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

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

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

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REVISA

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RESUMO

Objetivo: Compreender como a paraparesia espástica tropical (HAM/TSP) afeta a qualidade de vida das pessoas infectadas pelo HTLV. **Método:** Revisão integrativa, cuja pergunta de pesquisa guiada pelo PCC, "Como a paraparesia espástica tropical impacta na qualidade de vida das pessoas infectadas com HTLV?", os critérios de inclusão foram artigos sobre a temática e texto completo. As buscas ocorreram em março de 2025 nas bases de dados PubMed, MEDLINE e Lilacs, essas últimas pela BVS. Foram empregados descritores do DeCS e MeSH. A seleção de estudos ocorreu através da leitura dos títulos, resumos e leitura na íntegra, com posterior síntese dos resultados. **Resultados e discussão:** Os estudos selecionados compreendem o período de 2009 a 2024 e foram predominantemente quantitativos. O principal sintoma relatado foi a dor muscular agravada com a evolução da doença fator que intensifica a limitação funcional. Desse modo, os pacientes geralmente necessitam de dispositivos para locomoção. Contribui-se também no desencadeamento de transtornos mentais. Adicionalmente, têm-se a incontinência urinária que interfere nas relações sociais dos pacientes. **Conclusão:** constatou-se que a HAM/TSP, exerce um impacto substancial na qualidade de vida dos indivíduos acometidos. Reforça-se assim a importância de estratégias terapêuticas para controle dos sintomas físicos e suporte psicossocial.

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

ABSTRACT

Aim: To understand how tropical spastic paraparesis (HAM/TSP) affects the quality of life of people infected with HTLV. **Method:** Integrative review, whose research question guided by the PCC, "How does tropical spastic paraparesis impact the quality of life of people infected with HTLV?", the inclusion criteria were articles on the subject and full text. The searches took place in March 2025 in the PubMed, MEDLINE and Lilacs databases, the latter through the BVS. DeCS and MeSH descriptors were used. The studies were selected by reading the titles, abstracts and full text, with subsequent synthesis of the results. **Results and discussion:** The selected studies cover the period from 2009 to 2024 and were predominantly quantitative. The main symptom reported was muscle pain, aggravated with the progression of the disease, a factor that intensifies functional limitation. Thus, patients usually require devices for locomotion. It also contributes to the onset of mental disorders. Additionally, there is urinary incontinence that interferes with the social relationships of patients. **Conclusion:** it was found that HAM/TSP has a substantial impact on the quality of life of affected individuals. This reinforces the importance of therapeutic strategies to control physical symptoms and provide psychosocial support..

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

RESUMEN

Objetivo: Comprender cómo la paraparesia espástica tropical (HAM/TSP) afecta la calidad de vida de las personas infectadas con HTLV. **Método:** Revisión integrativa, cuya pregunta de investigación guiada por el PCC, "Cómo impacta la paraparesia espástica tropical en la calidad de vida de las personas infectadas con HTLV?", los criterios de inclusión fueron artículos sobre el tema y texto completo. Las búsquedas se realizaron en marzo de 2025 en las bases de datos PubMed, MEDLINE y Lilacs, esta última a través de la BVS. Se utilizaron descriptores DeCS y MeSH. La selección de los estudios se realizó mediante la lectura de títulos, resúmenes y lectura completa, con posterior síntesis de los resultados. **Resultados y discusión:** Los estudios seleccionados abarcan el período de 2009 a 2024 y fueron predominantemente cuantitativos. El síntoma principal reportado fue dolor muscular, el cual empeoró a medida que progresó la enfermedad, factor que intensificó las limitaciones funcionales. Por lo tanto, los pacientes a menudo necesitan dispositivos de movilidad. También contribuye al desencadenamiento de trastornos mentales. Además, existe incontinencia urinaria que interfiere en las relaciones sociales de los pacientes. **Conclusión:** se encontró que la HAM/TSP tiene un impacto sustancial en la calidad de vida de los individuos afectados. Esto refuerza la importancia de las estrategias terapéuticas para controlar los síntomas físicos y brindar apoyo psicosocial. y su salud.

Descriptores: Grupo de Atención al Paciente; Seguridad del Paciente; Hospitales.

