

The Response to HTLV in the Framework of Maternal and Child Health

**Meeting Report
18 August 2022**

PAHO



**Pan American
Health
Organization**



**World Health
Organization**
REGIONAL OFFICE FOR THE
Americas

The Response to HTLV in the Framework of Maternal and Child Health. Meeting Report, 18 August 2022
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Washington, D.C., 2022

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ACRONYMS AND ABBREVIATIONS

ATLL	Adult T cell leukemia/lymphoma
EMTCT	elimination of mother-to-child transmission
HAM	HTLV-1-associated myelopathy
HBV	hepatitis B virus
HIV	human immunodeficiency virus
HTLV	human T-lymphotropic virus
MTCT	mother-to-child transmission
PAHO	Pan American Health Organization
STIs	sexually transmitted infections
WHO	World Health Organization

SUMMARY

Human T-lymphotropic virus type 1 (HTLV-1) infection is a matter of concern. Prevention of mother-to-child transmission is a priority. The Pan American Health Organization (PAHO), in partnership with HTLV Channel, organized a workshop to discuss “The Response to HTLV in the Framework of Maternal and Child Health” in the Americas. HTLV-1 impact is broad and significant, as discussed during the technical intervention and explained by the people living with HTLV representative from Argentina. There are effective interventions to prevent mother-to-child transmission. Barriers that hamper the implementation of policies targeting mother-to-child transmission of HTLV-1 were identified, and strategies to overcome them were discussed. The framework for the elimination of mother-to-child transmission of HIV, syphilis, hepatitis B, and Chagas disease (EMTCT Plus) represents an opportunity to advance the response to HTLV-1. Brazil is pioneering the response to HTLV-1 in the Region. The integration of HTLV-1 into the sexually transmitted infections program, the recommendation of HTLV-1 antenatal screening, provision of formula for babies born from seropositive women, and awareness campaigns are examples of good practices. Chile and Colombia shared some recent progress and perspectives. Chile has a clinical guideline for HTLV-1, which includes recommendation of exclusive formula feeding for babies born from mothers living with HTLV-1. Colombia has included HTLV-1 as a priority topic in its strategic planning, established an advisory group, and is currently developing clinical guidelines and economic analysis focusing on HTLV-1 response. PAHO’s continuous support was unanimously identified as crucial to the progress of this agenda. The definition of baselines, milestones, and targets for the response to HTLV-1 focusing on the elimination of mother-to-child transmission are necessary next steps. To achieve additional progress in the region, it is essential to increase awareness, to foster collaboration, and to stimulate research on prevention of mother-to-child transmission of HTLV-1.

RATIONALE

Human T-lymphotropic virus type 1 (HTLV-1) affects at least 5–10 million individuals, particularly vulnerable population groups, including people living in areas of low Human Development Index. The scientific community and civil society emphasized that the time has come for a public health response to this infection. The first step is to increase awareness about HTLV and to support an effort for the inclusion of the topic in the international health agenda. In 2021, the Pan American Health Organization (PAHO), in partnership with the Ministry of Health of Brazil and HTLV Channel, held the “HTLV World Day Webinar: International Health Policy Forum for the Elimination of HTLV.” This online seminar aimed to promote discussion on public policies and actions targeting the prevention and control of HTLV and its sequelae (1, 2). In this context and following up on this earlier event, a virtual workshop was organized to discuss the response to HTLV-1 as part of maternal and child health programs, identifying opportunities for cooperation between programs, academia, civil society, and other actors in the Region of the Americas. The discussion focused on the framework for the elimination of mother-to-child transmission of HIV, syphilis, hepatitis B, and Chagas disease (EMTCT Plus) and the opportunity to use this platform to promote the elimination of mother-to-child transmission (MTCT) of HTLV. The recordings of the workshop are available at PAHO TV on YouTube® in the original audio, Portuguese, English, and Spanish.

The organization of the webinar and the preparation and publication of this meeting report was funded by the Government of Canada.

