descriptive analyses and presentation in absolute and relative frequency tables. **Results:** during the study period, six HIV cases and seven TB cases were identified in children with a respective average annual incidence of 0.033 and 0.031 cases/1,000 inhabitants aged up to 13 years. There were 146 notifications of HIV-exposed children. There was a difference of months to years between the dates of diagnosis and notification, which deviates from the Ministry of Health recommendations. Incompatibility was found between municipal and state registration platforms, which shows a breakdown in flow of information on notifications. **Conclusion:** there have been HIV and childhood TB cases in the last ten years. Structural problems were identified in the fragmentation of the flow of information that subsidizes health actions according to the population's needs, which overshadows the health system's ability to respond.

Keywords: *Human Immunodeficiency Virus. Tuberculosis. Child Health. Neglected Diseases.*

RESUMO

Justificativa e Objetivos: crianças ainda são afetadas pelo HIV e pela tuberculose (TB). Dessa forma, o objetivo do estudo foi identificar a ocorrência de casos de HIV e TB em crianças. **Métodos:** trata-se de estudo epidemiológico, não experimental, retrospectivo, em que a população foi constituída pelo registro de casos infantis de HIV e TB residentes em um

município do interior do estado de São Paulo, no período de 2012 a 2022, na faixa etária de zero a 13 anos de idade. Após a coleta de dados, foi realizada a verificação de consistência e validade dos dados, seguida do tratamento categorizado das informações para análises descritivas e apresentação em tabelas de frequência absoluta e relativa. **Resultados:** no período de estudo, foram identificados seis casos de HIV e sete de TB em crianças com média anual respectiva de 0,033 e 0,031 casos/1.000 habitantes com idade até 13 anos. Verificaram-se 146 notificações de criança exposta ao HIV. Houve diferença de meses a anos entre as datas de diagnóstico e de notificação, o que diverge do recomendado pelo Ministério da Saúde. Foi verificada a incompatibilidade entre plataformas de registro de âmbito municipal e estadual, o que evidencia uma quebra do fluxo de informação das notificações. **Conclusão:** houve ocorrência de casos de HIV e TB infantil nos últimos dez anos. Foram identificados problemas estruturais na fragmentação do fluxo da informação que subsidia ações de saúde de acordo com as necessidades da população, o que ofusca a capacidade de resposta do sistema de saúde.

Descritores: *Virus da Imunodeficiência Humana. Tuberculose. Saúde da Criança. Doenças Negligenciadas.*

RESUMEN

Antecedentes y Objetivos: los niños siguen estando afectados por el VIH y la tuberculosis (TB). El objetivo de este estudio fue identificar la ocurrencia de casos de VIH y TB en niños. **Métodos:** se trata de un estudio epidemiológico, no experimental, retrospectivo, en el cual la población fue constituida por los registros de casos de VIH y TB en niños residentes en un municipio del interior del estado de São Paulo entre 2012 y 2022, con edad entre cero y 13 años. Después de la recolección de datos, se verificó la consistencia y validez de los mismos, seguido del tratamiento categorizado de la información para análisis descriptivos y presentación en tablas de frecuencias absolutas y relativas. **Resultados:** durante el periodo de estudio, se identificaron seis casos de VIH y siete de TB en niños, con una incidencia media anual respectiva de 0,033 y 0,031 casos/1.000 habitantes de hasta 13 años. Hubo 146 notificaciones de niños expuestos al VIH. Hubo una diferencia de meses a años entre las fechas de diagnóstico y notificación, lo que se desvía de lo recomendado por el Ministerio de Salud. Hubo incompatibilidad entre las plataformas de registro municipal y estatal, lo que muestra una ruptura en el flujo de información sobre las notificaciones. **Conclusión:** se han registrado casos de VIH y de tuberculosis infantil en los últimos diez años. Se identificaron problemas estructurales en la fragmentación del flujo de información que subvenciona las acciones sanitarias según las necesidades de la población, lo que ensombrece la capacidad de respuesta del sistema sanitario.

