Impact of HTLV-associated myelopathy/tropical spastic paraparesis (HAM/TSP) on activities of daily living (ADL) in HTLV-1 infected patients

Impacto da mielopatia associada ao HTLV/paraparesia espástica tropical (TSP/HAM) nas atividades de vida diária (AVD) em pacientes infectados pelo HTLV-1

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ABSTRACT

Aim: To describe the performance of activities of daily living (ADL) of HTLV-1 infected patients with HAM/TSP and to measure the impact of the disease on the patients' quality of life. Methods: This study is a descriptive, cross-sectional study. A total of seventy-three HAM/TSP patients were enrolled at the HTLV Center of the Bahia School of Medicine and Public Health, Salvador, Bahia, Brazil. The index of functional independence was calculated using the Health Assessment Questionnaire HAQ. The quality of life, including functional capacity, pain, and physical appearance was assessed using the Short-Form Health Survey (SF-36).Results: A total of seventy-three HAM/TSP patients were enrolled with a mean age of 48.9 ± 11.4 years, 57 of whom were (78.1%) women. The duration of HAM/TSP disease was 10 to 37 years (in 50.7% of the patients). Thirty-six patients (49.3%) had a need for walking supports. The lowest ADL performance scores were observed among women and referred to mobility/locomotion (98.2%), dressing (73.7%), and self-care (57.9%) aspects. The quality of life score for the physical aspect was 24.2, and the functional capacity was 27.1. The average for pain was 41.7. Conclusion: HAM/TSP has a negative impact the on the ADL performance of the patients and their quality of life. Assistive technology devices should be used to improve functional capacity and quality of life for these patients.

Keywords: Paraparesis, Tropical Spastic, Human T-lymphotropic virus 1, Activities of Daily Living, Quality of Life

RESUMO

Objetivo: Descrever o desempenho nas atividades de vida diária (AVD) em pacientes infectados pelo HTLV-1 com TSP/HAM e medir o impacto da doença sobre a qualidade de vida dos pacientes. Método: Trata-se de um estudo descritivo, de corte transversal. Um total de setenta e três pacientes com TSP/HAM acompanhados no Centro de HTLV da Escola Baiana de Medicina e Saúde Pública, Salvador, Bahia, Brasil foram selecionados. O índice de independência funcional foi calculada usando o Health Assessment Questionnaire (HAQ). A qualidade de vida foi avaliada incluindo a capacidade funcional, dor e aspecto físico, utilizando do Short-Form Health Survey (SF-36). Resultados: Um total de setenta e três pacientes com TSP/HAM foram avaliados: a idade média foi de 48,9 ± 11,4 anos, e 57 (78,1%) eram mulheres. A duração da doença TSP/HAM foi de 10 a 37 anos em 50,7% dos pacientes. Trinta e seis pacientes (49,3%) necessitavam de ajuda de suportes para andar. As pontuações mais baixas no desempenho das AVD foram observadas entre as mulheres e se referiam à locomoção e à mobilidade / (98,2%), ao vestuário (73,7%) e ao auto-cuidado (57,9%). O escore de qualidade de vida para o aspecto físico foi 24,2 e o da capacidade funcional foi 27,1. A média de dor foi 41,7. Conclusão: A TSP/HAM afeta negativamente a qualidade de vida e o desempenho nas AVD dos pacientes. Dispositivos de tecnologia assistiva devem ser usados para melhorar a capacidade funcional e a qualidade de vida desses pacientes.

Palavras-chave: *Paraparesia Espástica Tropical, Virus Linfotrópico de Células T Humanas Tipo 1, Atividades Cotidianas, Qualidade de Vida*

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INTRODUCTION

It is estimated that approximately 20 million people worldwide are infected by the lymphotropic type 1 T-cell virus (HTLV-1). Areas with elevated prevalence of infection are found in the southeast of Japan and in the poor areas of the Caribbean, Africa, and Latin America. Brazil has the largest absolute number of individuals infected by the HTLV-1 in the world, however, the prevalence of the infection varies according to the geographical area.[1] The highest prevalence is observed in Salvador, Bahia, where approximately 2% of the population, (≈ 50.000 inhabitants) is infected.[2]

