

## Physiotherapy for individuals with HTLV-1

## Fisioterapia para indivíduos com HTLV-1

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**CONTEXT:** Individuals with HTLV-1 have dysfunctions that directly impact their quality of life. Physiotherapy uses resources that help a lot in the treatment of these changes. However, questions are asked about which modalities are most used and whether they are being properly applied. The only certainty is that the more we know about the physical therapy resources used in individuals with HTLV-1, the better the result of the treatment used. How, then, is this scientific scenario?

*"There are many hypotheses in science that are wrong. This is perfectly acceptable, they are the opening to find the right ones." (Carl Sagan)*

The Human T-Cell Lymphotropic Virus (HTLV) is a retrovirus transmitted from person to person through sexual intercourse, breastfeeding and blood contamination. The number of individuals infected with HTLV is increasing and silent throughout the world, since only 5% of those infected have signs and symptoms. It is estimated that there are 15 to 20 million people in the world living with this retrovirus.<sup>1</sup> Brazil is the country with the highest absolute number of infected, affecting about 2.5 million individuals.<sup>2</sup>

The disease can compromise several systems in the body, directly and negatively impacting the quality of life of those affected. Signs and symptoms include myelopathy or tropical spastic paraparesis, known as HAM/TSP. HAM/TSP is a neurological condition associated with HTLV-1, with a slow, chronic, progressive and demyelinating evolution, which predominantly affects the spinal cord and presents lower motor neuron symptoms.<sup>3</sup> Among the manifested complaints, there is chronic pain of moderate to high intensity, balance and gait disorders, and sexual and urinary dysfunctions. As it is a disease that still has no cure, treatment is based on prevention and relief of symptoms. Physiotherapy is one of the treatments that has proved to be of great value to this population since it uses low-cost resources that tend to alleviate the intensity of symptoms without producing side effects, contributing to the delay in the evolution of the disease.<sup>4</sup>

In HAM/TSP, the virus invades the central nervous system and causes inflammation of T lymphocytes that damage brain circuits and spinal tracts, causing dysfunction, pain and inability to perform activities of daily living.<sup>3</sup> With the progression and chronification of symptoms, the brain undergoes a

maladaptive change, further affecting the processing of pain and movement. The injury is more a result of the body's reaction to the virus than to the virus itself and can lead those affected to need a wheelchair two to ten years after the first symptoms. Many patients need adaptations to activities of daily living, which are associated with an increased physical disability, risk of falls, reduced quality of life and reduced work capacity. Living with this disease can generate social consequences, isolation and depression.<sup>5</sup> Therefore, physical therapy is necessary for protection, health promotion, treatment of physical and emotional disorders, and rehabilitation for greater social participation of those affected.

Despite research and clinical practice demonstrating the importance of physical therapy for this population, scientific production on the subject is still incipient, especially in testing therapeutic procedures. We carried out a scientometric study<sup>6</sup> on the topic and identified only 68 studies involving physical therapists, 21 of which were interventional. The most tested therapeutic resources were individual and group functional exercises, including Pilates<sup>7,8</sup>, home exercise booklets<sup>9</sup>, virtual therapy<sup>10,11</sup>, proprioceptive neuromuscular facilitation<sup>12,13</sup>, in addition to peripheral electrical stimulation and biofeedback for the pelvic floor.<sup>14,15</sup> Studies on kinesiotherapy and peripheral electrical stimulation have shown positive results in balance, mobility, muscle strength, functional independence and, therefore, quality of life.

However, therapeutic exercise protocols need to be improved, especially concerning dose and progression. On the one hand, individualized exercises, as used in proprioceptive neuromuscular facilitation, demonstrate effectiveness in reducing spasticity and improving movement control and the level of functionality, but they are isolated cases and have a higher cost. Group exercises are more accessible to the population, can have a professional assisting a group of infected, which reduces costs, and includes the aspect of sharing experiences with peers, improving relational function. Meanwhile, home exercises stimulate autonomy for self-care and generate access opportunities for those who are unable to participate in outpatient services. Therefore, the three modalities of therapeutic exercises need to be tested in clinical trials with larger sample size and greater detail of the protocols, for a longer follow-up

period to verify a larger effect size and improve the levels of recommendation.

HTLV-1 associated with spastic paraparesis can generate morphological and functional changes in the respiratory system. The process of progressive chronic demyelination leads to a weakening of the respiratory muscles. Some protocol studies developed with individuals with this dysfunction showed good results in improving muscle strength. In one of the studies, home exercises were performed under indirect supervision in a preventive way, improving the individuals' inspiratory capacity. In another protocol, improvement in both inspiratory and expiratory muscles was observed, but there was no improvement in thoracic mobility.<sup>16,17</sup> Breathing exercises, therefore, proved to be a valuable resource to assist impaired respiratory muscle performance in individuals who develop HAM/TSP. It is noteworthy, however, that one of the studies was a case study, and although it presented a good result, it is noted that it is necessary to develop new studies with a larger sample size.

Peripheral electrical stimulation is an interesting resource for muscle strengthening and motor control. In addition to applications in the pelvic floor region that have been tested with excellent results<sup>14,15</sup>, can also be applied to other specific muscle groups to improve postural control and gait. The results with virtual therapy in the few studies carried out were not interesting to justify insisting on this therapeutic modality for this population.<sup>10,11</sup>

Some studies have used transcranial neuromodulation by direct current stimulation (tDCS) and by magnetic stimulation (rTMS).<sup>18,19</sup> Non-invasive neuromodulation is a low-risk resource, with good tolerability and efficacy in several similar conditions, presenting itself as an alternative to be tested in this population.<sup>20</sup> Other studies may be carried out based on the limitations of the only two studies carried out, making it possible to find an efficient alternative with a greater effect size to alleviate the suffering of those infected by HTLV-1. A protocol<sup>21</sup> was developed to test this physical therapy modality. However, the pandemic that affected the world in 2020 has prevented this study from being carried out so far. It is believed that it may be a very relevant path for physiotherapy applied to HAM/TSP.

One can see the need to develop new research on the topic of physical therapy for patients with HTLV-1 and, in particular, testing intervention modalities so that one can identify new paths and improve the level of evidence for a safe and supported clinical practice. While there is no cure for this pathology, at least physiotherapy can relieve symptoms and improve quality of life with low risks and costs.

### Authors' contributions

Both authors conceived and wrote the final version of the report.

### Conflicts of interest

No financial, legal or political conflicts involving third parties (government, companies and private foundations, etc.) were declared for any aspect of the submitted work (including, but not limited to grants and funding, participation in an advisory board, study design, preparation manuscript, statistical analysis, etc.).

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