Palabras Clave: *Virus de la Inmunodeficiencia Humana. Tuberculosis. Salud Infantil. Enfermedades Olvidadas.*

INTRODUCTION

Tuberculosis (TB) and the human immunodeficiency virus (HIV), the etiological agent of Acquired Immunodeficiency Syndrome (AIDS), are transmissible diseases that still maintain high incidence rates, as despite scientific advances related to the prevention and treatments of both, are neglected infections. In fact, eliminating these public health problems by 2030 is one of the health and well-being goals of the Sustainable Development Goals (SDGs), established by the Pan American Health Organization (PAHO).¹

In Brazil, between 2021 and 2022, 40,880 new HIV cases and 78,057 TB cases were reported, respectively, across the entire population, regardless of age group.^{2,3} Therefore, co-infection between them is common, since people living with HIV are 20 times more susceptible to acquiring TB than individuals who do not live with the virus, which is evidenced by increased co-infection in the country in the last ten years.⁴

Aware that the incidence of these diseases in the child population is related to the prevalence in the adult population, when directing attention to children affected by these infections, the situation is more worrying, since children are prone to developing severe forms of these diseases. In 2020, it was estimated that there were 300,000 children living with the HIV virus and another 120,000 children died from AIDS-related causes worldwide.⁵

Inherent to aspects of TB, a large proportion of children affected by this infection, especially those under five years old, acquired the disease through living with people infected with TB.⁶ In Brazil, 2,703 new TB cases were registered in this population in 2022 alone.³

In line with the facts mentioned above, it must be considered that childhood pulmonary TB has common manifestations, which can be confused with other conditions, such as pneumonia or malnutrition.⁷ Furthermore, up to 20.0% of pediatric TB cases are extrapulmonary, which makes diagnosis even more difficult.⁶

Despite all the challenges faced by the health system in controlling preventable diseases and managing these communicable chronic conditions, there were also other impacts generated by the coronavirus pandemic (COVID-19). Syndemic interaction with other emerging and neglected infectious diseases and sociocultural weaknesses have increased the challenges in controlling various diseases, even causing environmental damage.⁸

It is estimated that the interference of the COVID-19 pandemic resulted in the interruption of 63.0% of prenatal care tests, 59.0% of postnatal tests, a drop in care services for sick children and an increase in malnutrition. As a result, HIV and TB diagnoses, notifications, treatments and prevention have also been affected in recent years.⁹

Thus, it is estimated that 800 thousand HIV-positive children left treatment during the pandemic period. Moreover, a third of children born to mothers living with HIV were not tested, and 50.0% of children with HIV died before of the second birthday in the same time interval.¹⁰

It was no different with TB, as there was a large reduction in those diagnosed in 2019 and 2020, which reflected in a 16.0% decrease in notifications in that period. However, the number of treatments also decreased, resulting in an increase in TB deaths, as, at the time of the pandemic, there was a regression to 2017 levels, with 1.3 million TB deaths among HIV-negative and 214,000 among HIV-positive.²

Therefore, in order to understand the epidemiology of these infections in the Brazilian population and, specifically, in the municipality considered a technological hub in the state of São Paulo, this study aimed to identify the occurrence of HIV and TB cases in children.

METHODS

This is an epidemiological, non-experimental, retrospective study, in which people are selected without considering the state of exposure or disease, i.e., exposure is investigated simultaneously with the disease.¹¹

The municipality where the study was carried out is in the center of the state of São Paulo (SP). It constitutes approximately 0.4% of the territory and 0.6% of the total population of the state, which is made up of 645 municipalities, divided into 15 mesoregions, totaling an area of 248,219.485 km², considered the most populous state in the country, with 44,420,459 inhabitants. Furthermore, it has a high rate of economic development, with a Human Development Index of 0.805.¹²

The research population consisted of notifications of childhood HIV cases, children exposed to HIV and TB, living in a rural municipality in the state of SP, from 2012 to 2022, in the age group from zero to 13 years old. This age group is justified by the operationalization of HIV data that are separated into children under 13 years old and over 13 years old, precisely due to the specificities of the disease.