HTLV-1 is the etiological agent of myelopathy associated with the HTVL/tropical spastic paraparesis (TSP/HAM), leukemia/lymphoma of T-cells in the adult (ATLL).[3-7] TSP/HAM is a progressive, chronic disease that occurs more frequently in women over 40, in a proportion of 3 women for each man. The main symptoms of the disease are spastic paraparesis or paraplegia and autonomic alterations of the sphincters with urinary retention and incontinence or constipation. Sexual impotence and loss of libido are also frequently observed. Deep sensorial alterations such as paresthesia and dysesthesia of the limbs, as well as cramps and pain in the lumbar region and lower limbs are also described.[10] Many times, patients present difficulty in locomotion, loss of balance, and muscular fatigue.[11] These symptoms can hinder the performance of their daily life activities (DLA), including self-care, the capacity to get dressed, and mobility/locomotion. Few studies have evaluated the quality of life and the performance of the DLA in patients infected with the HTLV-1.[12] The objective of this study is to describe the performance of the DLA in patients infected by the virus with TSP/HAM and to evaluate the impact of the disease on the quality of life of those individuals.

METHOD

This is a transversal descriptive study. The patients were monitored at the HTLV Reference Center from the Bahia School of Medicine and Public Health, in Salvador, Bahia, Brazil, between March and December of 2007. This is an ambulatory that offers free medical assistance, laboratory diagnosis, psychological assistance, and physiotherapy. Since 2002, a total of 1,070 patients infected with HTLV-1 were registered at the center, and of those, 50% were evaluated in medical consultations at least twice a year. Most patients were female, with a family income of one minimum salary per month and had less than 8 years of schooling. Thirty percent of the patients were diagnosed with TSP/HAM. The patients were invited to the study by telephone and were selected sequentially after a medical consultation. A total of 73 patients were included in the study. The criteria for inclusion were based on a neurological evaluation for the TSP/HAM diagnosis.[13] The project was approved by the Ethics Committee for Research from the Oswald Cruz Foundation (Fiocruz).

Table 1 - Clinical and socio-demographic characteristics of the TSP/HAM patients in Salvador, Bahia

	All the patients n= 73 (%)	**Male n=16 (%)**	**Female n=57 (%)**
Age (years)			
Average (SD)	48.9 (11.4)	51.6 (7.8)	48.4 (12.1)
Median (range)	48 (25-76)	52 (40-66)	47 (25-76)
Education			
< 8 years of study	40 (54.8)	11 (68.7)	29 (50.9)
> 8 years of study	33 (42.2)	5 (31.3)	28 (49.1)
Family Income			
<1 Minimum wage salary	63 (86.3)	15 (93.8)	48 (84.2)
>1 Minimum wage salary	10 (13.7)	1 (6.2)	9 (15.8)
Marital Status			
Single	56 (76.7)	12 (75)	44 (77.2)
Married	17 (23.3)	4 (25)	13 (22.8)
Duration of symptoms (years)			
> 10 years	37 (50.7)	9 (56.2)	28 (49.1)
< 10 years	36 (49.3)	7 (43.8)	29 50.9)
Gait assistance apparatus			
Canes	12 (16.4)	4 (25)	8 (14)
Crutches	7 (9.6)	2 (12.5)	5 (8.8)
Walker	1 (1.4)	0 (0)	1 (1.8)
Wheel-chair	16 (21.9)	1 (6.3)	15 (26.3)
Osame Functional Scale			
Grade 0-2	27 (37.0)	5 (31.25)	22 (38.6)
Grade 3-4	31 (42.5)	5 (31.25)	26 (45.6)
Grade 5- 6	10 (13.7)	4 (25.0)	6 (10.5)
Grade 7-8	3 (4.1)	2 (12.5)	1 (1.8

Duration of TSP/HAM symptoms, ** MS (minimum wage salary) US$ 220, Osame functional scale

Data Collection

The patients selected were interviewed by three team members. The evaluations were made during a structured interview, and the socio-demographic data was obtained via a specific questionnaire. The Quality of Life was evaluated between three categories in the SF-36 questionnaire: physical functions, physical aspect, and pain. The scoring for each scale varied from 0-100, with 0 corresponding to the worst state of health and 100 to the best state.[14] The DLAs were evaluated utilizing the first domain of the Health Assessment Questionnaire (HAQ).[15] Eight categories were evaluated: 1) dressing and grooming; 2) arising; 3) eating; 4) walking; 5) hygiene; 6) reach; 7) grip; and 8) common daily activities. The scale varied from 0 to 3 points, with 0 – with no difficulty; 1 – with some difficulty; 2 – with a lot of difficulty; and 3 – incapable. The functional incapacity index (FII) was interpreted in the following manner: 0 = no assistance necessary; 1 = a special device is used by the patient in their habitual activities; 2 = the patient normally needs help from another person; 3 = the patient normally needs as much help from special devices as from another person. The re-classification of the scale was done unifying the items "with some difficulty" and "with a lot of difficulty" utilizing the scale as follows: without any difficulty (ND), with some difficulty (SD) and incapable (INC). The motor dysfunction was evaluated by a neurologist, based on the motor deficiency Index (OSAME scale) in which motor dysfunction is classified on a scale that varies from 0 to 13, with 0 being a normal walking and 13 being for patients completely bedridden.[16]

