

## Functional capacity in individuals with tropical spastic paraparesis/HTLV-1-associated myelopathy

### Capacidade funcional em indivíduos com paraparesia espástica tropical/mielopatia associada ao HTLV-1

### Capacidad funcional en individuos con paraparesia espástica tropical/mielopatía asociada al HTLV-1

Received: 11/09/2017

Approved: 21/12/2017

Published: 30/03/2018

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This study aimed to evaluate the functional capacity of individuals with tropical spastic paraparesis/myelopathy associated with human T-lymphotropic virus type 1 (TSP/HAM). The study included 12 individuals diagnosed with HTLV-1 of both genders been treated in the Laboratory of Studies in Functional Rehabilitation (LAERF) of the Federal University of Pará (UFPA), Brazil, through the application of the Health Assessment Questionnaire (HAQ). This is a quantitative study conducted in 2016. Of the participants, 58.3% were female and 41.6% male. Fifty percent of those surveyed presented moderate to severe disability due to the difficulty of walking and changes in posture and balance, thus requiring help from third parties and crutches and wheelchairs. The issue of living with HTLV-1 is comprehensive and complex, interfering in the daily life, being related to the symptomatology of the disease and requiring palliative care in the day-to-day functional capacity, especially in the functionality involving lower limbs, transfers of postures and balance.

**Descriptors:** Paraparesis tropical spastic; Functional capacity; Human T - lymphotropic T vírus 1.

Este estudo teve como objetivo avaliar a capacidade funcional de indivíduos com paraparesia espástica tropical/mielopatia associada ao vírus linfotrófico humano de células T do Tipo 1 (PET/MAH). A pesquisa incluiu 12 indivíduos diagnosticados com HTLV-1 de ambos os sexos, em acompanhamento no Laboratório de Estudos em Reabilitação Funcional (LAERF) da Universidade Federal do Pará (UFPA), através da aplicação do Health Assessment Questionnaire (HAQ). Este é um estudo quantitativo realizado em 2016. Dos participantes 58,3% eram do sexo feminino e 41,6% do sexo masculino. Apresentaram incapacidade moderada à grave 50% dos pesquisados, devido à dificuldade de deambular e alterações na postura e equilíbrio, necessitando assim de auxílio de terceiros e muletas e cadeiras de rodas. A problemática do viver com o HTLV-1 é abrangente e complexa, interferindo no cotidiano, estando relacionada a sintomatologia da doença e requerendo cuidados paliativos na capacidade funcional do dia-a-dia, principalmente, na funcionalidade que envolve os membros inferiores, as transferências de posturas e o equilíbrio.

**Descritores:** Paraparesia espástica tropical; Capacidade funcional; Vírus 1 linfotrópico T humano.

Este estudio tuvo como objetivo evaluar la capacidad funcional de individuos con paraparesia espástica tropical/mielopatía asociada al virus linfotrópico humano de células T del Tipo 1 (PET/MAH). La investigación incluyó 12 individuos diagnosticados con HTLV-1 de ambos sexos, en acompañamiento en el Laboratorio de Estudios en Rehabilitación Funcional (LAERF) de la Universidad Federal do Pará (UFPA), Brasil, a través de la aplicación del Health Assessment Questionnaire (HAQ). Este es un estudio cuantitativo realizado en 2016. De los participantes 58,3% eran del sexo femenino y 41,6% del sexo masculino. Presentaron incapacidad moderada a grave 50% de los investigados, debido a la dificultad de deambular y alteraciones en la postura y equilibrio, necesitando así de auxilio de terceros, muletas y sillas de ruedas. La problemática del vivir con el HTLV-1 es amplia y compleja, interfiriendo en lo cotidiano, estando relacionada a la sintomatología de la enfermedad y requiriendo cuidados paliativos en la capacidad funcional del día a día, principalmente, en la funcionalidad que implica los miembros inferiores, las transferencias de posturas y el equilibrio.

**Descriptores:** Paraparesia espástica tropical; Capacidad funcional; Vírus 1 linfotrópico T humano.

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## INTRODUCTION

The human T-lymphotrophic virus type 1 (HTLV-1) is a virus that infects 10 to 20 million people worldwide, considered endemic in Japan, the Caribbean, Melanesia, Africa, Central and South America. There are approximately 2.5 million people infected in Brazil, with high prevalence in the North and Northeast regions<sup>1,2</sup>.

