

# Tropical spastic paraparesis and quality of life in individuals with HTLV: integrative review protocol

## Paraparesia espástica tropical e qualidade de vida em portadores de HTLV: protocolo de revisão integrativa

## Paraparesia espástica tropical y calidad de vida en personas con HTLV: protocolo de revisión integradora,

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# REVISA

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### RESUMO

**Objetivo:** Compreender como a paraparesia espástica tropical afeta a qualidade de vida das pessoas infectadas pelo HTLV. **Método:** Trata-se de um protocolo de revisão integrativa, cuja pergunta de pesquisa, definida pelo acrônimo PCC, será "Como a paraparesia espástica tropical impacta na qualidade de vida das pessoas infectadas com HTLV?", os critérios de inclusão serão artigos dos últimos 05 anos, com texto completo. As buscas serão realizadas nas bases de dados PubMed, MEDLINE e Lilacs, essas últimas por meio da Biblioteca Virtual em Saúde (BVS). Serão empregados descritores, indexados nos Descritores em Ciências da Saúde (DeCS) e no Medical Subject Headings (MeSH). A seleção de estudos será realizada através da leitura dos títulos e resumos, para elegibilidade de posterior leitura na íntegra, após leitura em profundidade e comparação constante dos dados, será elaborada síntese final com exposição narrativa e crítica dos resultados.

**Descritores:** Paraparesia espástica tropical; Qualidade de vida; Infecções por HTLV-I.

### ABSTRACT

**Aim:** To understand how tropical spastic paraparesis affects the quality of life of individuals infected with HTLV. **Method:** This is an integrative review protocol, whose research question, defined by the PCC acronym, that will be: "How does tropical spastic paraparesis impact the quality of life of individuals infected with HTLV?" The inclusion criteria will be articles from the last five years, with full-text availability. Searches will be conducted in the PubMed, MEDLINE, and LILACS databases, the latter two accessed through the Virtual Health Library (VHL). Descriptors indexed in the Health Sciences Descriptors (DeCS) and Medical Subject Headings (MeSH) will be used. The study selection will be carried out through the reading of titles and abstracts for eligibility, followed by full-text reading. After an in-depth reading and constant data comparison, a final synthesis will be prepared with a narrative and critical presentation of the results.

**Descriptors:** Paraparesis, tropical spastic; Quality of life; HTLV-I infections.

### RESUMEN

**Objetivo:** Comprender cómo la paraparesia espástica tropical afecta la calidad de vida de las personas infectadas por el HTLV. **Método:** Se trata de un protocolo de revisión integradora, cuya pregunta de investigación, definida por el acrónimo PCC, será: "¿Cómo impacta la paraparesia espástica tropical en la calidad de vida de las personas infectadas con HTLV?" Los criterios de inclusión serán artículos de los últimos cinco años, con texto completo disponible. Las búsquedas se realizarán en las bases de datos PubMed, MEDLINE y LILACS, estas dos últimas a través de la Biblioteca Virtual en Salud (BVS). Se utilizarán descriptores indexados en los Descriptores en Ciencias de la Salud (DeCS) y en el Medical Subject Headings (MeSH). La selección de estudios se llevará a cabo mediante la lectura de títulos y resúmenes para determinar la elegibilidad, seguida de la lectura completa de los textos. Tras una lectura en profundidad y comparación constante de los datos, se elaborará una síntesis final con exposición narrativa y crítica de los resultados.

**Descritores:** Paraparesia espástica tropical; Calidad de vida; Infecciones por HTLV-I.

## Introduction

The Human T-cell Lymphotropic Virus type 1 (HTLV-1) is a deltavirus from the *retroviridae* family, identified between the 1970s and 1980s<sup>1</sup>, which primarily infects CD4+ and CD8+ T cells in the human body.<sup>2</sup> It is the main etiological agent associated with Adult T-cell Leukemia/Lymphoma (ATL or ATLL) and Tropical Spastic Paraparesis (HAM/TSP), the primary complications resulting from HTLV-1 infection.<sup>3</sup> It is estimated that currently there are between 10 and 20 million people infected with HTLV worldwide<sup>4</sup>, with approximately 800.000 individuals affected by the virus in Brazil.<sup>5</sup>

HTLV is transmitted sexually (the most effective form of transmission),<sup>6</sup> vertically, especially through breastfeeding, and parenterally, through contact with sharp objects and transfusion of blood products, which are means of propagation with lower prevalence, since blood analysis tests are safer in some countries due to screening in blood donation banks.<sup>7</sup>

The HTLV infection process occurs through cell-to-cell contact between an uninfected host and contaminated material – breast milk, blood or semen. After the virus enters the cell, the HTLV genetic material is inoculated into the individual's DNA, participating in transcription and translation, which generates new strands of infected DNA. Then, a reverse transcription occurs to an RNA strand and, upon the cell division, new HTLV proviruses are released, resulting in the exponential distribution of the virus in the body. This process results in clinical repercussions associated with CD4+ T and CD8+ T cells, the most common being ATLL and HAM/TSP.<sup>8</sup>