Statistical analysis

The descriptive statistic, including the frequencies, percentages, median, average, and standard deviation (SD) were calculated for the socio-demographic variables and for the DLA, regarding the most critical activities related to mobility/locomotion, and to the three SF-36 quality of life domains. The chi-square test was utilized to compare the proportions of the gender. The statistical significance level was when the value of P was lower than 0.05. The Statistical Package for Social Sciences (SPSS 13.0) was utilized for statistical calculations.

RESULTS

The sample was composed of 73 patients with TSP/HAM, with the majority (78.1%) being female. The median age was 48 years (varying from 25 to 76 years), 95.9% of the patients were older than 30 years and 46.6% had only elementary-level education. In relation to their marital status, 41.1% of the patients were single. The monthly family income for 55.6% of the patients was of one minimum wage salary (approximately US$ 220). Thirty-seven patients (50.7%) had had TSP/HAM symptoms for more than 10 years. In addition, 36 (49.3%) of the patients needed special devices such as crutches, canes, or walkers, and 16 (22%) utilized wheel chairs. The degree of motor deficiency, measured by the Osame scale, was higher than seven (out of 13) in 5.4% of the patients (Table 1). The most compromised DLA were related to mobility/locomotion and grooming, followed by self-care. As to locomotion and mobility, 70.2% of the females reported great difficulty performing their activities and 28% were incapable, while for males these percentages were 56.2% and 25% respectively. In the getting dressed aspect, 71.9% of the females reported great difficulty and 1.8% were incapable of getting dressed by themselves, while 37.5% of the males reported great difficulty. The functional independence index (FII) evaluated by the HAQ was moderate to severe (average of 1.4 ± 0.8) (Table 2).

The main difficulty related to mobility/locomotion was reported as the capacity to lie down on or to get up from a bed. The incapacity to go shopping near their residences was reported by 39.7% of the female patients, while 24.6% could not remain standing on a bus. In the self-care aspect, 27.4% of the patients reported great difficulty in performing this activity and 4.2% were incapable of taking a shower. The majority of patients had difficulty in getting dressed and undressed (Table 3). The quality of life score for the physical aspect was 24.2 and the functional capacity was 27.1. The average for pain was 41.7 (Table 4).

Table 2 - Performance in the daily life activities of 73 TSP/HAM patients in Salvador, Bahia

Variables	Total =73 n (%)	Male=16 n (%)	Female=57 n (%)
Mobility/locomotion			
W/O difficulty	4 (5.5)	3 (18.8)	1 (1.8)
W difficulty	49 (67.1)	9 (56.2)	40 (70.2)
Incapable	20 (27.4)	4 (25.0)	16 (28.0)
Dressing			
W/O difficulty	25 (34.2)	10 (62.5)	15 (26.3)
W difficulty	47 (64.4)	6 (37.5)	41 (71.9)
Incapable	1 (1.4)	0 (0%)	1 (1.8)
Self-care			
W/O difficulty	33 (45.20)	9 (56.2)	24 (42.1)
W difficulty	39 (53.4)	7 (43.8)	32 (56.1)
Incapable	1 (1.4)	0 (0)	1 (1.8)
Eating			
W/O difficulty	70 (95.9)	15 (93.7)	55 (96.5)
W difficulty	3 (4.1)	1 (6.3)	2 (3.5)
Incapable	0 (0)	0 (0)	0 (0)
FII			
Average ± SD	1.43±0.77	1.3±0.74	1.4±0.78
Min	0	0.2	0
Max	3.0	3.0	3.0

The data represents the number (percentage) of patients.
II - Functional Independence Index