REVISÃO

Introduction

The Human T-lymphotropic Virus Type 1 (HTLV-1) is a deltavirus belonging to the *Retroviridae* family, identified between the 1970s and 1980s,[1] which primarily infects CD4+ and CD8+ T cells in the human body.[2] 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.[3] It is estimated that currently between 10 and 20 million people worldwide are infected with HTLV,[4] with approximately 800,000 cases reported in Brazil.[5]

HTLV transmission occurs sexually — the most efficient route of transmission[6] — as well as vertically, mainly through breastfeeding, and parenterally, via contact with contaminated sharps or blood transfusions. The latter route has lower prevalence since blood testing and screening procedures have become more reliable in many countries, reducing transfusion-related transmission.[7]

The infection process occurs through cell-to-cell contact between an uninfected host and contaminated material such as breast milk, blood, or semen. After entering the host cell, the genetic material of HTLV integrates into the individual's DNA, participating in transcription and translation, which generate new strands of infected DNA. Subsequently, reverse transcription produces RNA strands, and during cell division, new HTLV proviruses are released, leading to exponential viral distribution throughout the body. This process results in clinical manifestations involving CD4+ and CD8+ T cells, most commonly ATLL and HAM/TSP.[8]

Among these conditions, tropical spastic paraparesis stands out as a chronic manifestation of HTLV infection with gradual progression. CD8+ T cells play a major role in the spread of infection to the spinal cord and in local pathological progression, leading to demyelination and axonal loss in the lateral columns. Subsequently, these same cells induce inflammation of both the white and gray matter, especially at the thoracic level of the spinal cord. Cytotoxic T lymphocytes (CTLs) represent the only route of HTLV entry into the central nervous system (CNS), releasing chemokines and cytokines into nervous tissues.[9,10] Due to the fixation of infected cells within neural tissues, early symptoms include spasticity and muscle weakness. As the disease progresses, patients with HAM/TSP develop secondary signs and symptoms, which are more specific and linked to the affected regions — such as neurogenic bladder disorders and limb myelopathy.[11]

Typically, after approximately a decade of disease progression, patients with tropical spastic paraparesis require mobility assistance devices, and around 50% of them rely on wheelchairs by this stage.[11]

Moreover, the similarity between the transmission routes of HTLV and those of the Human Immunodeficiency Virus (HIV), combined with the absence of a cure for both infections, contributes to the stigmatization of individuals living with HTLV. This often leads to feelings of guilt, discomfort, and shame among patients. In particular, the absolute contraindication of breastfeeding imposes a source of embarrassment and self-stigmatization for infected women, profoundly affecting their experience of motherhood.[12]

Given the progressive and debilitating nature of tropical spastic paraparesis, combined with its profound psychosocial impacts and the stigma surrounding it, it becomes imperative to understand how this condition affects the quality of life of individuals infected with HTLV. Such understanding is essential for developing more effective management strategies, providing adequate psychosocial support, and formulating public health policies aimed at improving the well-being of affected individuals.

Methodology

Study design

This study is an integrative review, a method that allows the synthesis of knowledge on a given topic while identifying gaps in the existing literature.[13] The study was registered on the Open Science Framework (OSF) platform (DOI: 10.17605/OSF.IO/9W6VQ).

Review Question

The integrative review was developed through the following stages: formulation of the guiding question, literature search, study selection, data analysis and treatment, and presentation of results.[14,15]

The research question guiding this review was: "How does tropical spastic paraparesis impact the quality of life of individuals infected with HTLV?". The guiding question was structured using the PCC acronym, where: Population (P): individuals infected with HTLV; Concept (C): impact of tropical spastic paraparesis associated with HTLV; Context (C): quality of life.

Inclusion and Exclusion Criteria

The inclusion criteria established by the authors were: articles addressing the topic regardless of publication period and with full-text availability.

Exclusion criteria included: studies that did not specifically address the impact of tropical spastic paraparesis on the quality of life of people living with HTLV and/or that focused on other repercussions of HTLV infection.

Search Strategy and Information Sources

The search strategy was conducted in March 2025 across the PubMed, MEDLINE, and LILACS databases — the latter two accessed via the Virtual Health Library (VHL). Descriptors were based on Health Sciences Descriptors (DeCS) and Medical Subject Headings (MeSH). Search terms included: In English: "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 search strategies used in each database are presented in Table 1 below.