Notified HIV cases in children under 13 years old and records of children exposed to HIV of residents in the research setting were obtained from the Notifiable Diseases Information System (SINAN - *Sistema de Informação de Agravos de Notificação*). TB cases with the same characteristics were collected in the Tuberculosis Patient Control System in São Paulo (TBWeb - *Sistema de Controle de Pacientes com Tuberculose no Estado de São Paulo*). Furthermore, municipal population data from the free access platform of the Brazilian Institute of Geography and Statistics (IBGE - *Instituto Brasileiro de Geografia e Estatística*) were considered. Data collection took place on February 10, 2022.

After data collection, three separate spreadsheets were created using Microsoft Excel® for each problem. Subsequently, the data underwent validity and treatment of variables, coding the categories into real numbers and building a code record (Code Book). In this process, the research eligibility criteria were also applied, “records outside the specified period, with dates of birth over 13 years old and residences different from the research scenario were excluded”.

Sequentially, a descriptive data analysis was carried out, with calculations of minimum, maximum values and measures of central tendency (mean) for continuous quantitative variables of age and interval in days between the date of diagnosis and the date of notification. To present the data, absolute and relative frequency tables were constructed. To calculate the average annual incidence rate for HIV and TB cases, the criteria in the equation below were considered:

$$Tx = \frac{Yi}{Pi} \div Ti \times 1,000 \text{ inhabitants}$$

Thus, Tx represented the incidence, Yi , the number of cases registered according to established criteria, Pi , estimated exposed population from zero to 13 years with logarithmization of 13.0%, due to estimated population growth from 2010 to 2022, and Ti , time. Four and five years were considered to calculate HIV and TB cases, respectively, according to the incidence dates from 2012 to 2022.

In accordance with the rules contained in Resolution 466/2012, this research project was submitted and approved by the Research Ethics Committee on December 21, 2022, under Certificate of Presentation for Ethical Consideration (*Certificado de Apresentação para Apreciação Ética*) 66090722.6.0000.5504 and Opinion 5.833.876.

RESULTS

From 2012 to 2022, eight HIV cases in children under 13 years old and seven of childhood TB were identified in the municipality under study on the SINAN and TBWeb platforms, respectively. However, in the case of HIV cases, two of them were excluded.

Regarding HIV cases in children under 13 years old, it was identified that all were caused by vertical transmission. For this reason, mother demographic characteristics were observed, which are predominantly composed of women aged 21 to 30 years ($n=3$; 50.0%), with only two of them aged between 31 and 40 years (33.0%) and one from 41 to 50 years old (17.0%). Furthermore, mothers declare themselves to be white or brown, with an equal distribution between both races/colors, with a low level of education, since three (50.0%) of them had incomplete elementary education, two (33.0%) had incomplete high school and only one (17.0%) completed high school.

Concerning childhood TB, there was a greater diversity of tests performed concomitantly for TB diagnosis when compared to the adult population. Thus, one (14.2%) case was diagnosed with TB after smear microscopy and X-ray, one (14.2%) after X-ray and

culture, one (14.2%) with smear microscopy alone, one (14.2%) by histopathological analysis and two (29.0%) only by X-ray.

Finally, an intriguing fact would be that one case (14.2%) was reported as TB, but without specification of the diagnostic method, adding that this case presented a clinical form of the disease classified as extrapulmonary. Furthermore, it is worth noting that in no case was a sensitivity test performed and only six (86.0%) underwent a rapid HIV test, in order to investigate the existence of co-infections, in which all presented a negative result (Table 1).

Table 1. Description of HIV and tuberculosis cases in children under 13 years old according to the variables analyzed in SP, Brazil, 2023

Source: survey data.
Caption: NA - not applicable.