PURPOSE OF THE MEETING

The main objectives for the meeting included:

- Promote discussion about HTLV in the Region.
- Better understand the current scenario of policies on HTLV in the Region, with special interest on policies to prevent mother-to-child transmission.
- Identify barriers and opportunities for the inclusion of HTLV in maternal and child health programs, particularly within the EMTCT Plus initiative.
- Foster collaboration between countries and between different actors.

OPENING CEREMONY

Dr. Massimo Ghidinelli, PAHO

Dr. Ghidinelli opened the workshop affirming that, despite the gaps, recent advances have been observed regarding HTLV-1 globally. There is now ample recognition of HTLV-1 as a health problem, and different tools and opportunities have been identified to move the agenda forward. He highlighted that the present workshop itself was a testimony of this, as it aims to discuss the integration of HTLV-1 in the range of topics covered by EMTCT Plus—the framework for the elimination of mother-to-child transmission of HIV, syphilis, hepatitis B, and Chagas disease. He pointed out that this was already being pioneered in some countries in the Region, particularly in Brazil, and concluded that with the partnership of different actors, fast and additional progress can be made.

OVERVIEW ON HTLV-1

Dr. Carolina Rosadas, Imperial College London and HTLV Channel

HTLV-1 DISTRIBUTION AND IMPACT

Dr. Rosadas started her lecture by highlighting that HTLV-1 is a neglected retrovirus with no curative treatment or vaccine. Consequently, prevention strategies are crucial. Data on HTLV-1 prevalence in pregnant women are scarce in the Region. Where information is available, prevalence is generally high (Table 1). Social determinants of health, such as low income, low education level, and domestic violence are associated with higher risk of infection. Indeed, the prevalence of HTLV-1 in pregnant women increases as the gross domestic product per capita decreases and the Gini Index increases (3).

Table 1. HTLV-1 prevalence in pregnant women in the Americas

Countries and territories	HTLV-1 prevalence in pregnant women
Argentina	0.2%–0.25%
Brazil	0.0%–1.05%
French Guiana	3.8%–4.4%
Haiti	2.2%–4.2%
Jamaica	3.5%–3.8%
Martinique	1.9%–2.3%
Peru	1.3%–3.8%

Source: Adapted from Rosadas C, Taylor GP. Health inequities and HTLV-1. *Lancet Microbe*. 2022;3(3):E164 (4).

HTLV-1 may cause adult T-cell leukemia/lymphoma (ATLL) and HTLV-1-associated myelopathy (HAM). ATLL is a severe neoplasm with a median survival of less than one year. HAM is a chronic neurological disease that impairs quality of life. Dr. Rosadas indicated that 18% of patients with HAM from Brazil and the United Kingdom reported quality of life as low as death (5). HAM is reported to affect around 5% of those living with HTLV-1. However, mild neurological symptoms affect a higher proportion (~30% of patients in Brazil) (6, 7). HTLV-1

also causes a multitude of inflammatory diseases such as uveitis, infective dermatitis, and pulmonary disease (8), and was recently associated with higher risk of diabetes and chronic renal disease (9).

People living with HTLV-1 also have more chances of being coinfecting with a range of pathogens, may have severe outcomes, and may fail to respond to treatment. This virus is also associated with an increase in all-cause mortality and has a detrimental socioeconomic impact. Patients report stigma, social exclusion, fear, and guilt, and there is decrease in productivity, early retirement, and premature death. Socioeconomic impact is not only restricted to those living with the disease but also extends to caregivers and family members. Thus, HTLV-1 affects those in vulnerable conditions and contributes to perpetuate and accentuate health inequities (3).

