

# Prevalence of anxiety, depression and quality of life in HTLV-1 infected patients

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Submitted on: 05/18/2011

Approved on: 08/11/2011

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**Financial Support:** FAPESP e Coordenadoria de Controle de Doenças CCD/SES-SP.

We declare no conflict of interest.

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## ABSTRACT

The HAM/TSP caused by HTLV-1 infection usually affects patients to disabling states, and sometimes can lead them to paraplegia presenting symptoms of depression and anxiety, impacting on quality of life. **Objective:** The purpose of this study was to evaluate the frequency of depression and anxiety and its impact on quality of life in HTLV-1-infected TSP/HAM patients. **Material and Methods:** This was a cross-sectional study including 67 asymptomatic (control group) and 63 with TSP/HAM subjects. The instruments used were a demographic questionnaire, scales for anxiety and depression diagnosis (BDI and BAI), questionnaire for the assessment of Quality of Life of the World Health Organization (WHOQOL-Brief) and neurological scale to measure the disability level (Osame's Disability Status Scale). All patients had HTLV-I diagnosis by serological and molecular approaches, monitored at Instituto de Infectologia Emilio Ribas from May 2008 to July 2009. Data were analyzed statistically by frequencies, the Mann-Whitney test and the Spearman correlation test. Data among groups were analyzed and correlated with functional and severity aspects. **Results:** The results showed that patients with HAM/TSP compared to asymptomatic carriers had higher rates of depression ( $p < 0.001$ ) and anxiety ( $p < 0.001$ ), and impairment on quality of life in the areas of: dissatisfaction with health ( $p < 0.001$ ), physical ( $p < 0.001$ ) and the environment ( $p = 0.003$ ). The main factors that correlated with levels of depression and anxiety and the domains of the WHOQOL-brief were: education, family income and social class. **Conclusion:** A well conducted evaluation and counseling may help in treatment, for a better quality of life of these patients.

**Keywords:** anxiety; depression; quality of life; human T-lymphotropic virus 1.

## INTRODUCTION

Human T-cell lymphotropic virus type 1 (HTLV-1), first isolated in 1980, has been etiologically associated with a neurologic syndrome called HTLV-1 associated myelopathy/tropical spastic paraparesis (HAM/TSP) as well as with adult T-cell leukemia/lymphoma (ATLL) and with other clinical manifestations, such as uveitis, arthritis, infective dermatitis and polymyositis.<sup>1-4</sup> HTLV-1 infection is endemic in Brazil and, an estimation by the Ministry of Health<sup>5</sup> states that 750,000 people are carriers of HTLV, with a prevalence varying from 0.4% to 18% depending on the geographic region.<sup>6-10</sup>

Psychiatric disorders appear to be common in patients with chronic diseases, as in tropical spastic paraparesis/HTLV-1 associated myelopathy (HAM/TSP). Besides, depression and anxiety symptoms may contribute to progressive disability and limitations in daily living activities impacting their perceptions about quality of life.<sup>11-13</sup>

The association between HTLV and depression has not been extensively studied so far. Stumpf et al.<sup>12</sup> reported the presence of depressive symptoms in individuals infected with HTLV-1, followed in open prevalent cohort study of seropositive blood donors in a blood center in Minas Gerais. Preliminary results of a recent study in the cohort suggested greater prevalence of depression among carriers of HTLV-1 compared to seronegative blood donors (45.5% versus 18.8%,  $p = 0.0543$ ).

Souza<sup>13</sup> conducted a study of 36 patients infected with HTLV-1, which showed the presence of depressive symptoms in 10 (28%) patients, 20% with tropical spastic paraparesis and 8% asymptomatic. The author notes that 77% of patients interviewed had, at least, one symptom of depression. The most frequent symptoms were: sleep disturbance, lack of appetite, and anhedonia. Another study conducted by Carvalho et al.<sup>14</sup> with 50 patients

with HTLV-1 (26 were symptomatic and 24 asymptomatic) observed that 21 (42%) had psychiatric comorbidity, 17 (34%) presented mood change, and 11 (22%) anxiety.

