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POINT OF VIEW

Social impact and importance of tuberculosis in childhood and adolescence

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Abstract

Controlling TB requires a real improvement in the living conditions of children and their families. The solution is everyone's responsibility: the State, health systems and society in general. This article discusses the situation of tuberculosis in children and adolescents around the world and reflects on perspectives for controlling the disease.

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Around the world, about 1,250,000 children (12% of all disease cases) fall ill with tuberculosis (TB), with over 214,000 succumbing to the disease (16% of all TB fatalities)¹ and 7,500,000 becoming infected.² In the Americas, 10,151 children have been reported as having the disease out of an estimated 16,000 cases, revealing a significant gap of 5,849 undetected cases. Despite this alarming situation, cases of TB in children and adolescents have been largely overlooked and underestimated; the disease has been treated as secondary in public health initiatives and clinical practice, which focus primarily on adults for identification, treatment, and prevention of transmission. Conversely, TB in children typically presents as a primary infection that often goes unnoticed, affecting small populations with low contagion rates.

Given the high vulnerability of children and adolescents and the severity of the disease in this population, tuberculosis (TB) has become a priority for the World Health Organization (WHO) and the Pan American Health Organization (PAHO) in their control and prevention policies. These efforts focus on identifying contacts and patients for timely diagnosis and treatment. An urgent commitment to supporting children and adolescents is essential to address this situation.

Because of the peculiarities of children regarding immunological immaturity and their epidemiological, pathophysiological, and clinical differences from adults, the transition from infection to disease is not straightforward. It can progress rapidly and acutely, potentially leading to severe, disseminated disease. Collecting samples and conducting laboratory diagnostic tests can be challenging. The occurrence of tuberculosis in children and adolescents is often overlooked.³

In several regions of the continent, cases are underreported. Pediatric cases are not disaggregated by age or form of disease in many places, leading to inaccurate and highly variable numbers. On the other hand, there is a decline in risk awareness regarding the frequency of TB, along with insufficient detection of respiratory symptoms and infected or ill individuals. Incomplete or inadequate treatment, along with poor control and adherence, also contribute to increased exposure to the bacillus and hinder the effective interruption of the disease's transmission chain. Furthermore, in many Latin American countries, thousands of children do not "officially" exist for the State because they have never been registered as citizens due to residing in remote areas that are difficult to access or for other reasons. As a result, they lack coverage from any social or health system or activity. They do not appear in health programs or are considered in sanitation, education, or prevention initiatives.^{4,5}

While it is true that advances in diagnosis, treatment, and intervention implementation have aided global control of TB, and although the disease is preventable, controllable, treatable, and curable, it still results in millions of active cases and deaths despite access to inexpensive and effective treatments. It disproportionately impacts the poorest and

most vulnerable populations in low-income countries, and even in highly developed nations, it affects marginalized and disadvantaged groups.⁶ Furthermore, the COVID-19 pandemic has worsened care programs, reduced the number of detected cases, and increased TB morbidity and mortality, causing significant delays compared to the progress made in recent decades. TB diagnosis and treatment have also hindered routine immunization efforts, including BCG, and due to lockdowns, there has been a rise in TB transmission within households, which likely leads to an increase in pediatric cases related to home exposure, particularly in resource-limited countries.

The global resurgence of TB has directly impacted children through the deterioration of socioeconomic and living conditions, reduced income, inadequate diets, and overcrowding. The population vulnerable to the disease has increased due to rising migration and displacement from complex national conflicts, TB/HIV co-infection, increasing drug resistance, growing use of immunosuppressants, and underlying diseases. Undoubtedly, similar to adults, children are being seriously affected; TB in children reflects adult prevalence and serves as a sentinel event indicating recent progression in disease transmission. Half of exposed children become infected, facing an increased risk of progressing to severe TB (25%) in those under five years of age, particularly in children under 2 years old, as well as in cases of TB-HIV co-infection and malnutrition. Recent infection poses a substantial risk of illness. Therefore, prioritizing the search for exposed children is essential to determine if they are infected or ill and to implement appropriate measures. The cumulative disease risk in children infected with TB over two years is 20%.⁷