PREVENTION OF MOTHER-TO-CHILD TRANSMISSION OF HTLV-1 IS A PRIORITY

Prevention of MTCT of HTLV-1 is a priority, as infection early in life results in increased risk of developing disease. ATLL is associated with infection in infancy, and infective dermatitis occurs mainly in pediatric patients. Children with infective dermatitis have higher risk of developing ATLL and HAM in the future. In addition, MTCT contributes to familiar aggregation, frequently seen in HTLV-1 infection, accentuating health inequities; thus, prevention of MTCT of HTLV blocks a chain of transmission. Active surveillance is important, as most HTLV-1-associated diseases have a long incubation period, resulting in late diagnosis and missed opportunities to prevent transmission. HTLV-1 antenatal screening could also facilitate contact tracing. A study in Brazil revealed that 32% of family members of women living with HTLV-1 were also seropositive for HTLV-1.

INTERVENTIONS TO PREVENT MTCT AND THEIR EFFECTIVENESS

Available interventions focus on preventing transmission via breast milk, as there is no consensus on strategies to prevent HTLV transmission during pregnancy or at delivery. Avoidance of breastfeeding is effective and results in an 85% reduction in the risk of transmission. Data from Japan indicate that breastfeeding for 3–6 months doubles the risk of transmission compared to exclusive formula feeding.

BARRIERS TO IMPLEMENTING POLICIES TO PREVENT MTCT OF HTLV AND STRATEGIES TO OVERCOME THEM

Despite clear evidence of the effectiveness of interventions to prevent transmission, policies to avoid MTCT of HTLV-1 are not implemented globally. Some barriers prevent the implementation of policies, and proposed strategies to overcome these were discussed during the meeting and are summarized in Table 2.

Table 2. Barriers to the prevention of MTCT of HTLV and proposed strategies to overcome them

Barrier	Strategies to overcome the barrier
Unknown HTLV-1 situation	<ul style="list-style-type: none"> • Identify specialists and community leaders to support the response to HTLV-1 (locally and globally) • Understand HTLV-1 prevalence and distribution (literature review, prevalence data on blood donors, use of mathematical models)(10) • Evaluate existing policies (specific to HTLV-1 and policies that could benefit HTLV-1 response or where it could be easily integrated) • Define priorities (“SWOT” analysis is an interesting tool) (11)
Impact of HTLV-1 is underestimated	<ul style="list-style-type: none"> • Increase awareness about HTLV-1 and its broad impact on patients’ health and well-being and in their community
Lack of knowledge about HTLV-1 (healthcare professionals and society)	<ul style="list-style-type: none"> • Empower and support patients • Use of social media platforms (e.g., HTLV Channel) • Dedicated webinars and workshops (HTLV 2021 Webinar [1]) • Inclusion of HTLV in strategic planning (WHO) (12) • Inclusion of HTLV in professional training
Lack of cure is misconceived as lack of interventions	<ul style="list-style-type: none"> • Increase awareness • Develop clinical guidelines (examples: Brazil [13], Chile [14], United Kingdom [15])
Uncertainty regarding HTLV-1 diagnosis	<ul style="list-style-type: none"> • Delineate diagnostic algorithm that suits local scenario (examples: Brazil [13], Chile [14], Japan [16])
Lack of cost-effectiveness studies	<ul style="list-style-type: none"> • Develop economic studies • Support research on economic analysis
Cost of HTLV-1 screening	<ul style="list-style-type: none"> • Use screening test with higher sensitivity (reduce costs in up to 25%) (17) • Consider pooling samples (reduce costs in up to 75%) (18) • Support research on HTLV-1 diagnosis
Concerns about current interventions	<ul style="list-style-type: none"> • Empower patients and healthcare professionals for a proper informed decision • Develop guidelines on interventions to reduce risk of transmission • Support research on novel interventions

EMTCT PLUS INITIATIVE

Dr. Leandro Sereno, PAHO

OVERVIEW ON EMTCT PLUS

Dr. Sereno addressed EMTCT Plus (19) and how to use this platform as an opportunity to respond to HTLV-1. He presented a timeline of this initiative, which dates to 2010 when strategies to eliminate MTCT of HIV were integrated to the efforts to eliminate congenital syphilis. Since this initiative was launched, Cuba was the first country to be validated as having eliminated the vertical transmission of syphilis and HIV, followed by seven other countries and territories (Anguilla, Antigua and Barbuda, Bermuda, Cayman Islands, Dominica, Montserrat, and Saint Kitts and Nevis). In 2017, the EMTCT initiative was expanded with the addition of hepatitis B and congenital Chagas disease to the framework.

