## Webinar:

# International health policy forum for the elimination of HTLV

Advancing HTLV health policies around the world

10 November 2021

Web Annex - Abstracts

PAHO Pan American Health Organization
World Health Organization Americas
Regional Office for the Americas

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November 10th, 2021

Meeting Report

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## Introduction

Human T cell lymphotropic virus (HTLV) infection affects mainly vulnerable population groups: people living in poverty in areas of very low human development index, sex workers, men who have sex with men, people who inject drugs, epidemiologically closed and semi-closed population groups including traditional populations and indigenous people. This virus and its consequences have been neglected for decades, despite the high morbidity and mortality attributable to HTLV infection.

In this context, in 2018 an open letter to the World Health Organization (WHO) from HTLV researchers was published in the Lancet[*], emphasizing that the time had come to eliminate this infection in our midst. In response to this request, the initial step is to shine light onto HTLV and support an international effort towards the elimination of HTLV-1/2. Following the publication of a technical report on HTLV-1 by WHO, the Pan American Health Organization (PAHO/WHO), in partnership with HTLV Channel, a platform to increase awareness on HTLV, organized a webinar on November 10th, 2021.

The "*HTLV World Day Webinar: International health policy forum for the elimination of HTLV*" aimed to discuss the health policies already implemented in several countries, which may contribute to achieving the goal of HTLV elimination. These actions taken together intend to be an inspiration for those countries that are still in early stages of establishing national strategies for the prevention and control of HTLV-1/2 and to propel proposals for elimination of these viruses.

The organizers also invited researchers, healthcare workers, civil society, and other stakeholders to send abstracts to be presented during the Webinar. Seventeen manuscripts were received and presented in the format of video-posters, which are fully available at the HTLV Channel (https://yotube.com/c/HTLVChannel).

The Report of the HTLV World Day Webinar is available at https://www.paho.org/en/international-health-policy-forum-elimination-htlv, and this Web Annex includes the abstracts that have been received and presented.

[*] Martin F, Tagaya Y, Gallo R. Time to eradicate HTLV-1: an open letter to WHO. *Lancet* 2018; **391**: 1893–4.

## High prevalence of HTLV-1 infection among Japanese immigrants and their descendants in non-endemic areas of Brazil

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**Background:** Currently, there are approximately an estimated 1.5 million Japanese descendants living in Brazil, which is considered the country with the largest amount of Japanese people outside Japan. Most of them reside in the state of São Paulo (Southwest region), followed by the state of Paraná (South region) and Mato Grosso do Sul (Central-West region). Since South America has been considered as a very important focus of HTLV-1 carriers and associated diseases, and HTLV-1 is considered endemic in southwestern Japan, this study aimed to investigate the epidemiological and molecular aspects of the HTLV-1 infection among Japanese immigrants and their descendants living in São Paulo, SP and Campo Grande, MS. **Methods:** From April 2012 to December 2017, cross-sectional studies were conducted among 2,139 individuals from five Japanese associations from São Paulo, and 219 individuals from two Japanese associations from Campo Grande. All serum samples were tested for the presence of anti-HTLV-1/2 antibodies by ELISA and then positive serological samples were analyzed for the presence of HTLV-1 5'LTR proviral DNA by nested PCR. Partial sequencing of the 5'LTR region of HTLV-1 proviral DNA was performed by Sanger. **Results:** The overall prevalence of HTLV-1 infection was 5.1% (CI 95%: 4.2–6.0) in São Paulo and 6.8% (CI 95%: 3.5-10.2) in Campo Grande. HTLV-1 infection was associated with age ≥ 45 years in both populations. Female sex, being first and second-generation Japanese immigrants and having sexual partners with a history of blood transfusion showed an association between HTLV-1 in participants from São Paulo. Among the studied population from São Paulo, Transcontinental (A) and Japanese (B) subgroup of Cosmopolitan (1a) subtype were detected in 47.8% and 52.2%, respectively. In Campo Grande, 50% belonged to subgroup A (transcontinental) and 50% to subgroup B (Japanese). Epidemiological data, along with molecular results also demonstrated a high occurrence of similar sequences transmitted intra- and interfamily in both studies. **Conclusion:** The high prevalence of HTLV-1 infection and the occurrence of intra and interfamily transmission, highlight the urgent need to plan individual and collective effective prevention strategies and control HTLV infection such as health education actions, periodic serological screening, and follow-up of HTLV positive individuals to reduce the impact of HTLV-1 among this group population.

## Successful activities to make the HTLV visible among healthcare professionals in Sao Paulo, Brazil

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**Background:** Since 1992, the Instituto Adolfo Lutz (IAL), the Central Public Health Laboratory in São Paulo, Brazil, has been carrying out studies on HTLV-1 and HTLV-2 infections, and since 1998 has performed HTLV serology as routine. At the time, these retroviruses were unknown among healthcare professionals in São Paulo and in Brazil. Thus, to make these retroviruses and people living with HTLV (PLHTLV) more visible, we developed some activities.
**Methods:** (i) Disseminate data on the prevalence of HTLV in different at-risk populations: blood donors, patients from AIDS and STD Reference Centers, and HTLV out-patient clinics; (ii) Disclose problems encountered in the laboratory diagnosis and look for solutions for its improvement; (iii) Publish in the São Paulo Epidemiological Bulletin (BEPA), a magazine of the Center for Disease Control, Secretary of Health of São Paulo (CCD-SES/SP) the best laboratory diagnostic algorithms, based on its performance and cost-effectiveness; (iv) Offer scholarships for undergraduate and graduate students, including Masters and PhD students, in order to acquire specialization in HTLV; (v) Include the subject "Laboratory Diagnosis of Human Retroviruses" in the Postgraduate Course of the Faculty of Pharmacy, University of São Paulo (1996-2005) and the subject "Immunological and molecular biology procedures applied in the study of HTLV-1 and -2 infections" in the Postgraduate Public Health Course of the CCD-SES/SP (since 2005); (vi) Search for prognostic markers for diseases development in HTLV-monoinfected and HTLV/HIV-, HTLV/HBV- and HTLV/HCV-coinfected individuals; (vii) Give Lectures of HTLV and of the HTLV World Day, write articles, disseminate information in websites and in the Virtual Health Library of the SES/SP (BVS-SES/SP); and (viii) Make HTLV advertising banners.
**Results and conclusion:** All these activities were successful and promoted visibility to HTLV and PLHTLV. During this period (almost 30 years), the staff of IAL participated and presented 82 HTLV routine and research data in national conferences and 60 in international conferences, and published 62 articles. More than 30 lectures were presented, and 43 healthcare professionals were qualified in HTLV. Great interest in Postgraduate courses has been observed. Articles on HTLV World Day were published (BEPA 2018;15(179):27-30; Rev Inst Adolfo Lutz. 2018;77:e1751), and banners were displayed in the lobby of IAL and SES-SP, throughout the month of October since 2018.

## Line of care for HTLV patients: diagnosis of the care network in the state of Bahia.

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**Background**: The Integral Care Line for People Living with the HTLV virus in the State of Bahia, instituted through Ordinance Nº 460, from November 19, 2020, presents as guidelines: regionalization of assistance; health promotion; humanized care model centered in the user and his health needs; expansion of access to outpatient and specialized services in diagnosis and treatment, integrated by regulatory processes and effective reference and counter-reference flows. Considered a neglected disease, the HTLV notification became mandatory in the State of Bahia through the Ordinance No. 125 of January 24, 2011. All carriers must have special attention, given the complexity of the disease, in order to ensure the right to health in its entirety. The objective of this study was to carry out a diagnosis of the care network in Bahia, with the purpose of making evident aspects that hinder and facilitate the implementation of the Integral Care Line for People Living with the HTLV virus in the State of Bahia. **Methodology**: 112 key-informants from the nine macro-regions of the State of Bahia were interviewed using a Microsoft Forms form, containing questions about the components of the line of care, such as primary care; health surveillance; specialized care services (SAE/CTA), specialized outpatient clinics; rehabilitation; urgency and emergency network; and hospital care, in addition to the main doubts about the Ordinance. After data analysis, a tutorial was recorded using the Microsoft Teams platform and made available to the health macro-regions to help them implement the care line. **Results**: The main points that make up the Line of Care in terms of the healthcare network were categorized according to the data: a) Reference and Counter-Reference Flow for Sexually Transmitted Infections (STIs) in their region; b) Rehabilitation Services (own or hired); c) Medical Specialties; d) Pre-Christmas Screening for HTLV in pregnant women; e) Knowledge of Ordinance nº 460, from November 19, 2020. From the total of 112 participants, 86% (96) answered that they have reference and counter-reference flow for STIs; 87% (97) have rehabilitation services; 50% (55) have the main medical specialties to assist HTLV carriers. The municipalities that do not have them refer the patients to the agreed network via Regional Polyclinics, APAE or according to the Agreed and Integrated Programming of health care. 99% (111) perform prenatal screening for HTLV. 78% (87) said they were aware of Ordinance # 460/2020. **Conclusion**: The existence of an assistance network indicates that it is a facilitator for the implementation of the Line of Care for People Living with the HTLV virus. Although the Ordinance 460 was released in November 2020, 22% of the interviewees were unaware of the existence of this state regulation. Thus, the tutorial was carried out to solve the doubts identified in the questionnaire applied, reaching the 9 health macro-regions of the State of Bahia.