TB influences every aspect of quality of life, and when quality declines, it creates challenges that need to be addressed. This extends beyond a purely biological or organic perspective and moves past a solely clinical and microbiological framework. It is essential to consider the sociocultural and psychological dimensions that affect individuals with the disease. While there have been some advancements in this area, consistent data in pediatrics is still lacking.⁸

Equally underestimated, but with increasing frequency, morbidity, and mortality, is maternal TB. The genital form of the disease, in addition to infertility, can cause congenital and neonatal TB.⁹ Pregnant women who are HIV-positive or have untreated TB (regardless of HIV infection) face a higher risk of obstetric and perinatal complications. Mothers with TB-HIV have a 2.5 times greater risk of vertically transmitting HIV. This condition is associated with prematurity, low birth weight, low weight for gestational age, and perinatal maternal death. In newborns, TB may manifest with nonspecific symptoms, leading to late diagnosis, insufficient treatment, and high mortality rates.¹⁰ Pregnant women with untreated multidrug-resistant TB face a higher risk of death, miscarriage, premature birth, having a baby with low weight for gestational age, and transmitting the disease to the fetus or newborn.¹¹

In the last decade, over ten million orphans lost one or both parents to TB worldwide. During that period, there were an estimated 2,900,000 cases of TB among women globally, with a mortality rate of 410,000 per year.⁹ Less than 60% of TB cases in women are detected, which could be disastrous for families. Death, orphanhood, increased poverty, abandonment, and suffering await children and adolescents facing parental TB.

In addition to the epidemiological and clinical data regarding TB in childhood and adolescence, it is crucial to consider the social determinants that explain the disease's existence. These determinants result from a complex interplay of factors, including the host's genetic characteristics, immunity, and nutritional status, alongside the socioeconomic, cultural, and environmental conditions affecting the child and exposure to *Mycobacterium tuberculosis*. This bacterium is the most lethal in human history, and its ability to infect and cause illness relates to its virulence, inoculum, and the responses it elicits.

The general risk factors for infection and disease that the PAHO and WHO have considered since 2014¹² include frequent contact with individuals with *M. tuberculosis*, being under five years old, HIV co-infection, malnutrition, belonging to a largely marginalized population, having been displaced, being a migrant, homelessness, living in poverty, and residing in overcrowded conditions. While these factors significantly increase children's vulnerability, it is essential to remember that, in essence, all children are susceptible to TB because they lack immunity to the disease. Multiple factors influence their ability to fight TB.

Children are not only likely to be exposed to a mother with TB or others with the disease in the household but also to various high-risk environments, such as daycare centers, orphanages, schools, juvenile detention centers, and other places where individuals may test positive for TB. In hospitals, the risk of transmission increases when biosafety standards are unclear, rooms are poorly designed, adequate ventilation is lacking, facilities are overcrowded with patients, waiting times are long, and care is inefficient. Other factors contributing to increased transmission to children include the fragility of health systems; low adherence to treatment; insufficient implementation of preventive therapy for latent TB and antiretroviral (ARV) therapy; scarcity of resources; poor communication and knowledge of TB among care teams; and, in some cases, a lack of understanding and respect for individuals with the disease. Over the past two decades, social activists have significantly contributed in many countries to the implementation of human rights, demanding that health service delivery be more equitable, regardless of social, economic, ethnic, religious, cultural, or gender status.¹³

A large proportion of children and adolescents living in developing countries face multiple determinants and risk factors that lead to contracting and becoming ill with TB. The likelihood of occurrence, frequency, and severity of the

disease are greater in younger infants and individuals with early and significant exposure to the disease, along with other conditions such as malnutrition, vitamin D deficiency, lack of BCG immunization, comorbidities, debilitating diseases like HIV and kidney failure, and the use of immunosuppressants, among others.¹⁴

The well-known aphorism labeling TB as a "disease of the poor" succinctly conveys a universally recognized truth. While it is an infectious disease caused by a pathogenic bacillus, we understand that socioeconomic, cultural, and environmental factors significantly influence how this disease presents itself. This is particularly evident in areas with fewer resources and limited access to healthcare, where the incidence of cases is higher. Furthermore, some patients may present nonspecific symptoms that can be mistaken for other endemic diseases (e.g., viral, bacterial, or parasitic infections). Compounding this issue is that certain regions still lack diagnostic tests with high sensitivity and specificity.