There are approximately 15 million pregnant women annually in the Region, with countries reporting good health care coverage with high access to antenatal care. This was seen as an opportunity to implement the EMTCT Plus initiative. The objective of EMTCT Plus is to achieve and sustain the elimination of MTCT of HIV, syphilis, Chagas disease, and perinatal hepatitis B in the Americas. Targets include: $\leq 2\%$ MTCT of HIV; ≤ 0.5 congenital syphilis cases per 1000 live births; $\leq 0.1\%$ HBsAg prevalence among 5-year-old children; and $\geq 90\%$ of children cured of Chagas infection with post-treatment negative serology. Countries should meet programmatic objectives to reach the target (Table 3). These include access to diagnosis, treatment, and vaccination. The EMTCT Plus framework also establishes a well-characterized list of interventions that should be implemented at different levels of the health system. Similar interventions focusing on the prevention of HTLV should be discussed and considered.

Table 3. EMTCT Plus programmatic objectives

	Impact targets
	<ul style="list-style-type: none"> • $\leq 2\%$ MTCT of HIV • ≤ 0.5 congenital syphilis cases per 1000 live births • $\leq 0.1\%$ HBsAg prevalence among 5-year-old children • $\geq 90\%$ of children cured of Chagas infection with post-treatment negative serology
	Programmatic objectives
For all	<ul style="list-style-type: none"> • $\geq 95\%$ coverage of antenatal care and hospital deliveries • $\leq 10\%$ of unmet family planning needs among women (15–49 years)
HIV	<ul style="list-style-type: none"> • $\geq 95\%$ coverage of HIV testing of pregnant women • $\geq 95\%$ antiretroviral therapy (ART) coverage in pregnant women
Syphilis	<ul style="list-style-type: none"> • $\geq 95\%$ coverage of syphilis testing of pregnant women • $\geq 95\%$ coverage of adequate syphilis treatment in pregnant women
Hepatitis B	<ul style="list-style-type: none"> • $\geq 95\%$ coverage of hepatitis B vaccine birth dose (<24 hours) • $\geq 95\%$ coverage of hepatitis B vaccine third dose in the first year • $\geq 85\%$ coverage of birth and third dose in all provinces [supporting target-country level] • $\geq 80\%$ coverage of HBsAg testing of pregnant women [supporting target-country level] • $\geq 80\%$ coverage of HBIG to exposed neonates [supporting target-country level]
Chagas disease	<ul style="list-style-type: none"> • $\geq 90\%$ testing of pregnant women • $\geq 90\%$ testing of neonates of seropositive mothers • $\geq 90\%$ treatment of seropositive mothers

Notes: HBsAg, hepatitis B surface antigen; HBIG, hepatitis B immunoglobulin.