## Screening for HTLV-1/2 infection in a cohort of pregnant women in Recife, northeastern Brazil: preliminary results

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**Introduction:** The Human T-Lymphotropic Virus type 1 and 2 (HTLV-1/2) causes a chronic and incurable infection, and the vertical transmission is its main rout. Globally, there are 800,000-2.5 million people living with HTLV. The HTLV can cause severe diseases in up to 10% of cases, as adult T-cell leukaemia, and HTLV-associated myelopathy. Brazil is the country with the highest number of HTLV-1/2 cases, but little is known about the transmission pattern in our population, while HTLV testing is still not part of the prenatal screening nationwide. This setting can contribute with a silent HTLV spreading in the families, specially at Northeast of the country, the region with highest prevalence. **Objective.** To screen HTLV-1/2 infections in women, during the prenatal care, in a single hospital at Northeast of Brazil. **Methods:** A cohort of 816 pregnant women was recruited from April 2017 to July 2018 (cohort follow-up until May 2019), in a prenatal-care centre, regional reference for maternal and childbirth health. After the informed consent process, a standardized questionnaire was carried out, as well the blood collection to screen vertically transmitted infections: toxoplasmosis, rubeola, cytomegalovirus, herpes, syphilis, HIV and Zika. The screening for anti-HTLV-1/2 antibodies (kit ELISA Murex anti-HTLV-1/2, Diasorin©) is retrospectively performing, and so far, serum samples from 240 women were tested. **Results:** 77% of the women was 20-35 years-old; 50% was not employed at study inclusion and had a family income less than ½ minimal salary *per capita*. Only a third of them were at normal weight, and 50% had overweight/obesity (Atalah classification). The women were at the 1st trimester of pregnancy (40/240) or 2nd (200/240); 40% was in the 1st pregnancy; 25% had a previous miscarriage. Four women were positive for HIV, six for syphilis, 23 for herpes simplex virus (HSV IgM), and a women had positive HTLV-1/2 antibodies. This woman was at 2nd trimester of pregnancy and had not previous history of miscarriage. She had not positivity for HIV or syphilis, but a positive HSV IgM. **Conclusion**: Eventually, disclosing the HTLV cases in our entire cohort will allow us to investigate their descendants, sexual partners, and ascendants. Afterwards, our results may support the local setting-up of the National Policy for HTLV Prenatal Screening and Vertical Transmission.

**Table 1**. Serologic testing of 240 pregnant women (Institute of Integral Medicine Prof. Fernando Figueira, Recife, Brazil, Apr2017 - Jul2018)*

| Variables | n (%) |
|---|---|
| **Toxoplasmosis IgG (N 196)** | |
| Reactive | 115 (58.7) |
| Non Reactive | 79 (40.3) |
| Inconclusive | 2 (1.0) |
| **Toxoplasmosis IgM (N 195)** | |
| Reactive | 3 (1.5) |
| Non Reactive | 191 (97.9) |
| Inconclusive | 1 (0.5) |
| **HIV (N 213)** | |
| Reactive | 4 (1.9) |
| Non Reactive | 209 (98.1) |
| **VDRL (N 216)** | |
| Reactive | 6 (2.8) |
| Non Reactive | 210 (97.2) |
| **Cytomegalovirus IgG (N 238)** | |
| Reactive | 220 (92.4) |
| Non-Reactive | 18 (7.6) |
| **Cytomegalovirus IgM (N 238)** | |
| Reactive | 2 (0.8) |
| Non Reactive | 234 (98.3) |
| Inconclusive | 2 (0.8) |
| **Herpes simplex IgG (N 239)** | |
| Reactive | 220 (92.1) |
| Non Reactive | 18 (7.5) |
| Inconclusive | 1 (0.4) |
| **Herpes simplex IgM (N 238)** | |
| Reactive | 23 (9.7) |
| Non Reactive | 188 (79.0) |
| Inconclusive | 27 (11.3) |
| **Rubeola IgG (N 238)** | |
| Reactive | 223 (93.7) |
| Non Reactive | 6 (2.5) |
| Inconclusive | 9 (3.8) |
| **Rubeola IgM (N 238)** | |
| Non Reactive | 237 (99.6) |
| Inconclusive | 1 (0.4) |
| **HTLV-1/2 (N 240)** | |
| Reactive | 1 (0.4) |
| Non Reactive | 239 (99.6) |

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## Prevalence of HTLV-associated uveitis in patients of Salvador, Brazil

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**BACKGROUND**: HTLV-associated uveitis (HAU) is an inflammatory reaction of the choroid, retina, optic nerve, and vitreous that can lead to visual deterioration. The prevalence of HAU varies from 1,61% to 14,5% worldwide and from 1,9% to 2,85% in Brazil.
**OBJECTIVE**: To determine the prevalence of HAU in HTLV-1-infected patients and to describe the types of uveitis and associated symptoms.
METHODS: This was a cross-sectional analytical study to determine the prevalence of uveitis in HTLV-1-infected patients. Patients were recruited in Bahia, Brazil, a region considered endemic for HTLV-1 infection. Medical records of HTLV-1-infected (exposed) and uninfected (unexposed, comparison group) individuals who underwent ophthalmologic examination for the diagnosis of uveitis from June 2019 to June 2021 were analyzed. Patients were selected at the reference center for HTLV (exposed) and at the ophthalmology outpatient clinic (unexposed group). All patients were examined by the same ophthalmologist according to the same protocol. Prevalence rates(PRs) were calculated.
**RESULTS**: 171 HTLV-1-infected patients (consecutively examined) and 410 noninfected patients (randomly selected) were included. The proportion of women was 81.9% in the exposed group and 65.4% in the unexposed group ($p<0.001$). The mean age of exposed and unexposed patients was 54.5% and 62.6, respectively ($p<0.001$). The prevalence of uveitis in HTLV-1-positive (exposed) patients was 7% and the prevalence in HTLV-1-negative (unexposed) subjects was 0.73% (PR=9.6;CI95%:2.7-33.6;$p<0,001$). Bilateral intermediate uveitis associated with symptoms of visual disturbances and floaters was most common in exposed patients (66,6%), while unilateral panuveitis associated with symptoms of blurring and eye pain was more common in the unexposed group (66,6%).
**CONCLUSION**: The prevalence of uveitis in patients with HTLV-1 was higher than in previous national studies, and these results may be related to a more specific diagnostic method.

## The importance of NATIONWIDE htlv-1 antenatal screening in Brazil: a case report of a HAM/TSP - ATL family

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**INTRODUCTION**

Human T-lymphotropic virus 1 (HTLV-1) is a retrovirus that causes persistent infection. There are about 5-10 million cases in the world. Brazil has around 800,000-2.5 million cases. The main transmission routes include sexual and vertical (mother to child transmission), mainly by breastfeeding. It may explain the family aggregation. The prevalence of HTLV-1 infection in pregnant women from Brazil varied between 0–1%. The SUS does not perform prenatal serological testing, although there is a recommendation that infected mothers should not breastfeed (DAB/CAB23, 2009). Five to 10% of HTLV-1 carriers develop complications, such as HTLV-1-associated myelopathy (HAM/TSP) and adult T-cell leukemia/lymphoma (ATL). Here, we report a Brazilian family infected by HTLV-1, complicated with HAM/TSP and ATL.