Table I – 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 relacionada à saúde")	194
PubMed	(Paraparesis, Tropical Spastic) AND (quality of life)	46
Total		240

For the study selection stage, an adapted checklist was followed based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines, represented by the flowchart in Figure 1. The data were organized in a table including the following elements: authors/year of publication, title, and impacts on quality of life (Table 2). As this study was conducted using data previously published in the scientific literature, ethical approval by a Research Ethics Committee was not required.

Study Selection

The retrieved articles were subjected to title and abstract screening, duplicate removal, and application of the inclusion criteria, followed by full-text reading and data extraction of information relevant to the review, as outlined in Table 1 below:

Table 1 – Data Extraction Instrument

Tropical Spastic Paraparesis and Quality of Life in Individuals with HTLV: Integrative Review Protocol
Objective: To understand how tropical spastic paraparesis affects the quality of life of individuals infected with HTLV PCC Question: How does tropical spastic paraparesis impact the quality of life of individuals infected with HTLV?
Study Characterization
Author/Year of Publication: Title: Country of Origin: Objective: Methodology: Participants (sociodemographic characteristics – age, sex, race/ethnicity, sample size): **Results and Conclusions:** Reported Impacts on Quality of Life: Conclusions:

Data Analysis

The data from the review were subjected to in-depth reading and constant comparison, followed by the development of a final synthesis with a narrative and critical presentation of the results.

Results and Discussion

In the initial stage of study selection, 240 articles were identified, including 46 articles from PubMed and 194 articles from MEDLINE and LILACS via the Virtual Health Library (VHL). After analysis and application of the inclusion criteria, only 14 studies were included in the final sample. The study selection process is detailed in Figure 1.

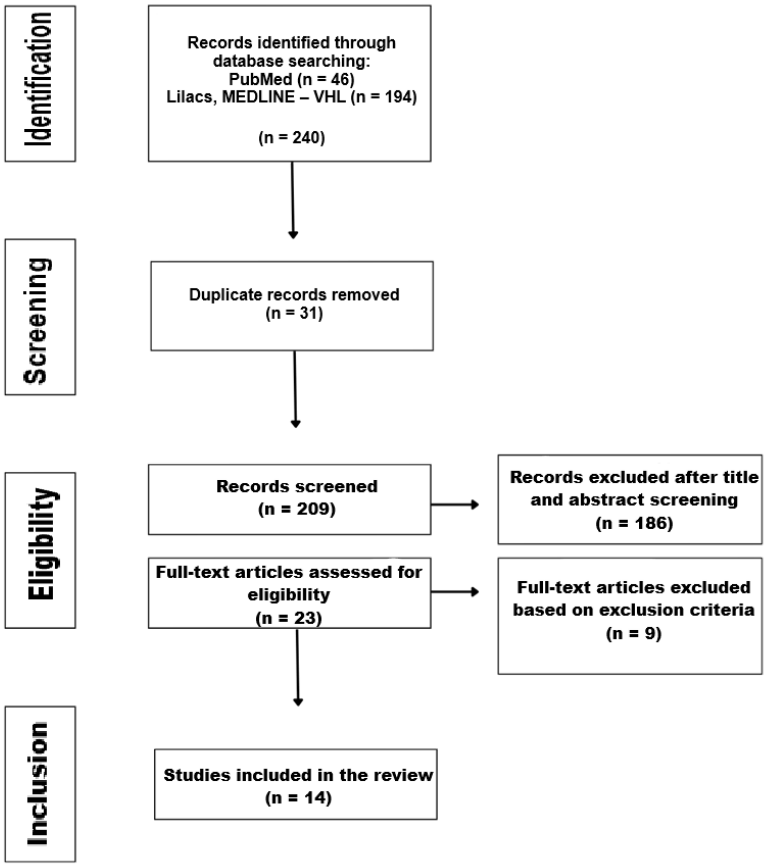

Figure 1 – Methodological flowchart of study selection. Eunápolis-BA, Brazil, 2025. Source: Adapted from PRISMA, by the authors, 2025.

The selected studies were published between 2009 and 2024, with the highest number of studies published in 2011 (21.42%), followed by 2012, 2020, and 2024 (14.28% each). The years 2009, 2016, 2018, 2022, and 2023 accounted for 7.14% each. Regarding the place of publication, the South American continent was the most prominent (92.85%), followed by Europe and Asia (3.57% each). Concerning study methodology, the majority were quantitative (92.85%), while qualitative

studies represented a minority (7.14%). Table 2 provides a detailed description of the studies, including author/year, title, and impacts on quality of life.