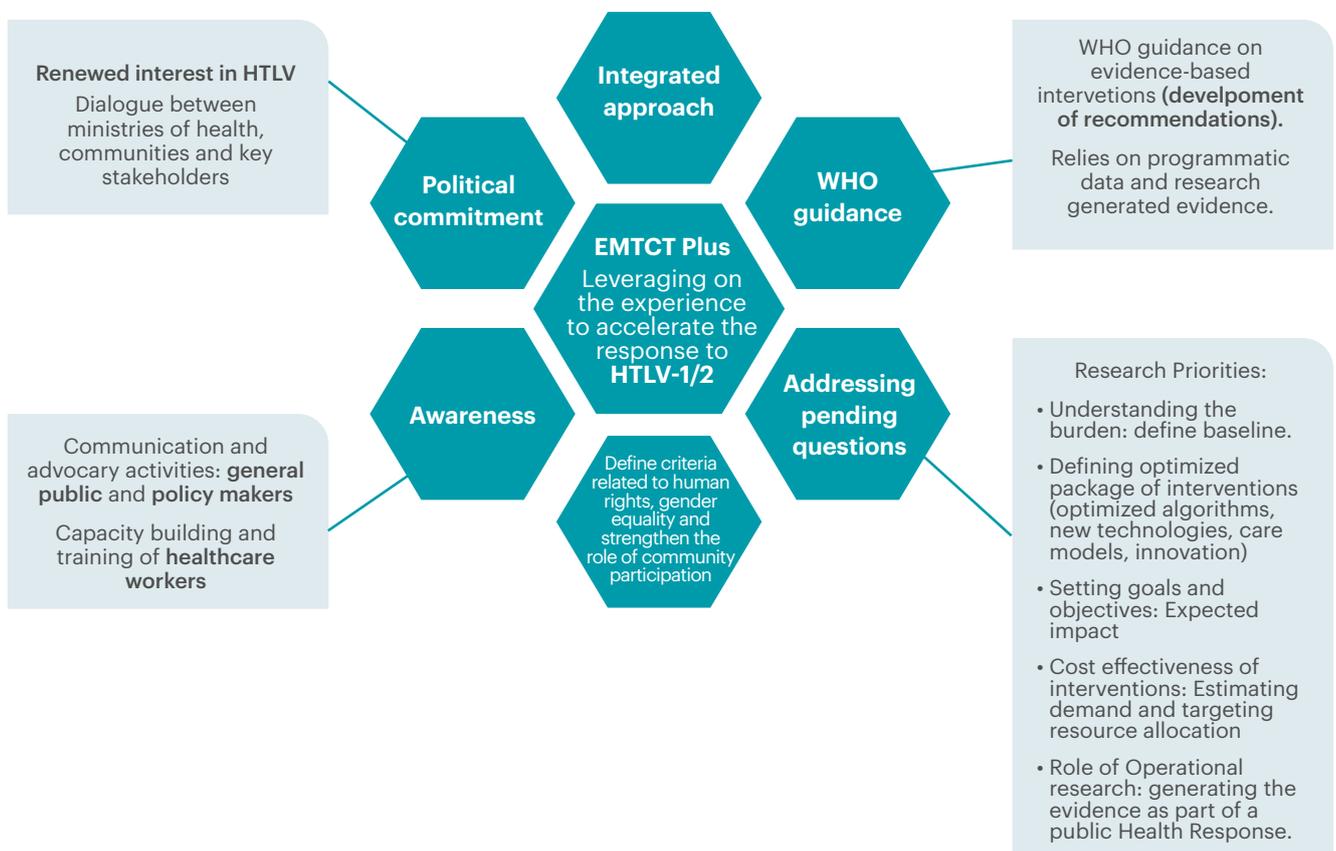
FACTORS THAT CONTRIBUTE TO SUCCESSFUL IMPLEMENTATION OF EMTCT PLUS AND CHALLENGES

EMTCT Plus has prevented 50 000 new HIV infections in infants since its implementation in the Region; however, some challenges remain. These include transforming political commitment into action; the verticality of the programs; the need to expand access to diagnosis, treatment (prophylaxis), and prevention interventions; the need to ensure the quality and supply of medicines and diagnostic tests; and the need to implement a functional information system to capture programmatic objectives. To succeed, the EMTCT Plus initiative requires interprogrammatic work with a focus on strengthening maternal and child health. Expansion of the use of new technologies and algorithms for the diagnosis of infection is needed, and the use of rapid and multiplex testing is an interesting option. In addition, there is a need to stimulate the inclusion of EMTCT Plus indicators in national information systems and strengthen community participation, gender equality, and human rights. It was noted that several guidance documents, tools, methodologies, and reports were produced, and a specific structure was organized—including PAHO secretariat, Regional Validation Committee, and Technical Advisory Groups—and this could be used to benefit the response to HTLV-1.

EMTCT PLUS AS AN OPPORTUNITY TO ADVANCE THE RESPONSE TO HTLV

Dr. Sereno identified some opportunities to use the EMTCT Plus framework to leverage the response to HTLV-1. These are summarized in Figure 1. He highlighted that although there are still some gaps, there is already enough knowledge to respond to HTLV-1, particularly to implement policies to prevent MTCT.