**CASE REPORT**

We report three cases of HTLV-1 infection in an Afro-descendent Brazilian family from Rio de Janeiro. The mother, a 53-year-old woman presented progressive weakness on lower and upper limbs. Restricted to wheelchair. Her parents had undiagnosed similar symptoms. The daughter, a 29-year-old woman reported progressive weakness of the lower limbs and urinary incontinence since 19-year-old, also restricted to wheelchair. On neurological examination, mother and daughter present absent gait, weakness (+1/+4), spastic hypertonia and deep tendon hyperreflexia on lower limbs, bilateral Babinski and Hoffman signs. Both were diagnosed as HAM/TSP. The mother also evolved with ATL. The son, a 26-year-old man, is currently asymptomatic. Neurological examination revealed bilateral hyperreflexia of patellar. Both children were breastfed.

**CONCLUSION**

This report highlights the importance of including free HTLV testing in prenatal care in Brazilian public health system. It could block the vertical transmission of the virus, thus avoiding disabling, and sometimes fatal, complications. Manifestations of the disease can significantly affect the quality of life of an infected person, and burden the public health system, since many complications such as HAM/TSP are chronic and require multidisciplinary care. The transmission could be avoided by including serological screening on the schedule of the prenatal care, allowing the professionals to identify pregnant patients and provide the appropriate orientation. In this scenario, keeping HTLV-positive from breast-feeding and testing their close relatives would result in preventing family aggregation episodes.

## *Grupo cuidar HTLV* and social media: a strategy for the dissemination of HTLV knowledge

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Background

Aiming to promote health education focused on HTLV infection, the extension project *Grupo Cuidar HTLV*, created in April 2018 at the School of Medicine of the Federal University of Minas Gerais (UFMG) - Brazil, has two pages in the social networks, one on Facebook, created in August 2018 and the other on Instagram, created in June 2021.

Methods

The pages of the Cuidar HTLV Group on social networks Instagram and Facebook are updated weekly by students of the School of Medicine of UFMG. The students idealize and produce the content under supervision. The content, in Portuguese, addresses the definition of HTLV infection, epidemiology, transmission, prevention, the main diseases and symptoms associated with HTLV and their treatments. Both technical language, aimed at health care professionals and students, and popular language are used, so that information about HTLV is accessible to the general population.

Results

Currently, the Instagram profile has 147 followers. In the last month, there was a reach of 229 accounts, posts were viewed 1461 times and the profile had 145 visits. This meant a 127% increase in content interactions, a 19.5% increase in followers and profile visits increased 66.6% over the past month. Regarding the Facebook page, it currently has 391 followers, from 10 different countries and more than 10 cities around the world, mostly women between 35 and 44 years old (Figure 1).

Conclusions

The engagement results show that the pages on social networks have an increasing reach, having an increasingly relevant impact. Thus, social networks have proven to be an important tool for the dissemination of knowledge, fulfilling the objective of promoting health education in HTLV both for the general population and for health care professionals, increasing awareness about HTLV in Brazil and worldwide.

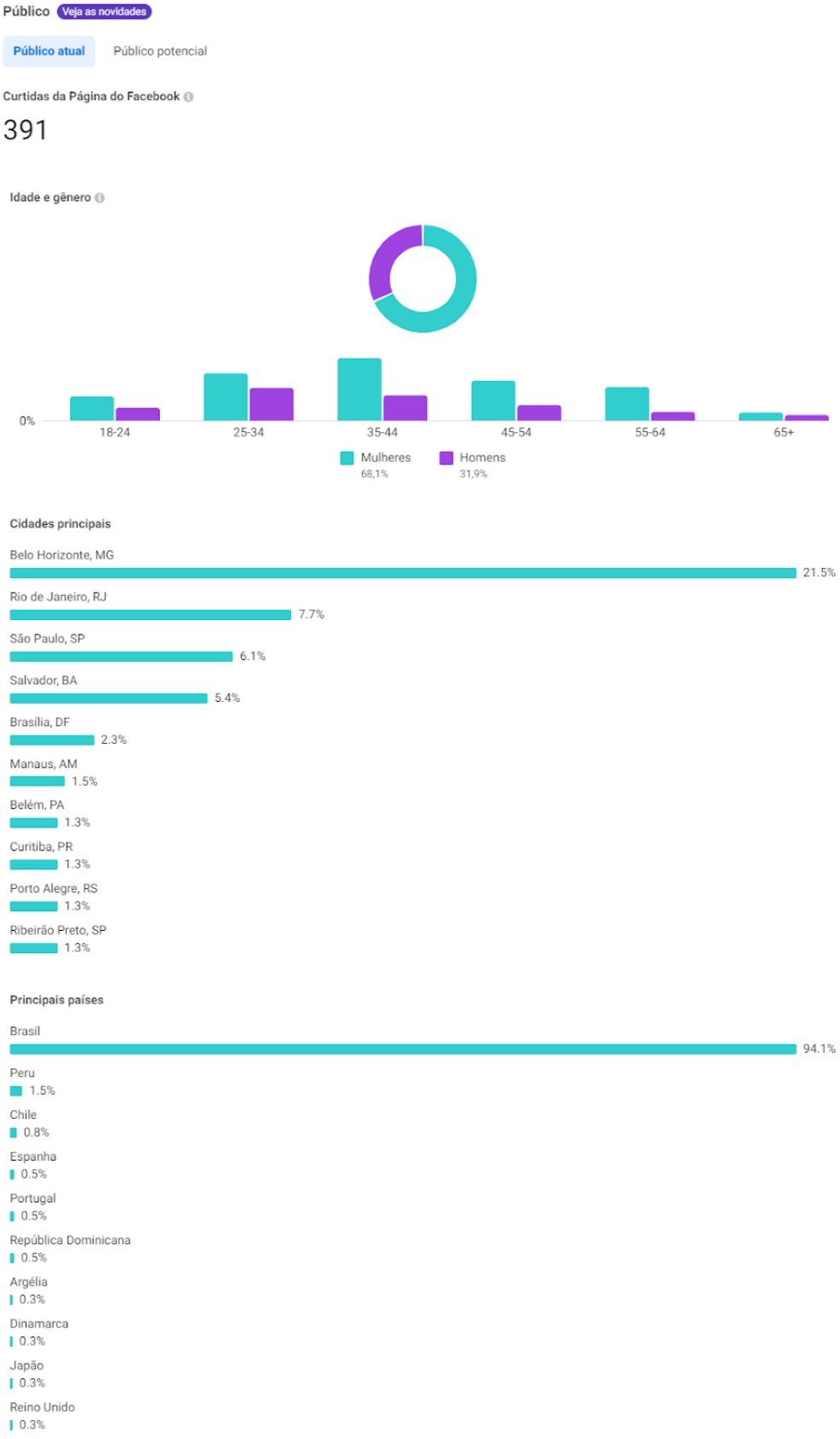


Figure 1. *Grupo Cuidar HTLV*'s followers profile according to the insights report from the Facebook page.

## Grupo cuidar HTLV: the university extension allied with research and public health policy

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Background

From 1997 to 2017, the Interdisciplinary HTLV Research Group (GIPH) monitored a cohort of more than 500 individuals with HTLV in Minas Gerais (MG), Brazil. In 2018, the GIPH, the Federal University of MG (UFMG) and the Municipality of Belo Horizonte (PBH) entered into an agreement to establish the first HTLV reference clinic in the municipality: the Cuidar HTLV Group, a university extension project of UFMG. The project continued the monitoring of the GIPH cohort and constituted a public policy action, guaranteeing specialized assistance to individuals with HTLV in the public health system.

Methods

The university extension consists of the transforming interaction between the University and Society, through the exchange of knowledge, integrated with research and education. In the case of the Cuidar HTLV Group, the protagonists of this interaction are patients with HTLV, researchers, university students and professors, and public health managers. During care, patients state their reality, perceptions and needs. Students, professors and researchers interact with these subjectivities and, based on their scientific knowledge, propose educational, research and public policy actions that address these gaps, in a virtuous cycle of improvement in the social scenario regarding HTLV.