Table 2 – Characterization of the studies, Eunápolis, BA, Brazil, 2025.

Author/Year	Title	Impacts on Quality of Life
Bordallo L, Montaño-Castellón I, Lins-Kusterer L, Brites C | 2024	Cognitive Assessment in HTLV-1 Patients Followed Up at a Reference Center in Salvador, Brazil.	Among all analyzed patients, only 61% had a diagnosis of HAM/TSP. Among those with HAM/TSP, 71% presented cognitive dysfunction according to the Mini-Mental State Examination (MMSE). The Montreal Cognitive Assessment (MoCA) identified 82% of patients with cognitive impairment, and there was an overall prevalence of depression of 20%.
Davoudi M, Boostani R, Manzari ZS | 2024	Lived Experience of Human T-cell Leukemia Virus type-1 -Associated Myelopathy/Tropical Spastic Paraparesis (HAM/TSP): A Phenomenology Study.	The 20 interviewed patients reported several changes in their daily lives after the diagnosis of HAM/TSP, which fit into different categories. The main ones included: interference in personal life, changes in self-perception regarding functional abilities, and lifestyle modifications imposed by the disease.
Landim C, Dias CMCC, Nascimento C, Goes ALB, Araújo THA Ribeiro A, Oliveira FT, Castro-Lima H, Boa-Sorte N, Galvão-Castro B | 2023	Impaired flexibility in patients with tropical spastic paraparesis/HTLV-associated myelopathy: evaluation via pendulum fleximeter.	It was observed that patients with HAM/TSP showed a higher prevalence of low back pain, reduced flexibility in general tests, greater pelvic instability, decreased plantar flexion, and reduced knee flexion, among other factors limiting movement. It was also identified that patients with myelopathy consistently exhibited greater reductions in flexibility compared to HTLV carriers without HAM/TSP.
Ramos DS, Conceição CS, Ribeiro NMS | 2022	Myelopathy or Tropical Spastic Paraparesis (HAM/TSP) and the SF-36 Domains	The results suggest that the main factors affecting patients with HAM/TSP are related to the reduction in functional capacity caused by physical impairments. In addition, it was reported that emotional factors in general were negatively impacted as a consequence of the physical signs and symptoms. Symptomatic patients showed higher rates of anxiety and depression compared to asymptomatic individuals, as well as a greater risk of suicide.

Martins JV, Baptista AF, Araújo A de Q. | 2012	Quality of life in patients with HTLV-I associated myelopathy/tropical spastic paraparesis	It was observed that patients with HAM/TSP who presented milder symptomatology regarding urinary symptoms and better bladder control experienced a lower impact on quality of life. In addition, there was a direct positive relationship between social and mental functioning and engagement in physical activity. Conversely, pain was notably associated with reduced vitality and mental health, demonstrating a strong negative correlation with quality of life.
Gascón MR, Capitão CG, Casseb J, Nogueira-Martins MC, Smid J, Oliveira AC| 2011	Prevalence of anxiety, depression and quality of life in HTLV-1 infected patients	It was found that patients with HAM/TSP exhibited considerably higher levels of depression and anxiety, as well as a greater impact on quality of life compared to the control group (asymptomatic individuals), particularly concerning dissatisfaction with health, the physical domain, and the environment domain.
Gascón MRP, Mellão MA, Mello SH, Negrão RM, Casseb J, Oliveira ACP| 2018	The impact of urinary incontinence on the quality of life and on the sexuality of patients with HAM/TSP	The most significant implication of urinary incontinence was related to the patients' perception of quality of life and their sexuality, due to urinary leakage and other possible discomforts during sexual intercourse, in addition to a lack of interest and sexual desire. Furthermore, patients reported constant concern about the worsening of disease symptoms.
Netto EC, Brites C | 2011	Characteristics of Chronic Pain and Its Impact on Quality of Life of Patients With HTLV-1-associated Myelopathy/Tropical Spastic Paraparesis (HAM/TSP)	The degree of disability was mainly associated with the need for bilateral support for ambulation in most patients, or the use of a wheelchair. Most reported chronic pain, more frequently in the lumbar region, followed by the lower limbs. In addition, it was observed that patients presenting higher levels of depressive and anxiety symptoms showed an association between these symptoms and chronic pain.
Rosadas C, Assone A, Yamashita M, Adônis A, Puccioni-Sohler M, Santos M, Paiva A, Casseb J, Oliveira ACP, Taylor | 2020	Health state utility values in people living with HTLV-1 and in patients with HAM/TSP: The impact of a neglected disease on the quality of life	In Brazil, mobility was the main issue that most affected the quality of life of nearly all patients with HAM/TSP. In contrast, in the United Kingdom, the most recurrent problem impacting patients with HAM/TSP was the limitation in performing usual activities. Thus, it was observed that the average quality of life among Brazilian patients with HAM/TSP was extremely low. In the United Kingdom, when compared with other comorbidities—such as multiple sclerosis, epilepsy, diabetes mellitus, and cerebral degeneration—HAM/TSP showed the lowest quality of life index. The study revealed that it is not the duration of the disease, but rather its severity, that is associated with impaired quality of life.