Figure 1. Opportunities for HTLV-1 response within EMTCT Plus



PERSPECTIVE OF A PERSON LIVING WITH HTLV

Mrs. Ema Moyano, people living with HTLV representative from Argentina

Mrs. Ema Moyano shared her personal experience, reporting that breast milk transmission of HTLV-1 has affected her family across generations with fatal impact on two of her siblings, who died recently due to ATLL. She stressed that HTLV-1 also impacts quality of life and mental health. Many women feel guilty when they transmit the virus to their babies and affirm that it is hard to cope. Mrs. Moyano herself felt relieved when she found out that her sons were not infected, and she decided to act and help to avoid new transmissions. She recognized that the future is promising and requested the World Health Organization (WHO) to formally recognize November 10th as World HTLV Day, as this would be a catalyst to increase awareness about the virus. Lack of awareness was recognized as a barrier in her country. She also urged policymakers in Argentina to implement a program targeting HTLV, expanding on the screening of blood donors, which commenced in 2005. She pledged the implementation of antenatal HTLV-1 screening and screening of milk banks.

BRAZIL'S EXPERIENCE IN PREVENTION OF MOTHER-TO-CHILD TRANSMISSION OF HTLV-1

Prof. Angelica Espinosa Miranda, Ministry of Health, Brazil

Prof. Miranda opened her talk addressing the importance of initiatives such as this workshop to discuss HTLV-1 and to foster the inclusion of HTLV-1 in the agenda. She explained that there is still a lack of data about HTLV-1 prevalence in pregnant women in some areas in Brazil, and there is no register system to notify HTLV-1 infection in the country. To overcome this barrier, the Brazilian Ministry of Health funded an ongoing national HTLV-1 prevalence study in pregnant women. Brazil implemented screening of blood donors in 1993 and has an HTLV Clinical Guideline (with the third edition published in 2021) (13). In addition, early clamping of umbilical cord, avoidance of breastfeeding (including use of cabergoline), and provision of formula is recommended for women living with HTLV-1 (20–22). In April 2022, antenatal HTLV-1 screening was included in the novel national maternal and child health program (23). This recommendation is now under review by the Brazilian National Committee for Technology Incorporation (CONITEC).

In Brazil, the inclusion of HTLV-1 in the department of chronic diseases and sexually transmitted infections (STI) was crucial. All funding opportunities (research grants and funding to support civil society organizations) and awareness campaigns focusing on STIs now also include HTLV-1. Brazil is also evaluating the feasibility of implementing centers for multidisciplinary care of people living with HTLV-1 and is planning a national meeting to discuss this topic. Prof. Miranda also addressed the importance of increasing awareness about HTLV-1 and the collaboration between community, researchers, and policymakers. Brazil has adopted different strategies, including the distribution of calendars to primary health care units with an HTLV-1 diagnostic diagram (STIs and antenatal care settings), publication of manuscripts regarding the clinical protocol for STIs (24), and inclusion of HTLV-1 in online training courses (11). According to Prof. Miranda, Brazil needs to effectively implement HTLV-1/2 antenatal screening in the public health system. She highlighted that HTLV-1/2 distribution varies across the states; therefore, those with high prevalence of infection will start the implementation first, while areas with low prevalence will discuss the implementation at later stages.

PANEL DISCUSSION

Dr. Tatiane Assone, Universidade de São Paulo, HTLV Channel, Brazil

Dr. Hortencia Peralta, PAHO

Prof. Angelica Espinosa Miranda, Ministry of Health, Brazil

Dr. Jorge Valdebenito, Ministry of Health, Chile

Dr. Diana Maria Librado Cardona, Ministry of Health, Colombia

CURRENT POLICIES ON HTLV IN CHILE AND COLOMBIA

Dr. Librado pointed out that Colombia implemented compulsory HTLV-1/2 screening of blood donors in 2014. Before then, screening was done only in regions considered as having high prevalence of infection. Organ donors are also screened since 2004 in the country. HTLV-1 has now been included as a priority topic in the strategic planning for public health 2022–2031 in Colombia. The target is to provide clinical care for at least 70% of those living with HTLV-1 identified during blood donor screening. The Ministry of Health of Colombia is currently developing a clinical guideline for HTLV-1, in collaboration with local and international experts, and with PAHO support.