Results

The Cuidar HTLV Group's outpatient clinic has been operating weekly since 2018 and monitors more than 250 patients. In a sample of 200 patients, we observed the majority aged between 60 and 69 years (22%) (Figure 1), prevalence of females (71%) and 26% with a confirmed diagnosis of HTLV-1 associated myelopathy ( HAM) (Table 1). The project has promoted two World HTLV Day Acts (2018 and 2019), with the participation of patients, researchers, professors, university students and health managers. In 2020 the meetings were suspended due to the COVID-19 pandemic, but in 2021 the meeting is scheduled to take place virtually on November 10th. In addition, the project participates, together with municipal managers, in public policy decisions related to HTLV, such as HTLV screening in all pregnant women in the municipality.

Conclusions

The Cuidar HTLV Group relies on the interaction of knowledge of citizens involved in its activities, that is, patients, university students, professors, researchers and public health managers to improve the social reality of people affected by HTLV infection and its associated diseases, through prevention, treatment and education.

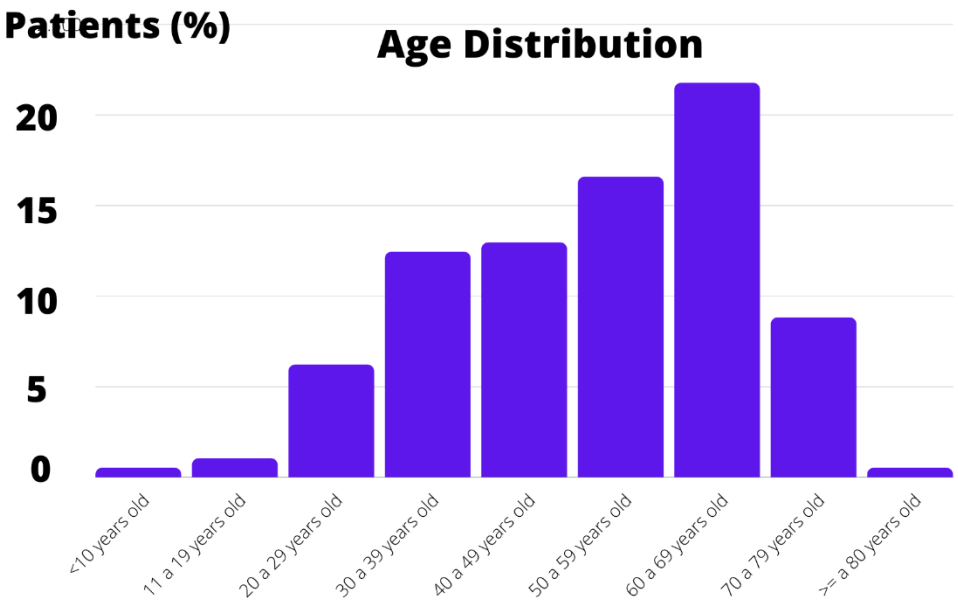


Figure 1 – Age distribution of 200 HTLV patients of the outpatient clinic

| SEX | |
|---|---|
| **MALE 29%** | 29% |
| **FEMALE 71%** | 71% |
| **HTLV-ASSOCIATED DISEASES** | |
| **LEUKEMIA LYMPHOMA** | 1.6% |
| **Under investigation** | 25.1% |
| **HAM 26.2%** | 26.2% |
| **ASYMPTOMATIC 47.1%** | 47.1% |

Table 1 – Sex distribution and HTLV associated diseases of 200 HTLV patients of the outpatient clinic

## How to improve the knowledge on HTLV infection among the risk population in Recife, northeast of Brazil

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**Background.** The human T-Cell Lymphotropic Virus (HTLV) is a retrovirus present worldwide. Globally, Brazil is the country with the highest number of HTLV infection cases (2.5 million), the majority of which is at North and Northeast regions. A poor knowledge about the HTLV by population, and even by health professionals, can contribute with such a chronic and silent infection to remain neglected since 80's decade. However, the current spreading of information and digital technologies allow the scientific knowledge to be largely available and accessible everywhere and to anyone. **Objective.** To improve the knowledge on HTLV infection and HTLV-associated diseases among populational risk-groups in the city of Recife. **Methods.** Cards, videos, and animations are being developed, using a common language. These materials will be shared with researchers, healthcare professionals and students. Moreover, to widely reach the general population, people living with HTLV and reproductible-aged women, it also will be publicized in health and education institutions, and in digital medias. We will assess the knowledge on HTLV by before-and-after questionnaires, which will be applied to a sample of professionals and users at three prenatal-care services and two HTLV-associated diseases healthcare centres. **Results/Perspective.** We created the page HTLV Brasil on Instagram (@htlvbrasil), where our digital materials, as well others news and evidence-based information, will be posted every week. Our materials and fieldwork, beside the available digital interfaces, will result in a physical-digital-social (*phygital*) framework. Eventually, we hope that the knowledge on this virus and its transmission mechanisms can stimulate healthcare professionals to order HTLV testing, especially during pregnancy and to investigate HTLV-associated symptoms, and to encourage people to look for HTLV testing in our public health system. **Conclusion.** Outreach campaigns on HTLV should be used to spread the scientific knowledge among population. This may go beyond just disseminating information, but might contribute with a timely diagnosis, effective prevention, and prevalence reduction of the HTLV infection.

## The invisibility of HTLV-1 amongst homeless persons: a case report of a pregnant woman with neurological complications

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**Background**

HTLV is a human retrovirus that can cause silent infection. The estimate is that 800,000-2.5 million individuals are infected with HTLV-1 in Brazil, with a higher prevalence in African descendent women, with less education and of advanced age. Considering risk groups, the homeless population stands out for its social invisibility. Currently, in Brazil, there are 221,000 people living on the streets and this number has been growing sharply due to the pandemic. This increase brings with it the warning of the possibility of increased dissemination of HTLV in this vulnerable group.

**Methods**

We report a case of HTLV-1 infection in a vulnerable individual, complicated with HTLV-1 associated myelopathy (HAM/TSP)

**Results**

A 23-year-old woman, African descendent, single, low level of education, homeless. She never worked and lived on the streets until discovered she was pregnant, with a gestational age of 20 weeks. Abortion at 18-year-old. Cocaine and loló user, suspended upon pregnancy, when she opted to return to her family. HIV diagnosis in 2017, without treatment adherence. Syphilis episodes in 2015 and 2020. Attended eight prenatal consultations. Initial VDRL was 1/256 with a drop to 1/16 after 2 months. The started ARV regimen was effective. During the entire prenatal period, she reported difficulty in walking, complaining of progressive weakness in the lower limbs, starting 7 years ago. Serological screening for HTLV-1/2 was positive, which corroborated her referral and follow-up to the Hospital Universitário Gaffrée e Guinle Neuroinfection clinic (UNIRIO). The outcome of the pregnancy was a cesarean delivery, without complications. Neurological evaluation identified spastic paraparesis, lower limbs hyperreflexia, Babinsky's sign and Hoffman's sign bilaterally. Cerebrospinal fluid examination revealed anti-HTLV-1/2 antibodies, with non-reactive VDRL. HAM/TSP was diagnosed. The initial approach was the prescription of baclofen, methylprednisolone pulse-therapy, without adherence to treatment and follow-up.

**Conclusions**

This case report highlights that the absence of strategies to control the HTLV transmissibility in the homeless population allows not only the increase of contagion within this population, but also the worsening of the presented symptoms. Access to adequate screening, prevention and treatment are essential to avoid worsening the individual's health with the possibility of irreversibility of the condition.