Data from developed nations indicate that the annual cost of care for children with pneumonia (including TB) is US\$1,000 per child, amounting to approximately US\$16 billion each year.¹⁶ This figure is likely several times larger than the budget allocated for healthcare in many Latin American countries.

The risk factors for TB do not operate solely to facilitate infection or disease. The disease leads to the loss of protective factors and exacerbates existing risk factors and determinants. A clear example is a person with limited resources who is experiencing malnutrition and lacks basic sanitation, who, upon becoming ill with TB, sees the further deterioration of economic status and becomes unemployed. This creates a negative cycle that must be broken to achieve improvements. Particularly vulnerable are displaced children, individuals living in overcrowded conditions or refugee camps, and migrants.^{17,18}

TB thrives among highly vulnerable populations facing multiple risk factors, particularly children and adolescents from indigenous communities. This is evident in several Latin American countries. In Chiapas, a state in southeastern Mexico with a high level of poverty, 32.7% of the population is indigenous and lives in rural or semi-rural areas under poor conditions, facing inadequate housing, limited food access, overcrowding, insufficient healthcare, and low education levels. Additionally, factors like migration, loss of cultural identity, and heightened insecurity and violence contribute to exclusion, inequity, and inequality. The highest rates of TB cases in the region are found in areas with a dense concentration of indigenous people, especially among women, the less educated, and individuals working in agriculture.¹⁹

In Colombia, 17,460 cases of TB of all forms were reported in 2022; among these, 577 involved children under 15 years old.²⁰ The relative risk of TB for indigenous peoples was calculated at 2.8. Over the eight years ending in 2022, the proportion of indigenous children with TB fluctuated between 11.9% and 16.6%. As is typical for indigenous populations

across our continent, factors such as marginalization, poverty, malnutrition, limited access to healthcare and education, inadequate vaccination, and living in remote areas prevail, leading to a high percentage of pediatric tuberculosis cases in departments of the Orinoquía and the Colombian Amazon.

Charles Dickens was present when Charles West opened the first children's hospital in London. In support of his work, he expressed confusion over why England took so long to establish a children's hospital, considering that a third of the coffins produced were for children. Their workdays stretched to 18 hours, they ate tied to the machines they operated, and were forbidden to go outside. They fell ill quickly, especially from tuberculosis. This shocking story highlights the connection between living conditions and diseases like tuberculosis.²¹ In many areas of the world, child slavery still exists to varying degrees, particularly in developing countries.

Individuals with tuberculosis are among the most socially stigmatized for having a disease.²² Since ancient times, diseases have been viewed as punishments or curses and considered divine proof or forms of atonement for "moral stains" and sins. Conditions like the plague, smallpox, leprosy, tuberculosis, typhus, malignant fevers, and others were interpreted as devilish forces or traps, generating mass terror. They were often regarded as fatal since the treatments available were mainly palliative or aimed at ensuring a peaceful death.²³ As time passed, people began to understand the significant influence of living conditions, particularly poverty, on these diseases.²⁴ Many illnesses, including TB, started to be associated with poverty, contributing to the discrimination and stigmatization faced by those with the disease.

Despite the scientific explanations for the causes of leprosy, tuberculosis, the plague, and other diseases, understanding their etiology and transmissibility was not enough to dispel the fear of contagion. The belief that segregating and isolating patients was necessary became deeply ingrained. Unfortunately, these prejudices and misguided beliefs continue to persist in modern societies.

In addition to everything mentioned above, there exists among those affected—families, communities, and society—a significant number of myths, false beliefs, and popular misconceptions surrounding the disease. These reflect the problematic circumstances, experiences, and profound suffering of individuals, ranging from deep-rooted prejudices to the romanticization of tuberculosis.²⁵ During the 19th and 20th centuries, much was written about the supposed creative genius during fever attacks and the "alabaster beauty" attributed to the characteristic pallor seen in individuals suffering from tuberculosis. Understanding communities' perceptions about the disease is critical for its control. Exploring and recognizing the various social, familial, and emotional dimensions related to the disease and its perception enables the development and dissemination of educational materials that contribute to improving comprehensive and respectful care for those affected.²⁶

A determined stance and a steadfast commitment to confronting tuberculosis directly are necessary when considering the disease's impact on children and adolescents. The presence of children infected with *M. tuberculosis* and exhibiting active disease serves as a significant indicator of recent transmission. Children with the disease function as reservoirs of infection and will contribute to a future generation of sick adults unless they receive timely diagnosis and treatment. Tuberculosis in children can be both highly transmissible and severe, potentially leading to death and leaving behind irreversible effects that can inflict deep emotional trauma and suffering on the patients and their families.