HTLV-1 was the first human retrovirus to be discovered and isolated and was reported in a clinic in 1977 in Japan. A cluster of patients was also discovered in the southwestern part of Japan, and researchers had hypothesized that the disease could be induced by a virus<sup>3,4</sup>.

There are 4 known subtypes of HTLV, the most important being HTLV-1 and 2, regarding pathogenesis and epidemiology. It is transmitted through sexual intercourse, in which in females the transmission is four times higher compared to the transmission of the woman to the man through the sexual, blood and vertical way<sup>2,4,5</sup>.

Other means of transmission are by products infected with blood from the individual with the disease, and vertical transmission from mother to child; however, approximately 90% of the infected will remain asymptomatic, maintaining a silent transmission network, but with low morbidity<sup>4,5</sup>.

HTLV-1 can be associated with several pathologies, including Tropical Spastic Paraparesis/HTLV-Associated Myelopathy (TSP/HAM), a neurological manifestation in which its main symptom is motor deficit of the lower limbs, affecting 2% to 3% of those infected<sup>4,6</sup>.

TSP/HAM is an associated myelopathy evidenced by chronic progressive paraparesis and lower limb compression, disc herniation, sensorial loss, urinary incontinence, sexual impotence, constipation, orthostatic hypotension, attention deficits, visual deficits and some have lumbar pain with irradiation to the lower limbs. It can also present pyramidal signals with the presence of Babinski signal<sup>4,7</sup>.

In view of the characteristics of TSP/HAM, some organic changes and loss of

functional capacity (FC) appear. FC can be defined as the degree of preservation of the ability to perform, in an autonomous and independent way, activities of daily life (ADL) and instrumental activities of daily living (IADL), depending on physical and mental abilities and environmental conditions, such as physical barriers and time constraints, being permanently in palliative care<sup>8</sup>.

Palliative care comprises a differentiated care approach, which aims to promote the quality of life of the patient and his/her family through appropriate prevention and treatment to alleviate suffering through early diagnosis, effective evaluation, observation to avoid physical problems, besides providing psychosocial and spiritual support. Palliative care is referred as intensive care, requiring specialized professionals with individualized knowledge and skills for each client<sup>9-11</sup>.

Palliative care should not be considered as an option after an ineffective curative treatment, but rather a set of care provided to the patient from the beginning of the therapy in chronic diseases, being considered a specialized approach to help the individual to live better until the moment of his/her death<sup>12</sup>.

In this sense, the integrality of the human being is highlighted in the palliative care so as to enable the expression of the thoughts and feelings that involve their finitude, in the perspective of helping them to close the cycle of their existences.

It is important not to rush or advance death, but to assert life and understand that death is a natural process. Palliative care are aimed to relieve pain and other symptoms that lead to distress; provide patients with psychic and spiritual care; give support so that patients can stay active until death; as well as help the family to understand the disease, or even in their mourning process<sup>13</sup>.

FC is essential for the health promotion of individuals affected by chronic-degenerative diseases such as TSP/HAM, and can provide data that can be added to the diagnosis, treatment, rehabilitation and prevention of secondary complications<sup>14,15</sup>.

Therefore, it is important to investigate this aspect in the public of this research with the purpose of electing the main functional aspects that present deficits in daily activities and affect the routines of these individuals, causing in the rupture and modification of their previous occupational roles. In this sense, the objective of this study was to evaluate the functional capacity of individuals with tropical spastic paraparesis/HTLV-associated myelopathy (TSP/HAM).

## METHOD

This is a descriptive study with a quantitative approach, which is a research method in which numerical data are obtained. It is characterized, both in the data collection phase and in its treatment, by the use of statistical techniques<sup>16</sup>.

This research was carried out in the Laboratory of Studies in Functional Rehabilitation (LAERF) of the Faculty of Physiotherapy and Occupational Therapy (FFTO) of the Health Sciences Institute (ICS) of the Federal University of Pará (UFPA) from 2015 to 2016.