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## Use of Western Blot (WB) to detect HTLV-1 and/or 2 infections

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**Background:** There are two commercial kits to confirm human T-cell lymphotropic virus type 1 and 2 (HTLV-1/2) infection, Western Blot (WB) and Inno-Lia assays. However, around 3% of the WB tests do not show optimal reactivity to specific proteins for diagnosis. **Aim**: The aim of this study was to differentiate and quantify the intensity of protein reactivity between HTLV-1 and HTLV-2 diagnosis in typed WB assays. **Methods**: All tests were performed at the Institute of Infectology of Emílio Ribas, between 2018 and 2021. The reactivity was determined by comparing the intensity of the bands with the semiquantitative values of the intensity finder (3+ for reagent, 1+ weak reagent and 0 for bands without reactivity). Later, their respective values were used to create a *scatter dot plot*, to quantify the mean reactivity for each protein used in the test, according to the viral type. **Results:** We selected 205 WB results for these analyses. 164 tests were positive for HTLV-1, 34 for HTLV-2 and seven co-infected for HTLV-1 and 2. Among the reactive samples for HTLV-1 discriminatory proteins, 54.6% showed immunoreactivity for all proteins and average reactivity intensity of approximately 2.85+, for p19, gp21 and gd21. In these samples, all proteins had an average between 2-3+ (except gp46 and p53, which had lower values, < 1.20) (Figure 1a). However, among the reactive samples for HTLV-2, none showed reactivity for all bands, with a considerable decrease in the intensity (mean index < 1+), exceptions for p24 and gd21, which presented 2.59+ to 2.82+ (Figure 1b). By other side, individuals co-infected for HTLV-1 and 2, presented mean intensity similar to that compared to type 1, of 3.0+ for p19, gp21 and gd21, and ranging from 2-3+ for all proteins, with except for the gp46 and p53, which presented values <0.86+ (Figure 1c). **Conclusions**: HTLV-1 infected serum showed reactivity in 99.3% for The gp21, p19 and gd21 proteins. Despite the key role in the immune response, gp46 (surface glycoprotein) showed lower reactivity than p28, related accessory protein to HTLV-2 viral escape. In this study, individuals infected with HTLV-1 and co-infected with HTLV-1 and -2 had similar reactivity. In contrast, a low overall protein immunoreactivity was found in HTLV-2 infected serum (with the exception of p24 and gd21), including p28, suggesting that the increased reactivity is linked to the viral type.

Figure 1 - Sample reactivity to Western Blot proteins for HTLV diagnosis

Figure - 1a

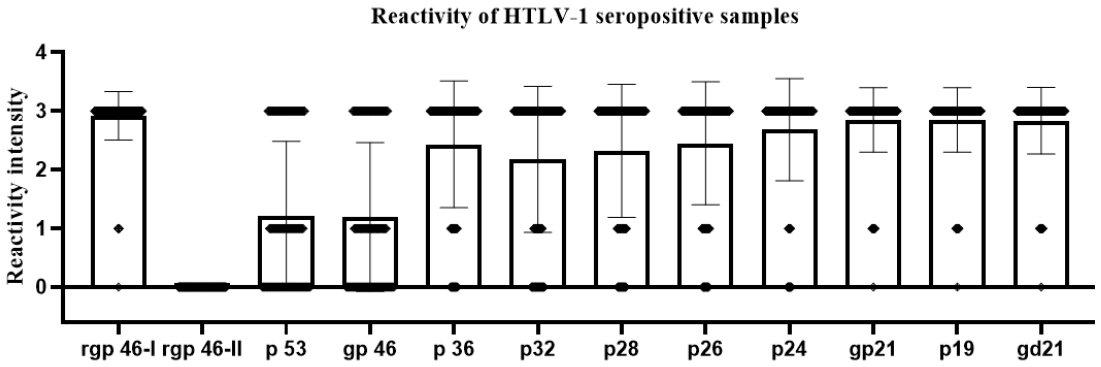



Figure - 1b

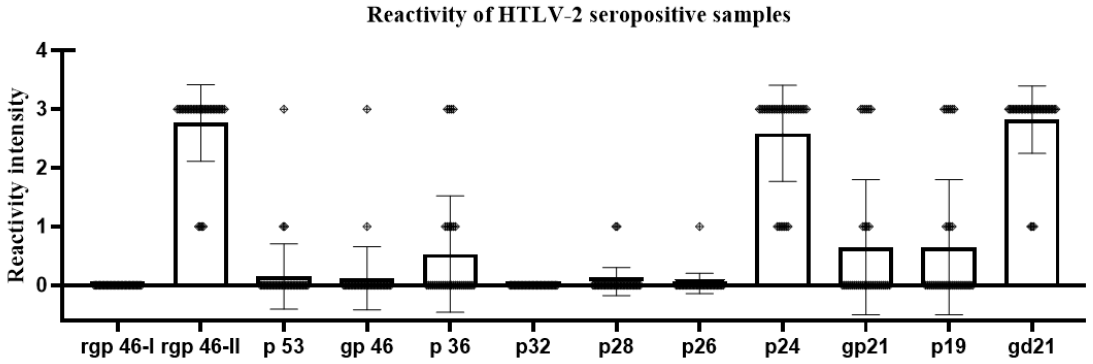
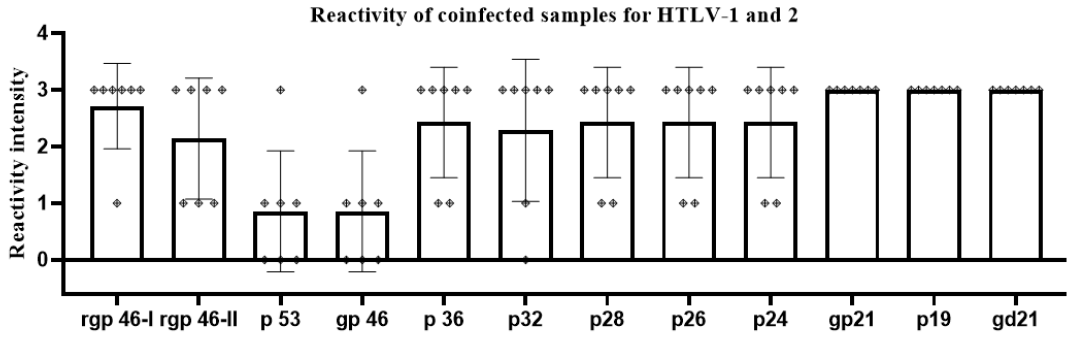



Figure - 1c



## Unveiling the underlying logic to health care for htlv-1: the paradigm that interferes in coping actions to eradication

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ABSTRACT
Faced with a hitherto incurable infection, discovered for so long (38 years approximately), HTLV-1 prevention should be taken as fundamental action in public health. However, screening initiatives to identify people living with HTLV-1 (PLVHTLV-1) and campaigns are almost inexistent, so it has become reasonable to question why.
It is well known that symptomatic HTLV-1+ patients (around 1%) demand biomedical care and control of symptoms, but the majority will be asymptomatic, although they may transmit the virus to sexual partners and offspring. Therefore, the majority of PLVHTLV-1 present "non-medical" needs, such as psychosocial demands and counseling about family relations, reproductive decisions, emotional and social consequences of the interruption of breastfeeding, etc.
In aim to bring more elements to corroborate with the proposal to eradicate HTLV-1, as it is highlighted the lack of effective coping actions in the world, making HTLV-1 a worldwide serious threat and a neglected public health problem, we propose a reflection that can contribute to the unveiling an underlying logic: although public health discourses emphasize the importance of prevention, health policies are still based in a biomedical conception focus, fundamentally centered on illness. Another consequence of this logic is that current public policies, focused only on illness, make care centered on medical knowledge and, for this reason, health teams end up unprepared to deal with the complex demands of PLVHTLV-1
Thus, a vicious circle is established: ignorance about the HTLV-1 virus (among health professionals and lay people) leads to the non-recognition of the need to identify it in society. On the other hand, prevention actions are not structured, leading to the non-identification of the real dimension of this infection in society (in fact, there is little epidemiological data available). And as a consequence, HTLV-1 perpetuates itself in our society and remains invisible from the point of view of public health.
It can therefore be verified that HTLV-1 is a paradigmatic case from the epistemological point of view. In other words, this case allows the opening for the construction of a new paradigm of care. Thus, from the perspective of comprehensive care, it is considered the need to advance interdisciplinary and interprofessional work in public health to cover their complex needs, as well as giving visibility to the real dimension of this singular infection.