Variables	HIV in < 13 years old						TB in <13 years old					
	Male		Female		Total		Male		Female		Total	
	n	%	n	%	n	%	n	%	n	%	n	%
Year of incidence (date of diagnosis)												
2012	1	100.0	0	0.0	1	100.0	1	100.0	0	0.0	1	100.0
2013	0	0.0	0	0.0	0	0.0	1	100.0	0	0.0	1	100.0
2015	0	0.0	2	100.0	2	100.0	0	0.0	1	100.0	1	100.0
2016	1	50.0	1	50.0	2	100.0	0	0.0	0	0.0	0	0.0
2018	0	0.0	0	0.0	0	0.0	2	100.0	0	0.0	2	100.0
2019	0	0.0	1	100.0	1	100.0	0	0.0	0	0.0	0	0.0
2020	0	0.0	0	0.0	0	0.0	2	100.0	0	0.0	2	100.0
Total for the period	2	33.0	4	67.0	6	100.0	6	86.0	1	14.0	7	100.0
Age range												
0-2	0	0.0	2	33.0	2	33.0	2	29.0	0	0.0	2	29.0
3-5	1	17.0	2	33.0	3	50.0	1	14.0	0	0.0	1	14.0
6-8	1	17.0	0	0.0	1	17.0	0	0.0	0	0.0	0	0.0
9-11	0	0.0	0	0.0	0	0.0	1	14.0	0	0.0	1	14.0
12-13	0	0.0	0	0.0	0	0.0	2	29.0	1	14.0	3	43.0
Race/color												
White	2	33.2	3	49.8	5	83.0	2	29.0	1	14.0	3	43.0
Brown	0	0.0	1	17.0	1	17.0	4	57.0	0	0.0	4	57.0
Clinical form of tuberculosis												
Pulmonary	NA	NA	NA	NA	NA	NA	4	57.0	0	0.0	4	57.0
Extrapulmonary	NA	NA	NA	NA	NA	NA	2	29.0	1	14.0	3	43.0
Type of closure												
In treatment	1	15.7	3	50.2	4	67.0	0	0.0	0	0.0	0	0.0
Cure	NA	NA	NA	NA	NA	NA	6	74.0	1	12.0	7	86.0
Abandonment	0	0.0	0	0.0	0	0.0	1	7.0	0	7.0	1	14.0
Death not related to the injury	1	16.5	1	16.5	2	33.0	0	0.0	0	0.0	0	0.0
Interval in days between the date of diagnosis and the date of notification in total cases												
More than 1095 days	1	16.6	0	0.0	1	16.6	0	0.0	0	0.0	0	0.0
731 to 1095 days	0	0.0	1	16.6	1	16.6	0	0.0	0	0.0	0	0.0
366 days to 730 days	0	0.0	1	16.6	1	16.6	0	0.0	0	0.0	0	0.0
91 to 365 days	1	16.8	1	16.8	2	33.6	0	0.0	0	0.0	0	0.0
30 to 90 days	0	0.0	1	16.6	1	16.6	1	7.0	0	7.0	1	14.0
Up to 7 days	0	0.0	0	0.0	0	0.0	3	43.0	0	0.0	3	43.0
0 days	0	0.0	0	0.0	0	0.0	2	29.0	1	14.0	3	43.0

As for the average annual incidence rate, it was possible to observe 0.033 cases per 1.000 inhabitants aged 0 to 13 years for HIV and 0.031 cases per 1.000 inhabitants aged 0 to 13 years for TB.

Furthermore, regarding the context of HIV cases in children under 13 years old, it was possible to identify on this same platform, SINAN, 146 notifications of children exposed to HIV, in which 28 records were excluded due to incompatibility of the municipality of residence and age in relation to established criteria, following only 118 records for descriptive analysis. There was a considerable time interval between the date of diagnosis and the date of notification, since only three (3.0%) were registered on the same day, 87 (74.0%) took up to eleven months, 17 (14.0%) took from one to five years and 11 (9.0%) were notified only after five years.

In relation to the demographic characteristics of these children, males stood out, with 63 (53.0%) of them and 55 (47.0%) of females. Furthermore, are mostly white, accounting for 83 (71.0%) of the records, followed by brown race/color (n=18; 15.0%) and black (n= 6; 5.0%), whereas in 11 (9.0%) records race/color statement was ignored. Finally, in relation to age group, 106 (90.0%) of them are between zero and two years old, five (4.0%) are between three and five years old and seven (6.0%) are between six and eight years.