These harmful effects can only be countered through prevention, improved biosafety protocols, enhanced detection of children and adolescents with the disease, rapid diagnostic methods, adequate preventive therapy, and noninjectable medications for children.²⁷ Additional measures involve understanding the living conditions of children and their families, their level of education, mental health status, combating stigmatization, applying the principles of confidentiality and respect for human rights, and coordinating education and training programs for clinical staff, volunteers, and the community.³

Aiming to reduce TB incidence and inequalities, the WHO's End TB Strategy has been the primary framework for TB since 2015. It emphasizes people-centered TB care and prevention to achieve the targets set for 2030. This shift from previous paradigms highlights the importance of communities, individuals, and human and gender rights.²⁸ It involves civil society, groups, and communities collaborating with national TB control authorities. Approaches like the PAHO/WHO ENGAGE-TB view TB not merely as a medical issue but as a broader socioeconomic and community challenge. The strategy underscores the significance of collaboration and partnerships among NGOs, civil society, and national TB control programs, in alignment with the principle: "People have the right and the duty to participate individually and collectively in the planning and implementation of their health care."

In the last century, several Latin American countries enacted laws regarding health education, particularly related to tuberculosis (TB). In Colombia, Law 20 of 1937 established the "anti-tuberculosis campaign." Article 5 stated: "The teaching of prophylaxis for infectious diseases (especially TB) in primary and secondary schools is compulsory."²⁹ As with many other laws, this has often been disregarded. However, it raises reflections on the need to introduce cross-curricular courses on diseases that affect adults and children (such as tuberculosis) in public and private primary and secondary schools and medical schools, where many view TB as a non-issue. Tuberculosis was a problem in the past, is a problem today, and will continue to be a problem in the future unless we responsibly acknowledge our duty to combat it.

Individuals affected by TB, particularly women, children, and adolescents, continue to face discrimination and stigma. Their human rights have been historically violated despite numerous international agreements that affirm them, including the right to attain the highest possible standard of health.

These rights are guaranteed by legally binding agreements, which adhere to the Declaration of Human Rights and the Convention on the Rights of the Child.³⁰ They also endorse the rights and duties of individuals affected by TB, enshrined in international and regional legislation such as the Declaration of the Rights of People Affected by Tuberculosis and the United Nations General Assembly High-Level Meeting on the fight against tuberculosis.³¹ They emphasize promoting and protecting human rights as a legal, ethical, and moral imperative, crucial for effectively responding to the disease and alleviating the suffering of affected individuals and communities. These rights are further supported by guidelines on primary care established decades ago in the Declaration of Alma-Ata.³² Some countries provide practical educational resources regarding these rights and duties.³³

An essential yet often overlooked aspect of the interaction among the healthcare team, the affected individual, and their family is the choice of language. Language choices impact stigma, beliefs, and behaviors, affecting whether a person can communicate well with their caregiver and feel at ease. Those who care for children and adolescents understand the importance of good communication and all forms of verbal and nonverbal expression in the medical experience. Language structures thought and communication; thus, its respectful and inclusive use, avoiding unnecessary jargon, and alignment with the feelings and identity of the person in the other end are crucial for adequate interaction. To enhance the understanding of tuberculosis among those affected, their families, and the community, simple and practical glossaries can be created that avoid strictly technical medical jargon, making information and education accessible to everyone.³⁵

TB control requires genuine improvements in the living conditions of children and their families. Solutions must involve the government, the healthcare system, and society. Medical doctors, especially those caring for children and adolescents, are responsible for accurate diagnosis and treatment. As Dr. EM Lincoln noted decades ago: “There are many contributions that pediatricians can make to a TB control program: overcoming the belief that it does not exist, raising awareness that it is a widespread issue, and recognizing that where there are adults with TB, there are children who are infected or ill with TB because no one is immune.”³⁶

We strongly believe in the motto: “Today’s children must have hope that one day they will live in a world where no one suffers from TB: zero children with TB, forever.”

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