## Promotion of knowledge regarding human t-lymphotropic virus infection

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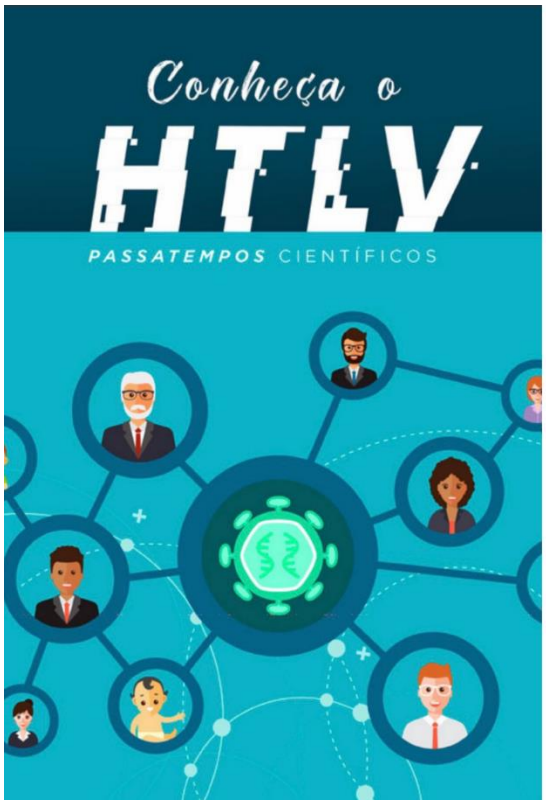
**Background:** The HTLV (Human T-Lymphotropic Virus) infection is a worldwide public health concern. Four types have already been identified, among this HTLV-1 is the most widespread and associated with severe illness such as adult T-cell leukemia/lymphoma (ATL), HTLV-1-associated myelopathy/tropical spastic paraparesis (HAM/TSP), and inflammatory diseases. Around the world it is estimated that at least 5 to 10 million individuals are infected with HTLV-1. However HTLV infection remains unknown and neglected for most of society. This proposal goal's to provide accessible material with relevant information for health education about HTLV infection in Brazil and worldwide. Therefore, didactic and illustrated digital educational booklets (Figure 1) were created. The access to those booklets has been available on QR CODE bookmarks and also on traditional link form.

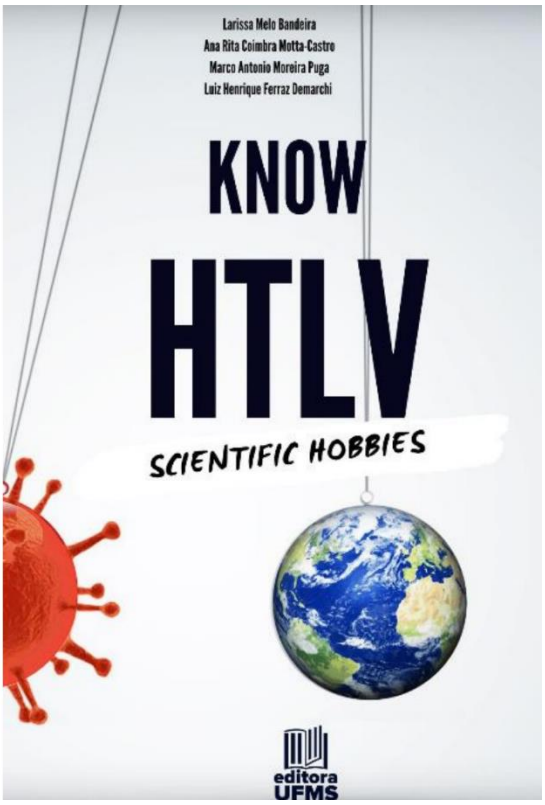
**Method:** From a narrative literature review the educational materials in English and Portuguese were elaborated in digital booklet using online platforms. The access to the booklets is available on QR CODE Bookmarks and link form. The material was spread to undergraduate and postgraduate students from health courses on campus and in lectures.

**Results:** Booklets in Portuguese and English languages are available for free access on the following links: https://issuu.com/lari.bandeira/docs/cartilha_htlv and https://issuu.com/lari.bandeira/docs/cartilha_know_htlv, respectively. The portuguese version "Conheça o HTLV, passatempos científicos" at the first year of publication (2019 to 2020), had more than three thousand accesses, with national admission in all regions. Furthermore, the booklet "Know HTLV, cientifics hobbies" was published in 2021 and in less than a year has been accessed in more than seven regions like Ireland, Australia and Tasmania, United States of America, Alaska and Hawaii.

**Conclusion:** Didactic material on the booklets provides information about clinical aspects, transmission, diagnosis and prevention of HTLV infection, and may contribute to knowledge about this silent, neglected and unknown infection for general public and health students.

**Figure 1:** Covers of educational booklets in Portuguese and English languages, respectively.



## Prevalence human t lymphotropic virus 1 in the world population: systematic review with meta-analysis

**AUTHORS:** Gleice C L Sampaio[1]; Bernardo Galvão-Castro[1]; Ney Cristian A Boa-Sorte[1]; Jéssica R Ribeiro[1]; Maria Fernanda R Grassi[1]; Katia N Sá[1]; Cristiane Maria C C Dias[1].

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**BACKGROUND** : The number of people living with HTLV-1 (PLWH) is estimated to be about 10 million worldwide. With the exception of Japan, most PLWH are from low- and middle-income countries. In this study, it was hypothesized that countries with a lower human development index (HDI) would have a higher prevalence of HTLV-1 infection. **OBJECTIVE**: To summarize the evidence on the prevalence of HTLV-1 in the general population, in pregnant women, and in blood donors and to review the association with HDI. **METHODS**: Systematic review with meta-analysis according to PRISMA and registered at PROSPERO (CRD42021223146). Cross-sectional studies of HTLV-1 infection with at least 100 participants and serologic testing (screening and confirmatory) were included. Incomplete, unavailable, or duplicate studies were excluded. Data were collected by two independent investigators and analyzed using R software, the meta package, and forest and funnel plots. Countries were compared using an HDI cutoff ≥ 0.8. Methodological quality was assessed using the JBI scale. **RESULTS:** Global prevalence was 0.96% (95% CI: 0.81-1.03), $I^2$ = 99%; in high HDI countries, it was 0.15% (95% CI: 0.09-0.22), $I^2$ = 96%; and in low HDI countries, it was 1.61% (95% CI: 1.23-2.03), I2 = 99%**,** Figure 1.A and 1.B. Studies in the general population found a prevalence of 1.74% (95% CI: 1.00-2.67), $I^2$ = 98%; in pregnant women, 0.34% (95% CI: 0.17-0.57), $I^2$ = 98%; and in blood donors, 0.07% (95% CI: 0.02-0.13), $I^2$ = 98%. The effect measure was reliable and had a low risk of publication bias despite the large heterogeneity. **CONCLUSION**: The worldwide prevalence of HTLV-1 infection is 0.96%, being ten times higher in the poorest countries and four times higher in the general population than in pregnant women and blood donors.

**Figure 1.A** Forest plot with 71 studies included in the meta-analysis divided by HDI classification as low (<0.8) and high (≥ 0.8) and the prevalence of individuals infected with HTLV-1