Twelve individuals diagnosed with HTLV-1, who had TSP/HAM and had been followed up on LAERF/UFPA, participated in this study. The inclusion criteria were patients of both sexes, with HTLV-1, who had TSP/HAM, has been followed up at the LAERF and who accepted to participate in the study. The exclusion criteria were patients who did not present HTLV-related symptoms, had not been treated at LAERF or who did not agree to participate in the study.

According to Resolution 466/12 of the National Health Council (Brazil, 2012), the research project was approved by the Ethics Committee of Research with Human Beings of the Health Sciences Institute of the Federal University of Pará - ICS/UFPA, under opinion No. 1,426,227 of February 26, 2016. Participants expressed their acceptance in participating in the study by signing the Informed Consent Form (ICF).

We used the Health Assessment Questionnaire (HAQ), which consists of a

general questionnaire translated into Portuguese and validated in Brazil<sup>17</sup>. It has been developed approximately 30 years ago, which assesses functional capacity through 20 activities divided into eight categories: dressing and grooming, rising, eating, walking, hygiene, reach, grip and usual activities<sup>18,19</sup>.

The questionnaire is a self-evaluation, in which the person scores 0 to 3 points in each activity: 0 points means no difficulty, 1 point means some difficulty, 2 points means much difficulty and 3 points means the person is unable to do a given activity. Given this, the average of each category is obtained, and the higher the score, the more impaired is the functional capacity of that person. The functional evaluation also provides knowledge not only about the physical strength, but also about the individual's dexterity and cognitive state<sup>14,19</sup>.

Age and treatment time were expressed as mean and standard deviation. The other data were expressed as follows, (n): absolute frequency; F (%) frequency in percentage.

## RESULTS

Table 1 shows the demographic distribution of the patients participating in the research. Of the 12 patients interviewed, 58.4% were female and 41.6% were male. The mean age for women was 55.7 years and 49.6 years for men.

The majority of the individuals are from Pará state, 83.4%, and the other 16.6% is divided between Ceará and Amapá.

Regarding the marital status, there were prevalence of married individuals, with 58.4%, 25% were single, and 16.6% were separated or widowed.

The treatment time was on average 3.5 years, which demonstrated the late manifestation of the virus and of TSP/HAM. Most had discovered the disease from blood donation and/or the onset of symptoms. It is also highlighted that only 25% have been followed-up by an occupational therapist.

**Table 1.** Epidemiological profile of patients with HTLV-1 - TSP/HAM. Belém/PA, 2015-2016.

Variable	Patients N = 12		Mean
	N	F (%)	
<b>Sex</b>			
Female	07	58.4%	
Male	05	41.6%	
<b>Age</b>			
Women	-	-	55.7 (mean)
Men	-	-	49.6 (mean)
<b>Marital status</b>			
Single	03	25.0%	
Married	07	58.4%*	
Separated	01	08.3%	
Widowed	01	08.3%	
<b>Schooling</b>			
<9	05	41.7%	
>9	07	58.3%	
<b>Origin</b>			
Pará	10	83.4%	
Ceará	01	08.3%	
Amapá	01	08.3%	
<b>Religion</b>			
Catholic	05	41.7%	
Evangelical	07	58.3%	
<b>Profession</b>			
Formal	05	41.7%	
Informal	07	58.3%	
<b>Treatment Time</b>			
Months	-	-	41.5 (mean)
Years	-	-	03.5 (mean)
<b>Professional monitoring</b>			
Physician	11	91.7%	
Physiotherapist	11	91.6%	
Occupational Therapist	03	25.0%	

On functional capacity, 50% have moderate to severe disability, difficulty in walking and changes in posture and balance, and some need assistance from family members, crutches and wheelchairs.

41.7% of the users presented "mild to moderate difficulty". A single user presented "severe or very severe disability" and was wheelchair dependent and dependent on family members (Table 2).

The limitations in performing the activities were measured by the Health Assessment Questionnaire (HAQ), divided into eight categories (Table 3). It can be seen in more details the activities the respondents present greater difficulties.

It can be noticed that the category hygiene had the worst score, as 41.6% cannot do it because it requires more gait, posture

and balance, aspects that are most affected by TSP/HAM, significantly in lower limbs.