Regarding the studies on quality of life, Shublaq,<sup>15</sup> in his MSc dissertation, assessed the functional capacity and quality of life in 30 patients with myelopathy associated with HTLV-1, and concluded that the progression of the deficit compromises functional independence in daily activities. Most participants were described as being dependent on external care, and the impact of this dependence was demonstrated by the measurement of quality of life.

In the study conducted by Coutinho et al.<sup>16</sup> with 57 patients with HAM/TSP, it was observed that the physical aspect is the factor that most affects the quality of life of these patients, and that the impairment in daily activities is directly related to the ability to mobility and locomotion.

The purpose of this study was to assess the frequency of depression, anxiety and quality of life in TSP/HAM and asymptomatic HTLV-1 infected patients, in relation to sociodemographic and clinical features.

## MATERIAL AND METHODS

We conducted a cross-sectional study with 130 patients: 63 with HAM/TSP and 67 asymptomatic HTLV-1 control group; a demographic questionnaire, scales for anxiety and depression diagnosis (BDI and BAI),<sup>17,18</sup> questionnaire for assessing Quality of Life of the World Health Organization (WHOQOL-Brief),<sup>19</sup> and neurological scale to measure the disability level (Osame's Disability Status Scale)<sup>4</sup> were used as instruments. All patients had HTLV-1 diagnosed by serological and molecular approaches conducted at Instituto de Infectologia Emílio Ribas from May 2008 to July 2009. Data were analyzed by frequencies, Mann-Whitney test and the Spearman correlation test, which were considered significant when  $p < 0.05$ .<sup>20</sup>

## RESULTS

Ninety-three patients (71.5%) were female and 37 (28.4%) male, with a mean age of 49.8 years (SD = 11.6 years). Most participants were white (39.2%), married (32.3%),

on social class C (54.6%), with a family income of one to five minimum wages (79.2%) and had an educational level of 0-4 years (34.6%), manual workers (30%), and coinfections: HTLV-1/HCV (7.2%), HTLV-1/HIV (7.2%), HTLV-1/HIV/HCV (4.8%), HTLV-1/HBV (0.8%) and HTLV-1/HIV/HBV (0.8%).

In Osame's scale, 21 patients had partial incapacity to walk without any help; 31 patients had partial incapacity to walk needing hand support; and 11 patients had incapacity to walk.

The frequency of moderate/severe depression was 40.3%/19% (59.3%) in the HAM/TSP group and 13.5%/8.9% (22.4%) in the control group (Table 1). The most prevalent symptoms were fatigue (74.6%), health concern (73.8%), irritability (65.3%), sleep disturbance (63.8%), difficulty to work (61.5%), reduction/lack of sexual desire (57.6%), apathy (54.7%), self-criticism (53.8%) and anhedonia (53%).

The presence/absence of HAM/TSP is significantly associated with high level depression ( $p < 0.001$ ). Other significantly associated factors were: educational level ( $p < 0.001$ ), family income ( $p = 0.002$ ), social class ( $p < 0.001$ ). In the group of symptomatic patients, also showed significance: beginning of clinical symptoms ( $p = 0.050$ ,  $p = 0.248$ ), serological tests for the family ( $p = 0.002$ ), kinship (children) ( $p < 0.001$ ,  $p = -0.449$ ) and kinship (children) with positive results ( $p = 0.005$ ). In the asymptomatic group, the variables significantly associated were: missing doctor appointments ( $p = 0.040$ ), time off from the clinic ( $p = 0.035$ ), absence of family/social support ( $p < 0.015$ ), coinfection ( $p = 0.03$ ).