DISCUSSION

The study sought to identify the occurrence of childhood HIV and TB cases in the municipality of rural São Paulo, from 2012 to 2022, with the aim of calculating the incidence rate of HIV and TB in the pediatric population and analyzing the demographic characteristics of children affected by these grievances.

Therefore, the existence of HIV and TB cases in children under 13 years old deserves attention, as it mostly reflects failures in the care provided to parents and adults who live with these children. Thus, the research shows that, despite the advances and strengthening of the Brazilian Health System (SUS – *Sistema Único de Saúde*), through the implementation of new free therapeutic schemes and greater control and intensification of epidemiological surveillance actions, there are still limitations, including scientific knowledge, for an effective improvement in communicable disease prevention and control¹³, as expected by the SDG goals.¹

Furthermore, the political-institutional situation in force as of 2018 undermined the public health advances achieved in recent years, through reduced funding, failure to promote science and new projects, which intensified with the COVID-19 pandemic.^{13,14} Thus, the predominance of HIV and TB cases in this age group makes up the representation of a SUS that, during the COVID-19 pandemic, was approached as a constitutional SUS, a problem SUS, a disputed SUS and an active SUS, but which, regardless of its context, aims to universalize access to health care services. However, for SUS to be able to act in accordance with its essential nature, it is necessary to expand and improve the scope of surveillance, prevention and control of diseases and health risks.¹³

In this regard, some specific initiatives in the field of HIV have already been implemented, such as the Brazilian National Pact for Vertical Transmission Elimination guidelines, which involves the services offered by Primary Health Care (PHC), directing prenatal care, postpartum monitoring, prophylactic measures, adequate treatment and health surveillance actions in accordance with the best scientific evidence and specificities. Furthermore, they encourage adherence to measures by health services through awards, such as

the implementation of the HIV and/or Syphilis Vertical Transmission Elimination Certification.¹⁵

As for the demographic aspects of cases of both diseases, regarding race/color and sex, it is worth mentioning that there was no difference in what is already evidenced in scientific literature.² However, a worrying aspect was the age range of TB cases, since there were cases in children up to two years old (29.0%) and between three and five years old (14.0%), which generates greater concern regarding symptoms and diagnosis of the disease.⁷

Therefore, when considering the intrinsic relationship between the incidence of childhood TB and the prevalence of TB in adults, numerous hypotheses are raised about follow-up of epidemiological surveillance for this population, such as failures in diagnosis, contact screening and non-adherence to preventive TB treatment.¹⁶ This scenario reflects and reinforces inequality in access to health services, which is became even more latent with the COVID-19 pandemic.¹⁷

Furthermore, regarding the clinical form of TB, all were new cases, most of which were pulmonary TB (57.0%), but there was a higher quantity of extrapulmonary TB (43.0%) than expected, as, when observing cases of childhood TB across the country, Brazil, only 19.4% of them are characterized by the extrapulmonary clinical form.³

Considering the diagnostic difficulties, due to the greater variation in clinical and symptomatological forms and the smaller number of bacilli than adults,¹⁸ diversity was observed in relation to exams; in fact, many of the cases (43.0%) were diagnosed after two tests. Furthermore, it was observed that almost everyone (57.0%) used the X-ray exam, which is assertive, as most children develop radiological signs of TB infection,⁶ while only one underwent a smear test only (14.2%).