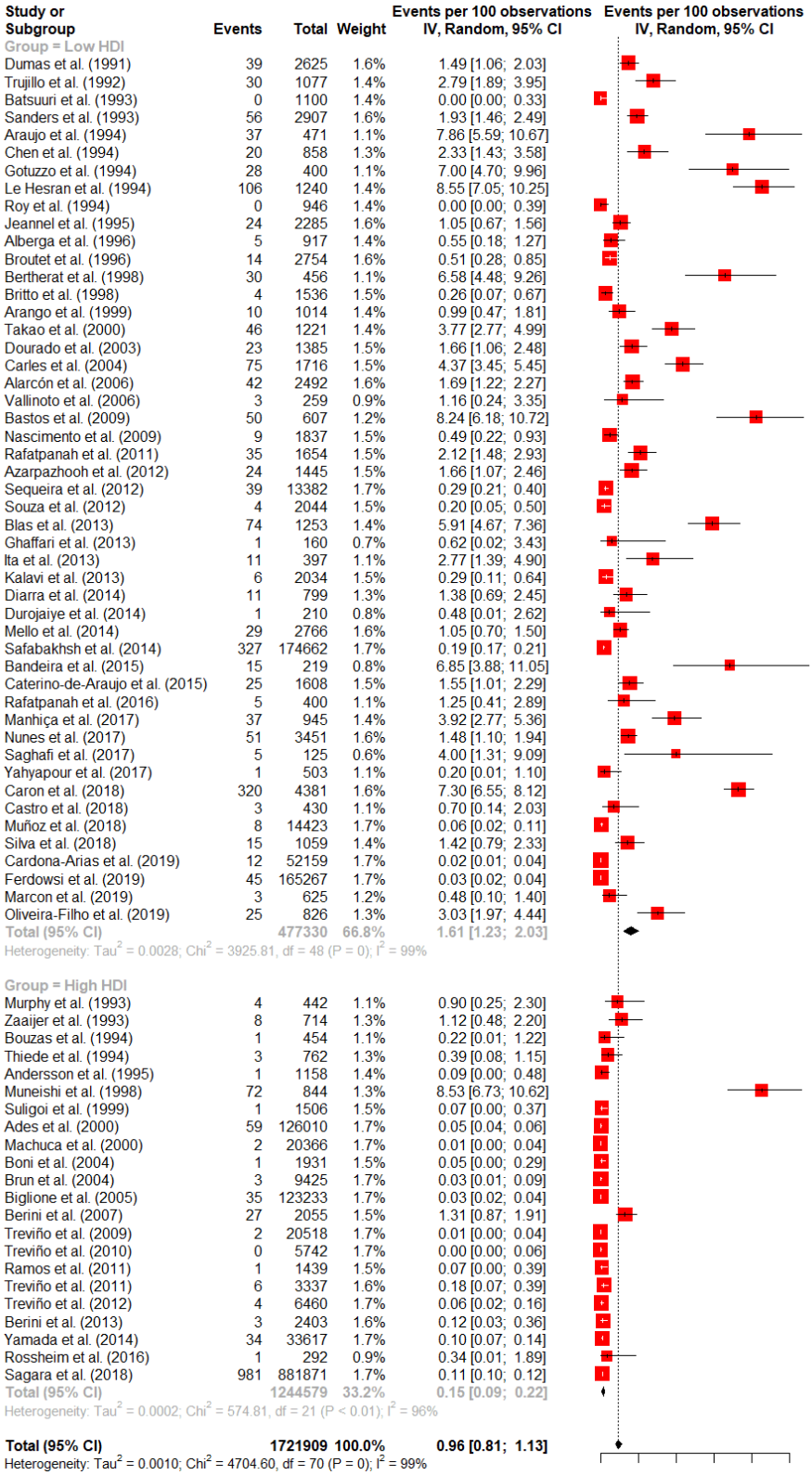
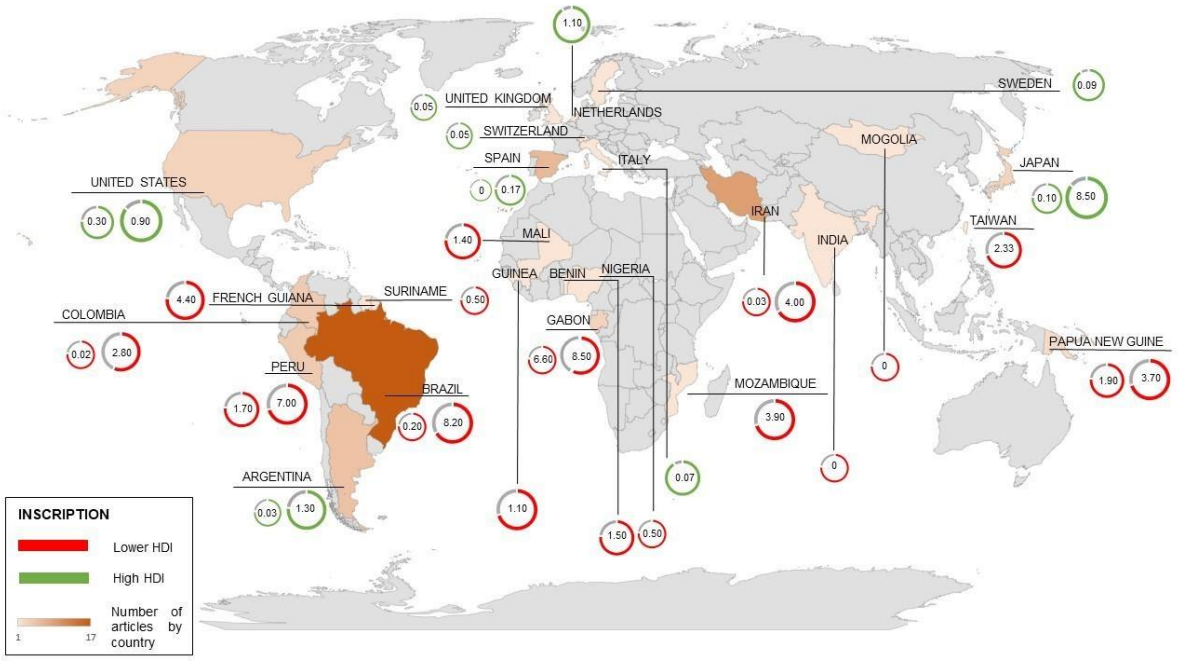


**Figure 1.B** Geographical distribution and HDI (low < 0.8 and high ≥ 0.8) of selected studies with the minimum and maximum prevalence of HTLV-1 by country



## Serological investigation of offspring of HTLV-1 infected mothers.

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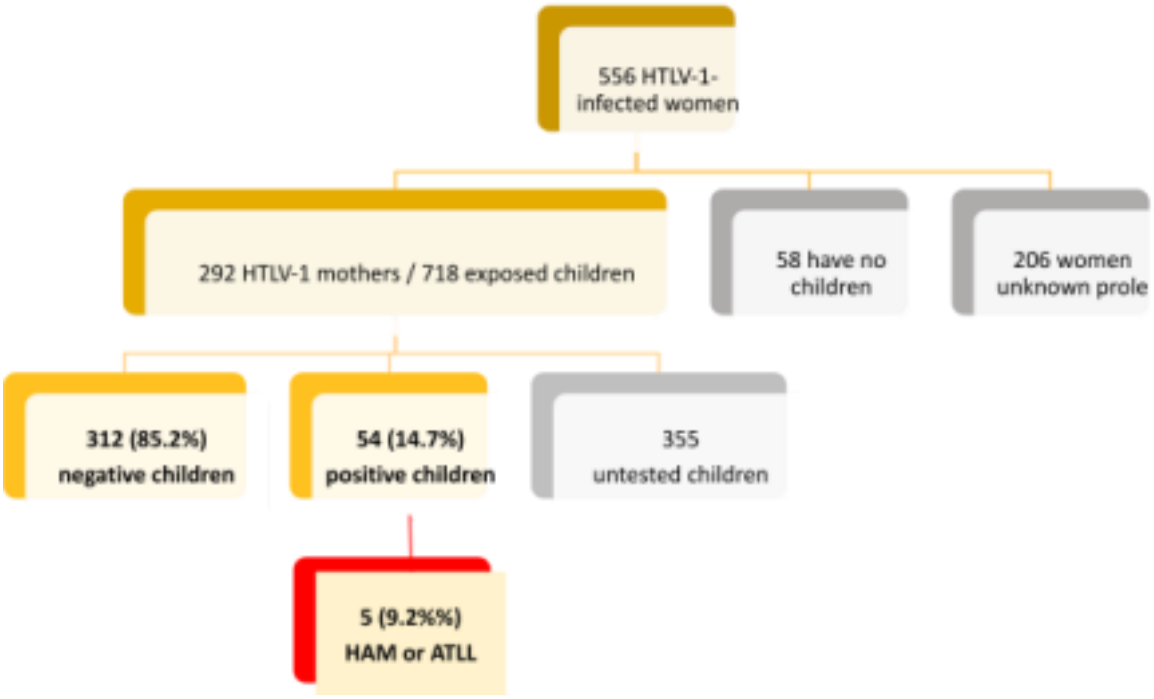
[2]Emílio Ribas Infectology Institute, São Paulo, SP, Brazil.