Diniz MS, Feldner PC, Castro RA, Sartori MG, Girão MJ | 2011	Impact of HTLV-I in quality of life and urogynecologic parameters of women with urinary incontinence	Urinary tract infection was observed more frequently in the seropositive group, which may be related to an early symptom of myelopathy, as most patients reported impaired urinary patterns caused by HTLV-I–induced neurogenic bladder. Pelvic dysfunction in women involved a correlated spectrum, including loss of pelvic floor function, pain during bladder filling, dyspareunia, pain upon vaginal palpation, perineal hypersensitivity, pelvic floor muscle hypertonia, and urinary tract infections. There was a noticeable reduction in activities of daily living, social relationships, sleep, and overall disposition.
Shublaq M, Orsini M, Puccioni-Sohler M | 2011	Implications of HAM/TSP functional incapacity in the quality of life	The most common initial symptoms included lower limb muscle weakness, sphincter disturbances, and paresthesia in the lower limbs. Low back pain and constipation were rarely reported among patients. Furthermore, it was found that all patients required some form of support for mobility—most commonly wheelchairs, followed by single-arm and double-arm crutches. Additionally, urinary incontinence was identified as a symptom with a negative impact on the quality of life of patients with HAM/TSP. Overall, all individuals exhibited compromised quality of life in both physical and mental health domains.
Caiafa RC, Orsini M, Felicio LR, Puccioni-Sohler M | 2016	Muscular weakness represents the main limiting factor of walk, functional independence and quality of life of myelopathy patients associated to HTLV-1	The most frequent symptoms among patients with HAM/TSP were lower limb muscle weakness and sphincter dysfunction. It was observed that almost all patients required some form of assistance for mobility. Most presented with mild dependence, followed by moderate dependence, while a minority exhibited severe dependence or independence—mainly related to mobility and bladder control. A more pronounced impact was demonstrated on general physical functioning and performance, as well as on emotional and social aspects.
Galvão-Castro AV, Boa-Sorte N, Kruschewsky RA, Grassi MF, Galvão-Castro B | 2012	Impact of depression on quality of life in people living with human T cell lymphotropic virus type 1 (HTLV-1) in Salvador, Brazil	Depression was identified as a significant symptom with a major impact on the quality of life of patients with HAM/TSP, leading to repercussions in psychological, social, and physical domains. Decreased functional capacity and pain were the most predominant factors associated with the physical domain, also contributing to a reduction in overall quality of life among these patients.

Aben-Athar CYUP, Pinto DDS, Lima SS, Vallinoto IMVC, Ishak R, Vallinoto ACR | 2020	Limitations in daily activities, risk awareness, social participation, and pain in patients with HTLV-1 using the SALSA and Participation scales	Symptomatic patients more frequently reported leg weakness and lower back pain, while knee pain was reported by all participants. The main factors associated with poorer quality of life were pain and its intensity, which negatively affected general activity, mood, mobility, normal work, sleep, and enjoyment of life. The only domain that showed no significant difference compared to asymptomatic patients was interpersonal relationships and mental health.

The results obtained were presented with the aim of deepening the understanding of the impact on the quality of life of individuals living with Tropical Spastic Paraparesis (HAM/TSP).

Through the analysis of the studies, common findings were identified regarding the quality-of-life impacts among individuals with HAM/TSP. Accordingly, the data were categorized and summarized into the following domains: physical conditions and psychosocial conditions.

Impacts on Physical Conditions

The influence on the physical health of individuals infected with HTLV-1 who develop HAM/TSP is primarily related to the loss of neuromuscular capacity, which is determined by genetic factors, the virulence rate of HTLV-1, and other variables[28].