The frequency of moderate/severe anxiety was 31.7%/23.8% (55.5%) in the HAM/TSP group and 14.9%/10.4% (25.3%) in the control group (Table 2). The most prevalent symptoms were nervousness (63.8%), numbness or tingling (59.2%), difficulty to relax (56.2%), lack of balance (55.4%) and fear of losing control (52.3%).

Statistical analysis by Mann-Whitney U test was in 1,217 ( $z = 4.297$ ) with a probability  $p < 0.001$ , which shows that presence/absence of HAM/TSP was associated with high level anxiety. Other significantly associated factors were: sex ( $p = 0.012$ ), family income ( $p = 0.003$ ), residence place ( $p = 0.040$ ), social class ( $p = 0.003$ ), onset of clinical

**Table 1. Frequency and intensity of depression in 130 patients attended at the Instituto de Infectologia Emílio Ribas from May to July 2009**

High level depression (BDI)	All patients (n = 130)	Symptomatic (n = 63)	Asymptomatic (n = 67)
Minimum	59 (45.4%)	18 (28.5%)	41 (61.1%)
Slight	19 (14.6%)	8 (12.6%)	11 (16.4%)
Moderate	34 (26.2%)	25 (40.3%)	9 (13.5%)
Severe	18 (13.8%)	12 (19%)	6 (8.9%)

symptoms ( $p < 0.001$ ), missing doctor appointments ( $p = 0.040$ ) and depression ( $p < 0.001$ ). The group of symptomatic patients also showed significance for: serological tests on relatives ( $p = 0.021$ ), kinship (children) ( $p = 0.014$ ) and depression ( $p < 0.001$ ). In the asymptomatic group the variables significantly associated were: family income ( $p = 0.017$ ), social class ( $p = 0.015$ ) missing doctor appointment ( $p = 0.006$ ), time off from the clinic ( $p = 0.048$ ), coinfection ( $p = 0.046$ ) and depression ( $p < 0.001$ ).

Regarding quality of life, it was observed that patients with HAM/TSP had scores related mainly to

satisfaction with health and physical environment. Patients with HAM/TSP reported almost three times more dissatisfaction with health (65%) than asymptomatic patients (26.7%), and in the physical domain 20.1% and 7.4%, respectively. In the environment domain, the frequency of dissatisfaction among patients with HAM/TSP was five times higher (30.4%) when compared to the group of asymptomatic patients (Tables 3 and 4).

The variables that associated satisfaction with the health field in the symptomatic group were: time of illness ( $p = 0.017$ ), serologic testing by relatives ( $p = 0.002$ ),

**Table 2. Frequency and intensity of anxiety in 130 patients attended at the Instituto de Infectologia Emilio Ribas from May 2008 to July 2009**

High level anxiety (BAI)	All patients (n = 130)	Symptomatic (n = 63)	Asymptomatic (n = 67)
Minimum	58 (44.6%)	15 (23.8%)	43 (64.1%)
Slight	20 (15.4%)	13 (20.6%)	7 (10.4%)
Moderate	30 (23.1%)	20 (31.7%)	10 (14.9%)
Severe	22 (17%)	15 (23.8%)	7 (10.4%)

**Table 3. Distribution of domains according to quality of life questionnaire (WHOQOL-Brief) among 63 symptomatic patients with infection by HTLV-1 treated at Instituto de Infectologia Emilio Ribas**

	Quality of life	Health	Physical domain	Psychological domain	Social relationships	Environment
Very satisfied	2 (3.2%)	13 (20.6%)	1 (1.6%)	0	2 (3.2%)	0
Dissatisfied	9 (14.2%)	28 (44.4%)	18 (18.5%)	11 (17.6%)	7 (11.2%)	19 (30.4%)
Neither satisfied/ nor dissatisfied	22 (34.9%)	12 (19.2%)	30 (47.6%)	19 (30.4%)	18 (28.8%)	28 (42%)
Satisfied	26 (41.3%)	10 (15.8%)	13 (20.6%)	25 (40%)	32 (51.2%)	23 (36.8%)
Very satisfied	4 (6.4%)	1 (1.5%)	1 (1.6%)	8 (12.8%)	5 (8%)	0