**Table 2.** Functional capacity as set by the Health Assessment Questionnaire (HAQ), referred to by patients with HTLV-1 - TSP/HAM. Belém/PA, 2015-2016.

Variable	TSP/HAM N = 12	
	F (n)	F (%)
Mild to moderate difficulty	05	41.7 %
Moderate to severe disability	06	50.0 %
Severe or very severe disability	01	08.3 %

On the other hand, the subdivisions that require greater effort from the upper limbs, such as eating and grip, had the best scores, as 66,66% and 83,33% respectively

can do them without difficulty on the listed activities.

The Usual Activities emphasize mobility both inside and outside home, justifying the fact that 41.66% of respondents do it with great difficulty. This balance is

probably due to the characteristics of the users. Some were at the beginning of the disease, with few symptoms, and others were completing a decade of symptomatology, of whom three, that is, 25% of the interviewees, were wheelchair users.

**Table 3.** Functional capacity as set by HAQ, subdivided into the eight categories of functional activities referred to by patients with HTLV-1 – TSP/HAM. Belém/PA, 2015-2016.

Variable	TSP/HAM N = 12	
	F(n)	F(%)
<b>Dressing and Grooming</b>		
0 (No difficulty)	05	41.8%
1 (Some difficulty)	05	41.6%
2 (Much difficulty)	02	16.6%
3 (Unable to do)	-	-
<b>Rising</b>		
0 (No difficulty)	03	25.0%
1 (Some difficulty)	03	25.0%
2 (Much difficulty)	03	25.0%
3 (Unable to do)	03	25.0%
<b>Eating</b>		
0 (No difficulty)	08	66.8%
1 (Some difficulty)	02	16.6%
2 (Much difficulty)	01	08.3%
3 (Unable to do)	01	08.3%
<b>Walking</b>		
0 (No difficulty)	04	33.3%
1 (Some difficulty)	02	16.6%
2 (Much difficulty)	03	25.1%
3 (Unable to do)	03	25.0%
<b>Hygiene</b>		
0 (No difficulty)	03	25.0%
1 (Some difficulty)	01	08.3%
2 (Much difficulty)	03	25.0%
3 (Unable to do)	05	41.7%
<b>Reach</b>		
0 (No difficulty)	04	33.3%
1 (Some difficulty)	02	16.7%
2 (Much difficulty)	04	33.3%
3 (Unable to do)	02	16.7%
<b>Grip</b>		
0 (No difficulty)	10	83.4%
1 (Some difficulty)	02	16.6%
2 (Much difficulty)	-	-
3 (Unable to do)	-	-
<b>Usual activities</b>		
0 (No difficulty)	03	25.0%
1 (Some difficulty)	01	08.3%
2 (Much difficulty)	05	41.7%
3 (Unable to do)	03	25.0%

**DISCUSSION**

Female predominance is justified by the fact that HTLV-1 transmission is more efficient from men to women, with two times more chances of contamination. Thus, being a female is a risk factor for virus infection<sup>4,20,21</sup>.

These data can be explained by the high rate of infection in Brazil, especially in endemic areas such as the North and Northeast<sup>2</sup>.

It is possible that sexual transmission is an important route of HTLV-1 infection. But it is also questioned whether the high number of married people infected by the virus would be due to extramarital affairs without the use of condoms<sup>2, 22</sup>.

The results are in line with other studies that claim that people with more than 10 years of symptomatology. It is also emphasized that most of them wander only

with the help of some resource<sup>6</sup>.

The HAQ is a self-administered questionnaire, being one of the most cited and used instruments in rheumatic diseases. Regarding HTLV, there are no studies that report the approach of this questionnaire with people with HTLV in the North of Brazil, specifically in the State of Pará<sup>23</sup>.

Second is Rising, Walking and Usual Activities, with 25%, each<sup>4</sup>.

This is due to the fact that paraparesis does not affect the strength in the arms, even though a percentage of these patients may present hyperreflexia. As a result, performance in these two categories remains satisfactory, as well as in the categories Dressing and Grooming and Reach<sup>4</sup>.

This condition reveals that these individuals are in palliative care, with emphasis on day-to-day activities. Such care has aroused growing interest in society, given that the number of people affected by chronic life-threatening diseases has increased, necessitating essential care as continuous and comprehensive care<sup>24</sup>.