Due to progressive muscular degeneration, the main symptom reported was muscle pain, generally persistent, ranging from mild to moderate intensity, and tending to worsen as the disease progresses. Pain was associated not only with motor impairment but also with joint stiffness, pelvic instability, reduced flexibility, and decreased range of motion—particularly in plantar and knee flexion. Pain was frequently reported in the lumbar region and lower limbs and was correlated with longer disease duration. The intensity of pain negatively affected general activity, mood, mobility, work performance, sleep quality, and enjoyment of life.[10,17,18].

These factors reduce tolerance to physical effort, compromise posture and gait, and contribute to increased fatigue, further intensifying functional limitations and directly impairing physical quality of life. As reported by Macêdo, physical exercise did not act as a decisive improvement factor; rather, it had greater positive effects among individuals who engaged in physical activity prior to the onset of HAM/TSP[28].

Additionally, a high prevalence of lower limb weakness was observed, often requiring the use of assistive devices for mobility, such as crutches and wheelchairs. This limitation directly affects autonomy, restricting participation in daily activities and social and occupational engagement. Reduced mobility emerged as the most affected domain in quality-of-life assessments, as measured by instruments such as the SF-36 and EQ-5D, particularly among patients with more advanced symptoms[11,21,24].

Moreover, sphincter dysfunction—particularly urinary incontinence resulting from neurogenic bladder—was identified as one of the main determinants of decreased physical quality of life. This was evidenced by symptoms such as urinary urgency, involuntary leakage, and recurrent urinary tract infections. These manifestations not only cause physical discomfort but also limit mobility and socialization, as patients often avoid leaving home for fear of incontinence episodes. They also affect health perception and sexuality. Among women, this factor exerts an even greater influence, as they are more prone to developing urinary infections[20,23,24].

Regarding cognitive aspects, a considerable proportion of patients with HAM/TSP exhibited cognitive dysfunction or impairment, identified through instruments such as the Mini-Mental State Examination (MMSE) and the Montreal Cognitive Assessment (MoCA), the latter being more sensitive for detecting such changes[5].

Impacts on Psychosocial Conditions

Beyond physical limitations, HAM/TSP entails profound psychosocial and emotional impacts. Patients with HAM/TSP presented significantly higher levels of depression and anxiety compared with asymptomatic control groups, as well as an increased risk of suicide.[18,19,21,22,25] The main contributing factor for these mental health comorbidities was the frequent occurrence of chronic pain in HAM/TSP[21,29].

Depression emerged as a major symptom with a substantial impact on quality of life, affecting psychological, social, and physical aspects. Although no direct relationship was found between cognitive impairment and depression, both conditions commonly coexisted among patients[5,25].

Social and emotional impacts were also observed in relation to the clinical presentation of HAM/TSP. In marital relationships, cases of divorce were reported, attributed to the difficulty of fulfilling conjugal roles due to lifestyle changes imposed by the disease. Sexual life was also affected, with decreased libido and embarrassment associated with urinary incontinence during sexual activity being frequently reported.[16,19,20,23].

Furthermore, difficulties in maintaining social interactions, performing occupational activities, and managing daily living tasks were consistently observed.[20–22,24,25] Symptoms such as fatigue, irritability, sleep disturbances, apathy, self-criticism, and anhedonia were recurrently reported, often linked to concerns about health and disease progression. It is noteworthy that HAM/TSP affects patients' quality of life more strongly according to disease severity rather than duration[19,21,22].

Conclusion

This integrative review revealed that Tropical Spastic Paraparesis (HAM/TSP), a complication associated with HTLV-1 infection, exerts a substantial impact on the quality of life of affected individuals. The progressive deterioration of neuromuscular capacity—manifested through physical and psychological signs and symptoms—demonstrates how autonomy and daily functioning are severely compromised by the disease. Study limitations include the inability to distinguish between physical and psychosocial impacts and the

lack of an integrated care model aimed at improving the quality of life of individuals with HAM/TSP.

Given these findings, it is essential to implement therapeutic strategies that address both physical symptom management and continuous psychosocial support. A multidisciplinary approach is indispensable to promote effective, individualized interventions that minimize limitations imposed by HAM/TSP and foster better functional and emotional adaptation. This is crucial for ensuring that the chronic and inevitable progression of HAM/TSP can be managed effectively and humanely.

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