DISCUSSION

The results of this study indicate that individuals infected with TSP/HAM HTLV-1 have a significant impairment in performing their DLAs. This impairment is not only related to mobility/locomotion, but also to their capacity to get dressed and to their self-care. To our knowledge, this is the first report in Brazil that evaluates the performance of the DLAs in patients infected with HTLV-1 and diagnosed with TSP/HAM. The DLAs related to mobility/locomotion, to the capacity to lie down and to get up, to move from one place to another, and to pick up objects from the ground were pointed out as the most difficult for most patients. Another study that evaluated the deficiency profile of HTLV-1 patients in Brazil has

shown that locomotion (walking, climbing up or going down stairs) and bladder control were the most affected functional areas.[12]

The loss of balance and spasticity present in TSP/HAM patients seem like important factors in the patient's capacity to dress and to remain in an orthostatic position (remain standing). These situations seem more pronounced among females. However, the results obtained for the Functional Incapacity Index (FII) from HAQ were similar for both genders, indicating moderate to severe difficulties that necessitated help from other people or caregivers. Furthermore, there were difficulties related to urban accessibility, as demonstrated by reports of difficulty in going shopping near their residences, as well as remaining standing on public transportation. These difficulties can be explained as much by the locomotion limitations caused by the disease as by the inadequate access conditions to residential areas and means of transport (car, bus etc.). These difficulties may constitute hindrances that impede the performance of various activities involving mobility/locomotion.

The limitations pointed out by the patients affect their quality of life negatively, especially in respect to physical condition, as observed in patients with multiple sclerosis[17] or with medullar lesions resulting from traumas.[18] Recently, a study made to determine the prevalence of chronic pain in TSP/HAM patients in Salvador, Brazil, has shown that chronic pain was significantly associated with anxiety and depression, and that there was a negative impact from pain on the quality of life.[19] Although the pain was already present in the TSP/HAM, its impact on the quality of life in our study was lower than the physical limitations and functional capacity. However, the low impact of pain on the quality of life can be underestimated, since patients with TSP/HAM can limit their activities to those that demand less physical effort. In addition, the pain was evaluated by one only parameter.

The sensory and motor alterations and the autonomic responses induced by TSP/HAM do not result only in the lack of independence and autonomy of these individuals, but also cause an important alteration of their life in their community, leisure activities, at work, and at school. The disease also carries a stigma: the main form of transmission of HTLV-1 in Brazil is by sexual contact and the infection is more prevalent in individuals with low income and little education.[2] This contributes to the isolation of the patient and to a smaller participation in social life.

Table 3 - Most critical activities related to mobility/locomotion of 73 TSP/HAM patients

Daily life activities	W/o difficulty n (%)	W difficulty n (%)	Incapable n (%)
Lying down on and getting up from a bed	10 (4.0)	44 (70.0)	19 (26)
Bending down to pick up clothes from the floor	12 (16.5)	49 (67)	12 (16.5)
Walking on level ground	15 (20.7)	48 (65.7)	10 (13.6)
Getting up erectly from a chair without back support	18 (14.8)	41 (65.1)	14 (20.1)
Climbing 5 steps	14 (19.0)	46 (63)	13 (18.0)
Performance sweeping with a broom and dragging water with a squeegee	19 (26.0)	38 (52.0)	16 (22.0)
Remaining standing on a bus or subway	20 (27.4)	30 (48)	18 (24.6)
Sitting down and getting up from the toilet	23 (31.5)	38 (52.0)	12 (16.5)
Going shopping near their residences	22 (26.1)	25 (34.2)	26 (39.7)

The functionality and incapacity of a person are conceived as a dynamic interaction between health conditions (diseases, lesions, and deficiency) and contextual factors (environmental and personal factors).[20] The rehabilitation process demands strategies for prevention and support to allow these individuals to reach and maintain an optimum level of functionality while interacting with their environment.

Table 4 - Average of the three areas evaluating quality of life in the SF-36 questionnaire of 73 TSP/HAM patients in Salvador, Bahia

SF-36 Domains	Average ±SD	Min-Max
Physical Aspect	24.2±24.6	0-100
Functional Capacity	27.1±23.7	0-94
Pain	41.7±34.4	0-100

* Standard Deviation (SD) ** Average (A)

CONCLUSION

The results presented here reinforce the need for a multidisciplinary team to monitor the TSP/HAM patients. Specific protocols must be created and barriers and facilitators must be identified to improve the quality of life. The health of these people depends not only on clinical evolution, but also on the improvement of access to the environment in which they live. Devices of assistive technology such as bars, handrails, adaptations in beds and chairs must be used to improve the functional capacity, independence, and quality of life of these patients.

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