In this context, Tropical Spastic Paraparesis is characterized by a gradual progression and is considered a chronic manifestation of HTLV infection. CD8+ T cells are primarily responsible for reaching the spinal cord and local progression, leading to the loss of myelin and axons in the lateral column. Subsequently, these cells inflame both the white and gray matter, especially at the thoracic level of the spinal cord. Cytotoxic T lymphocytes (CTLs) are the only pathway for HTLV to enter the Central Nervous System (CNS) and act by releasing chemokines and cytokines into the tissues.<sup>9,10</sup> Due to the fixation of infected cells in nervous tissues, the first identified symptoms are spasticity and muscle weakness. As the condition progresses, patients with HAM/TSP begin to exhibit secondary signs and symptoms related to the aforementioned ones, becoming more specific and associated with the affected area. Examples of localized impact includes neurogenic bladder disorders and lower limb myelopathy.<sup>11</sup>

Usually, after a decade of development of tropical spastic paraparesis, patients usually require some support mechanism for locomotion. Generally, 50% of patients use a wheelchair after this period.<sup>11</sup>

Furthermore, the similarity in transmission forms and the lack of a cure for HTLV—as with the Human Immunodeficiency Virus (HIV)—lead to societal stigmatization of individuals living with HTLV, creating feelings of guilt, discomfort, and shame. In addition, the absolute contraindication of breastfeeding causes distress for infected women, as well as self-stigmatization for not being able to breastfeed their children.<sup>12</sup>

Therefore, this review protocol aims to understand how tropical spastic paraparesis affects the quality of life of people infected with HTLV.

## Methodology

### Study design

An integrative review will be conducted, a method that allows for a synthesis of a given subject, in addition to revealing gaps in knowledge of the topic addressed.<sup>13</sup> The protocol was registered on the Open Science Framework (OSF) platform (DOI 10.17605/OSF.IO/9W6VQ).

### Review question

The integrative review will be developed in the following steps: elaboration of the guiding question, literature search, selection of studies, analysis and processing of data, and presentation of results.<sup>14,15</sup> The formulation of the guiding question was based on the PCC acronym: Population - individuals living with HTLV; Concept - impact of HTLV-associated tropical spastic paraparesis; Context - quality of life.

### Inclusion and Exclusion Criteria

The inclusion criteria defined by the authors will be: articles from the last 5 years and available in full text. Meanwhile, the exclusion criteria: not specifically addressing the impact on the quality of life of people with HTLV and spastic paraparesis and/or dealing with other repercussions of HTLV infection.

### Search strategy and sources of information

The search strategy will be carried out in the PubMed, MEDLINE and Lilacs databases, the latter two via the Virtual Health Library (VHS). Descriptors will be used, based on the Health Sciences Descriptors (DeCS) and Medical Subject Headings (MeSH). The descriptors in English include: "Paraparesis, Tropical Spastic", "Quality of Life"; in Spanish: "Paraparesia Espástica Tropical", "Calidad de Vida"; in Portuguese: "Paraparesia Espástica Tropical", "Mielopatia Associada ao HTLV-I", "Paraparesia Tropical Espástica", "Paraplegia Espástica Tropical", "Qualidade de Vida", "Qualidade de Vida Relacionada à Saúde". The complete search strategies are detailed in Chart 1 below.

**Chart 1 - Search Strategies in Each Database**

Information Source	Search Strategy	Number of Articles
Virtual Health Library (VHL): MEDLINE and LILACS	(paraparesia espástica tropical) OR (paraparesis, tropical spastic) OR (mielopatia associada ao HTLV-I) OR (paraparesia tropical espástica) OR (paraplegia espástica tropical) AND (qualidade de vida) OR (quality of life) OR (calidad de vida) OR (qualidade de vida	194

	relacionada à saúde)	
PubMed	(Paraparesis, Tropical Spastic) AND (quality of life)	46
<b>Total</b>		240

## Study Selection

The retrieved articles will be subjected to reading of titles and abstracts, exclusion of duplicates, application of the inclusion criteria and, subsequently, reading in full with extraction of data of interest for the review, as shown in Table 1 below:

**Table 1 - Instrument for data extraction**

<b>Tropical spastic paraparesis and quality of life in HTLV carriers: integrative review protocol</b>
<p>Aim: To understand how tropical spastic paraparesis affects the quality of life of people infected with HTLV</p> <p>PCC: How does tropical spastic paraparesis impact the quality of life of people infected with HTLV?</p> <p style="text-align: center;"><b>Study Characterization</b></p> <p>Author(s)/Year of publication:</p> <p>Title:</p> <p>Country of origin:</p> <p>Aim:</p> <p>Methodology:</p> <p>Participants (sociodemographic characteristics - age, sex, race/ethnicity, sample size):</p> <p style="text-align: center;"><b>Results and Conclusions:</b></p> <p>Impacts on quality of life described:</p> <p>Conclusions:</p>

### Data Analysis

The data obtained from the review will be subjected to in-depth reading and constant comparison. A final synthesis will be developed, presented through a narrative and critical analysis of the results.

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