Chile has been screening blood donors for HTLV-1/2 since 2008, and organs since 2015. Antenatal screening is not compulsory, but avoidance of breastfeeding is recommended in the national protocol (14). Recently, provision of formula was guaranteed for babies born to women living with HTLV-1. Dr. Valdebenito pointed out that in Chile, HTLV-1/2 diagnosis is centralized in the national public health laboratory, where all confirmatory tests for HTLV-1 are performed. Although there is no compulsory notification for HTLV-1/2 infection, there is laboratory surveillance. The Ministry of Health of Chile is planning to set up a technical committee to discuss HTLV-1 surveillance and for the implementation of HTLV-1 services in the context of maternal and child care, which is considered a priority in that country. He highlighted the importance of this meeting to advance the response to HTLV-1, a neglected infection.

STRATEGIES TO ENSURE THE IMPLEMENTATION OF POLICIES ON HTLV IN THE BRAZILIAN PUBLIC HEALTH SYSTEM AND TO IMPROVE PATIENT CARE

The major challenge that Brazil faces now is the effective implementation of recommended policies. Prof. Miranda highlighted that there is a need to articulate with local governments, as they need to cover the costs for the implementation of such policies. She stressed that the implementation of policies will not be homogeneous in the country due to the diversity of Brazil's regions. In fact, some Brazilian states have already implemented policies and programs before the inclusion of HTLV-1 in the national maternal–infant health program. Prof. Miranda drew attention to the necessity of collaboration between academia, community, states, and municipalities. She pointed out that increased awareness is imperative, and the inclusion of HTLV in WHO's strategic planning and in webinars and reports from PAHO will be crucial to stimulate the implementation of policies in the countries. Another important strategy is to work in collaboration with the Ministry of Education to lobby for the inclusion of HTLV-1 in the curriculum, to improve awareness among healthcare professionals.

PERSPECTIVES FROM CHILE AND COLOMBIA, FOCUSING ON MTCT

Dr. Valdebenito affirmed that it is crucial to include HTLV in EMTCT Plus and that Chile is looking forward to it in order to eliminate MTCT of HTLV-1. He addressed the importance of PAHO's support and the role of international agencies to include HTLV-1 in the agenda, to promote compulsory notification, and to determine strategies and targets. He recognized that there are many barriers, such as lack of awareness, lack of training of healthcare professionals, the costs associated with implementing screening, and the lack of treatment once the infection is diagnosed.

Colombia understands the importance of working on preventive strategies for HTLV-1, as there is no curative treatment for this infection. The national strategy includes the development of a clinical guideline to support healthcare professionals. This guideline focuses on women of reproductive age and pregnant women, and has been supported by PAHO. The program is also planning a cost-effectiveness analysis of antenatal screening in the country. The main barriers are the lack of epidemiological data and the absence of information on the cost-effectiveness of such policies. Colombia has been working on the implementation of EMTCT Plus, and this was recognized as an opportunity to leverage policies on HTLV-1.

Both countries recognized the importance of PAHO and the inclusion of HTLV-1 in EMTCT Plus to advance policies on HTLV-1 in the Region.

COLLABORATION BETWEEN COUNTRIES

Prof. Miranda addressed the need to discuss the challenges and perspectives regarding the prevention of MTCT of HTLV-1 in the context of EMTCT Plus with countries in the Region. She affirmed that the present workshop, as well as last year's webinar, is fostering collaboration and stimulating the discussion at the level of the Region. Brazil has been working in partnership with PAHO and has been discussing MTCT of HTLV together with countries from Mercosur. She pointed out that ample discussion between different countries is important, as they face similar problems and may together identify opportunities. She stressed the importance of having more moments like this workshop; representatives from Colombia and Chile agreed.