Furthermore, one of the cases of extrapulmonary TB (14.2%) had a negative result for smear microscopy, and no other tests were performed. It is believed that other tests were carried out, focusing on the organ affected by the disease.⁶

Finally, it was possible to analyze that the cure rate for childhood TB in the city was 86.0%, compatible with that recommended by the WHO.² Despite the encouraging estimate, one cannot fail to highlight the episode of abandonment, which was becomes extremely worrying, as interrupting treatment can worsen the situation.¹⁹

At the same time, the lack of access to health promotion and prevention information is also strongly highlighted from the analysis of HIV cases, since they all occurred through vertical transmission, which reveals the non-adherence to treatment by a large number of pregnant women living with HIV. However, this is also a reflection of the lack of

implementation of the protocol of good practices and adequate reception by the health service, which results in negligence and abandonment in relation to treatment.²⁰

Although transmissions to this audience are mostly vertical, it must be remembered that children in vulnerable situations are exposed to other forms of infection, through risky sexual relations and piercing with contaminated needles in unhealthy places, for instance.²¹

In this sense, in conjunction with the various factors related to monitoring these cases, there is the possibility of greater detail with the notification of children exposed to HIV. However, much important information is not covered by SINAN, due to a lack of updating, which prevents the analysis of important variables and the outcome of the case, generating greater susceptibility to underreporting.²²

Another factor that deserves to be highlighted is the large time interval between the date of exposure and the date of notification on SINAN, since very few were registered on the same day (3.0%), while the majority took up to 11 months (74.0%) and, even, some of them took more than five years to do so (9.0%). These extended periods contradict what is recommended by the Ministry of Health (MoH), as it is determined that the notification forms of children exposed to HIV are registered in SINAN within a maximum of seven days, in order to ensure the monitoring of these children.²²

This delay in SINAN notification also occurred in relation to HIV disease in children under 13 years old, with no case being reported on the same day or in the same week, as advised by the MoH²², with the minimum notification interval varying between one and three months (16.0%), whereas the maximum was more than two years (16.0%). This is detrimental to the functioning of the units that provide assistance to this population and carry out epidemiological surveillance of these diseases, because it is based on the number of cases registered in SINAN that the funds for the Fixed Health Surveillance Floor (FHSF) and the Variable Health Surveillance Floor (VHSF) necessary to maintain the service are calculated.²³

Thus, a break in the information flow of notification of these cases was proven, as, after carrying out a free search of HIV cases in children under 13 years old in the city under analysis on the São Paulo STD/AIDS Reference and Training Center platform (CRT - *Centro de Referência e Treinamento DST/AIDS*), only two records of this problem were found in the municipality under study in the last ten years, one in 2015 and one in 2019, while, in fact, according to the data collected in this research, there were six cases, i.e., four of them are not included in the CRT system, incidents in 2012, 2015 and 2016.

Knowing that this data from the CRT platform is fed by the Regional Health Departments in partnership with the State Department of Health, it is clear that there was a

break in the flow of information provided for Health Care Networks (RAS - *Redes de Atenção à Saúde*). These aspects corroborate the idea that there is a diversity of meanings attributed to SUS¹⁷, such as the effects we identified in this research as structural problems in the fragmentation of the flow of information responsible for supporting health actions according to the population's needs.

Scenarios like this obfuscate the system's responsiveness. On the other hand, only through these materials is it possible to mobilize investment prospects, strengthening and recognition of a health system considered a crucial national heritage, which has already overcome several obstacles and transformed into a historic enterprise recognized worldwide.¹⁷

It is worth mentioning that this study has limitations, due to the use of secondary data and the research design itself, as it is a descriptive study that does not allow for relationship analyzes to be carried out. However, it provided hypotheses for future studies.

Thus, hypotheses are raised about the repetition of this circumstance in other municipalities and states, as services can take this experience as a strategy for validating its epidemiological data and, consequently, contributing to the increase in national underreporting, which undermines the reliability of epidemiological bulletins of this disease.²

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Thamires Carraro Gatto contributed to bibliographical research, writing the abstract, introduction, methodology, discussion, interpretation and description of results, preparation of tables, conclusions, review and statistics. **Giovana Cristina Chirinéa Donida** contributed to writing the abstract, introduction, methodology, discussion, interpretation and description of results, conclusions, review and statistics. **Eliza Flori Rodrigues da Costa** contributed to analysis and interpretation of results and writing of discussion. **Monika Wernet** contributed to writing the introduction, methods and discussion. **Mellina Yamamura** contributed to project administration, fund acquisition, literature research, results analysis and discussion, review and statistics.

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