**Introduction:** The distribution of HTLV-1 infection is characterized by the formation of clusters due to a high rate of intrafamilial transmission. Sexual and vertical transmission are the pathways that contribute to this formation, as well as viral persistence for generations. The **aim** of this study was to report the prevalence of HTLV-1 in children of HTLV-1 positive mothers and characterize the profile of family clusters. **Methodology:** The participants of this research were followed at the Instituto de Infectologia Emílio Ribas, mostly, they were forwarded to this clinic after the diagnosis in the blood bank screening. Then, testing was offered to sexual partners, children, mothers and brothers, according to the diagnostic algorithm determined by the Ministry Health of Brazil. This was a study focused on women and their children, and vertical transmission was determined through the positive serology of the mother or siblings. **Results:** In total, 556 women with an average age of 52.4 years, are under investigation. So far, we know that 292 mothers exposed to a total of 733 children to HTLV-1 vertical transmission were indicated up to now. From 366 offspring tested, 85% (312/366) of them were negative for HTLV-1, 15% (54/366) were HTLV-1 positive. Among positive children, 9% presented serious manifestations (4 had HAM and 1 ATLL). A total of 388 have not been tested so far (Figure 1). We identified the formation of 86 family aggregations and 366 mother/child pairs. The maximum number of infected members into the families was 6, and 4 families (4.6%) had the HTLV-1 up to the third generation. São Paulo, Minas Gerais, Salvador and Pernambuco were the states with the high frequency of families with HTLV-1. **Conclusion:** The Ministry of Health of Brazil recommends the investigation of families with members with HTLV-1, and this strategy can be very efficient to combat HTLV-1 transmission. Through this and other studies, evidence is very strong for the high risk of intrafamilial transmission and potential for familial aggregation, indicating that would contribute to the spread of HTLV-1 in a highly endemic HTLV. In addition, São Paulo is attractive to migration, it was possible to identify that São
Paulo, Minas Gerais, Salvador and Pernambuco are the mean states of origin of these families.


556 HTLV-1-infected women
292 HTLV-1 mothers / 718 exposed children
58 have no children
206 women unknown prole
312 (85.2%) negative children
54 (14.7%) positive children
355 untested children
5 (9.2%%) HAM or ATLL

## Prevalence of htlv-1-associated uveitis in htlv-1 carriers: a systematic review

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[1] Escola Bahiana de Medicina e Saúde Pública, Salvador, Brazil.
[2] Instituto Gonçalo Moniz – Fundação Oswaldo Cruz (Fiocruz), Salvador, Brazil.

**BACKGROUND**: HTLV-associated uveitis (HUA) has been recognized as a new specific clinical entity. However, the prevalence of this disease is neither well established nor accurately described in the literature.
**OBJECTIVE**: To describe the prevalence of uveitis in HTLV-1 seropositive patients.
**METHODS**: Studies that collected sufficient data to calculate the prevalence of uveitis in a sample of seropositives were included in this review. Other systematic or narrative reviews were excluded, as were studies that calculated the prevalence of HTLV-1 positives in a sample of patients with uveitis. The search was performed in the PubMed and Scielo databases using the search strategy "(HTLV-I OR HTLV -I OR HTLV -1 OR HTLV infections) AND uveitis AND prevalence." The quality of articles was assessed using the Newcastle-Ottawa scale (NOS) adapted for cross-sectional studies.
**RESULTS**: A total of 96 articles were found using the search tools, but only 6 were included according to the inclusion and exclusion criteria. The prevalence found were 1.61% (2019, Argentina), 2.85% (1999, Brazil) 2.78% (2000, Brazil), 1.90% (2006, Brazil and 2.85% (2009, Brazil) and 14.50% (2002, France). Only 4 studies examined patients for other diseases that cause uveitis, such as toxoplasmosis, HIV (human immunodeficiency virus), and syphilis. Most articles had methodologic flaws, resulting in a low rating of NOS (1 article was rated 3/10, 3 articles were rated 4/10, and 2 articles were rated 6/10).
**CONCLUSION**: The prevalence of HAU varies worldwide. Most studies calculated the prevalence of HTLV-1 in patients with uveitis, and few calculated the prevalence of uveitis in a sample of HTLV-1 carriers. Even fewer studies screened patients for other uveitis etiologies to make a differential diagnosis, which is an obstacle to accurately understanding the prevalence of HUA, a specific clinical entity.

## From presential to virtual: a multidisciplinary experience of HTLV center in Salvador, Brazil during the sars-cov-2 pandemic.

Aidê N. Silva[1]; Selena M. Dubois-Mendes[1]; José G. Reis-Oliveira[1]; Ana K. Galvão-Barroso[1]; Ana V. Galvão-Castro[1]; Adriele Ribeiro[1]; Monique Lírio[1]; Humberto Castro-Lima[1]; Maria L. C. Soliani[1]; Thessika H. A. Araújo[1]; Ney C. A. Boa-Sorte[1]; Maria F. Rios-Grassi[1,2]; Bernardo Galvão-Castro[1], Integrated Multidisciplinary HTLV Center[1]

[1]Escola Bahiana de Medicina e Saúde Pública, Salvador, Brazil.
2. Laboratório Avançado de Saúde Públics (FIOCRUZ, Salvador, Brazil)

BACKGROUND: The SARS-CoV-2 pandemic and the lockdown measures imposed worldwide had a significant impact on clinical services and led to innovations to reconnect with patients. In order to continue to provide adequate multidisciplinary care, appointments and meetings had to be conducted in a telepresence model.

PURPOSE: To describe the experience of transitioning the HTLV referral center in Salvador, Brazil, to appointments and meetings in a telepresence model and the process of reconnecting with patients during this time.

CASE REPORT: the multidisciplinary team offered telehealth starting in April 2020. The team, composed of physicians (neurologists, infectiologists, and ophthalmologists), nurses, physical therapists, psychologists, and technical-administrative staff, prepared to develop this new mode of care and self-care based on the Bahiana Emergency Plan and professional associations. This appointment model allowed patients who did not adhere well to attendance care to resume it, since it was not necessary to move to another location, which was difficult due to transportation costs and the physical limitations of people with HTLV. In addition, virtual weekly clinical discussion groups were essential to qualify visit management and improve the quality of life of HTLV patients. Coronavirus vaccination monitoring was also possible.

CONCLUSION: The experience of telepresence in care opened new perspectives, including within the team, with the creation of treatment plans that were discussed and implemented collaboratively. The readmission of patients allowed the resumption of their treatment and follow-up by the team, which emphasized the needs of each individual in its wholeness. Given the benefits observed, we plan to move to a blended approach of face-to-face and virtual treatment to provide comprehensive and continuous care for patients.

## Call for Abstracts - Guidelines

We invite all for the submission of abstracts regarding HTLV surveillance and health policies to eliminate HTLV.

**Abstracts**

- Should be sent in a Word document to: htlvday@gmail.com
- Written in English.
- Font Times New Roman size 12.
- Should not exceed 2500 characters including spaces.
- Up to one Figure and one Table allowed.

**Topics:**

- Prevalence studies
- Surveillance of co-infections
- Health policies and clinical services: case report
- Approaches for the prevention and control of HTLV-1/2
- Specific strategies to prevent HTLV targeting vulnerable communities with high risk of HTLV infection
- Strategies to increase awareness about HTLV-1/2
- Acceptance of public health policies
- Economic analysis of health policies

**Contents:**

- Title – UPPER CASE – maximum 120 characters including spaces.
- Authors – First and last names only, indicating initials for middle names. Presenting author should be underlined.
- Brief affiliation of each author numbered (Institution, City and Country only) linked to superscript number after author's name.
- Abstracts should include Background, Methods, Results, and Conclusions

**Important information**

- Presenting authors from accepted abstracts will need to send a short video presentation (up to 3 minutes). All videos will be available online for public consultation. Guidance on video presentation will be send for the authors of accepted abstracts.
- Authors will be asked to answer questions from the audience (date and time to be confirmed).

**Deadline**

- 18/10/2021 – Closing date for abstracts submission
- 24/10/2021 – Closing date for submitting videos (accepted abstracts)
- 01/11/2021 – Videos will be available online