In addition to the comprehensive care to the patient who is in palliative care, it is also necessary differentiated attention to the relatives and caregivers. The World Health Organization considers as one of the main objectives of palliative care the attention to the needs and quality of life of patients, families and caregivers in the process of becoming ill, and for this, the WHO determines that special attention should be paid<sup>9</sup>.

The importance of the Occupational Therapist in the treatment of these individuals is emphasized, considering the various physical, psychic, emotional and social demands due to the pathology, and this professional can help reducing the impact of the manifestation of the symptoms, through new occupational possibilities.

Occupational Therapy is a field of knowledge and performance in health and education that seeks to prevent and treat physical and/or psychosocial difficulties, aiming at improving the quality of the individual's occupational life. It is used as a guiding element in the structuring of the

therapeutic process. Its intervention is fundamental, since it is responsible for analyzing and promoting occupational life in the patient's routine in the most diverse aspects<sup>25,26</sup>.

## CONCLUSION

The issue of living with HTLV is comprehensive and complex, provoking radical changes, interfering in the daily lives of people with TSP/HAM.

As evidenced in the study, such changes are highly correlated with the symptomatology of the disease and require special attention to day-to-day activities, functional capacity and abilities that require more of the lower limbs, transfer of posture and balance.

Based on the results found in this research, interventions and strategies, such as environmental adaptations, the use of adequate wheelchairs and training in daily life activities are proposed through Occupational Therapy, favoring greater autonomy and independence and seeking improvement in the quality of life of these individuals.

It is also worth noting that this study is the first one to use the HAQ in research with individuals with TSP/HAM, especially in the Amazon region.

In view of the results found, the importance of the scientific production, analysis and discussion about HTLV is confirmed for the development of health policies and strategies aimed at these individuals and the health professionals who monitor these cases.

In this context, the performance of Occupational Therapy in the care of this public is relevant to contribute to the reduction of the difficulties encountered by them in adapting to a new routine, to the change of occupational roles, in the discovery and learning of skills for a life with the maximum autonomy possible.

Among the limitations of this study, we highlight the non-causal analysis between TSP/HAM and functional capacity, and the small sample of the study due to difficulties related to the diagnosis of HTLV-1 infection and to the access of this public to health

services.

It recommend that functional capacity may also be identified and monitored as a further repercussion of HTLV-1 infection and may be a further condition in the prevention and promotion of HTLV-1 infection. In addition, due to the impact in health status, we suggest that other studies may examine the presence of these manifestations in similar groups.

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#### CONTRIBUTIONS

Ádria Cecília Botelho da Rocha e Priscila Sarmiento de Almeida carried out the field research, data analysis and organization, and writing. Luiz Fábio Magno Falcão, Denise da Silva Pinto and Hellen Thaís Fuzii contributed to the review of the paper. Victor Augusto Cavaleiro worked in the supervision of the paper and writing.

#### How to cite this article (Vancouver)

Corrêa VAC, Rocha ACB, Almeida PS, Pinto DS, Falcão LFM, Fuzii HT. Functional capacity in individuals with tropical spastic paraparesis/ HTLV-1-associated myelopathy. *REFACS* [Internet]. 2018 [cited in *insert day, month and year of access*]; 6(1):7-14. Available from: *enter access link*. DOI: *insert DOI link*.

#### How to cite this article (ABNT)

CORRÊA, V. A. C. et al. Functional capacity in individuals with tropical spastic paraparesis/ HTLV-1-associated myelopathy. *REFACS*, Uberaba, v. 6, n. 1, p. 7-14, 2018. Available from: < *enter access link* >. Accessed in: *insert day, month and year of access*. DOI: *insert DOI link*.

#### How to cite this article (APA)

Corrêa, V. A. C., Rocha, A. C. B., Almeida, P. S., PINTO, D. S., Falcão, L. F. M. & Fuzii, H. T. (2018). Functional capacity in individuals with tropical spastic paraparesis/ HTLV-1-associated myelopathy. *REFACS*, 6(1), 7-14. Retrieved in: *insert day, month and year of access* and *enter access link*. DOI: *insert DOI link*.