CLOSING REMARKS

Dr. Rubén Mayorga-Sagastume, PAHO

Dr. Mayorga-Sagastume summarized the meeting, highlighting the opportunities identified to reduce the cost of HTLV screening, the importance of economic analysis, and the range of opportunities identified in the EMTCT Plus framework to advance the elimination of vertical transmission of HTLV-1. He pointed to the importance of Mrs. Moyano's contribution to the meeting by sharing her personal statement. He highlighted the increasing political commitment and the need to push for the implementation of policies in different opportunities, using an integrative approach. Dr. Mayorga-Sagastume concluded that Brazil is an example and has shown substantial advance, and he also recognized the advances made and the perspectives of Chile and Colombia. There are many similarities in the Region, and countries will benefit from sharing experiences. He finalized his talk by stating that there are now clear ideas and perspectives on how to move forward with this agenda, and affirmed that WHO has great interest in the actions on HTLV in the Region and the need to stimulate collaborations toward concrete actions in the near future.

CONCLUSION

Prevention of MTCT of HTLV-1 is considered a priority in the global response to this virus. There are effective strategies to prevent MTCT of HTLV-1, and these have been implemented in some countries, such as Brazil. The EMTCT Plus framework provides a unique opportunity to leverage the response to HTLV-1. Collaboration is essential to promote the implementation of such policies. Continuous support from PAHO is crucial for a sustained response to HTLV-1.

PAHO, its Member States, and other stakeholders are encouraged to collaborate and implement some priority actions, including:

- Provide technical cooperation to define baselines, milestones, and targets for the response to HTLV-1, focusing on prevention of MTCT, with the ultimate goal to eliminate new infections in childhood.
- Identify opportunities in the EMTCT Plus initiative to leverage the response to HTLV-1 and develop a technical guideline focusing on strategies to prevent MTCT of HTLV-1.
- Provide technical cooperation and guidance for Member States on the development, implementation, or inclusion of policies to prevent MTCT of HTLV-1 at the local and regional level.
- Promote discussion and collaboration between countries and other stakeholders in the Region on this topic, creating opportunities to share experiences.
- Support civil society organizations, to empower people living with HTLV-1.
- Increase awareness about HTLV and its impact.
- Facilitate and promote research on the prevention of MTCT of HTLV-1, including implementation and scale-up studies.

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This workshop discussed “The Response to HTLV in the Framework of Maternal and Child Health” in the Americas. HTLV-1 impact is broad and significant, however, there are effective interventions to prevent transmission, particularly mother-to-child. Barriers that hamper the implementation of policies targeting mother-to-child transmission of HTLV-1 were identified, and strategies to overcome them were discussed. The framework for the elimination of mother-to-child transmission of HIV, syphilis, hepatitis B, and Chagas disease (EMTCT Plus) represents an opportunity to advance the response to HTLV-1. The integration of HTLV-1 into the sexually transmitted infections program, the recommendation of HTLV-1 antenatal screening, provision of formula for babies born from seropositive women, and awareness campaigns are examples of good practices that can be considered as part of the package of services included into the EMTCT Plus framework. Additional countries experiences include development of national clinical guideline for HTLV-1, which includes recommendation of exclusive formula feeding for babies born from mothers living with HTLV-1 and the development of economic analysis focusing on HTLV-1 response. PAHO’s continuous support was unanimously identified as crucial to the progress of this agenda. The definition of baselines, milestones, and targets for the response to HTLV-1 focusing on the elimination of mother-to-child transmission are necessary next steps. To achieve additional progress in the region, it is essential to increase awareness, to foster collaboration, and to stimulate research on prevention of mother-to-child transmission of HTLV-1. This report summarizes key discussion points for the implementation of public health policies to eliminate mother-to-child transmission of HTLV, and the collaborative work needed to promote the implementation of such policies.



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