**Table 4. Distribution of domains according to quality of life questionnaire (WHOQOL-Brief) among 67 asymptomatic patients with infection by HTLV-1 treated at Instituto de Infectologia Emilio Ribas**

	Quality of life	Health	Physical domain	Psychological domain	Social relationships	Environment
Very satisfied	1 (1.5%)	4 (5.9%)	0	0	0	0
Dissatisfied	3 (4.5%)	14 (24.3%)	5 (7.4%)	7 (10.5)	6 (9.0%)	4 (6%)
Neither satisfied/ nor dissatisfied	17 (25.4%)	15 (24.3%)	11 (16.4%)	12 (18%)	14 (21%)	23 (34.5%)
Satisfied	34 (50.8%)	27 (40.2%)	39 (58.2%)	32 (48%)	38 (57%)	36 (54%)
Very satisfied	12 (18%)	6 (8.9%)	13 (19.5%)	16 (24%)	9 (13.5%)	4 (6%)

kinship ( $p = 0.001$ ), seropositivity ( $p = 0.001$ ), depression ( $p = 0.001$ ) and anxiety ( $p < 0.001$ ). In the asymptomatic group the variables were housing ( $p = 0.005$ ), coinfection ( $p = 0.029$ ), depression ( $p < 0.001$ ), and anxiety ( $p < 0.001$ ).

In the physical domain, the variables associated with the outcome among symptomatic patients were: educational level ( $p = 0.012$ ), family income ( $p = 0.050$ ), social class ( $p = 0.041$ ), duration of treatment ( $p = 0.041$ ), relationship (children) ( $p = 0.002$ ), serologic test results ( $p = 0.016$ ). Among the asymptomatic patients, the following variables were significantly correlated: educational level ( $p = 0.008$ ), family income ( $p = 0.001$ ), housing ( $p = 0.028$ ), social class ( $p < 0.001$ ), family/social support ( $p = 0.004$ ), depression ( $p < 0.001$ ), and anxiety ( $p < 0.001$ ).

In relation to the environment field, the variables that influenced the perception the groups with HAM/TSP were: education level ( $p = 0.034$ ), family income ( $p = 0.002$ ), social class ( $p = 0.018$ ), family support ( $p = 0.033$ ), depression ( $p = 0.010$ ), transmission for mother ( $p = 0.001$ ), kinship (children) ( $p < 0.001$ ), kinship (children) with positive results ( $p = 0.010$ ) in group symptomatic patients. Among the asymptomatic patients, the following variables were significantly correlated: educational level ( $p = 0.001$ ), family income ( $p = 0.004$ ), social class ( $p = 0.010$ ), family support ( $p = 0.031$ ), depression ( $p < 0.001$ ) and anxiety ( $p < 0.001$ ), and doctor appointments ( $p = 0.028$ ).

## DISCUSSION

Level of schooling expresses differences between people, also in terms of access to information, with important determinants on health. According to the report on the causes of social health inequities in Brazil (2008),<sup>21</sup> access to information as a social determinant of health is not always recognized, being a mean of obtaining goods (tangible or intellectual) and growing professionally and personally.

The level of education, family income, social class, housing and social support can be identified as the central force that determines the socioeconomic impact of disease on daily life of a person. In accordance with the report on the causes of social health inequities in Brazil (2008),<sup>21</sup> socioeconomic, cultural and environmental impacts of a given society, generate a social-economic stratification of individuals and group of people, giving them distinct social positions which, in turn, cause health differentials. In other words, the distribution of health and illness is not random, being associated with social status which, in turn, sets the conditions for life and work of individuals and groups.

Low level of education is an important factor in regard to occupation, as it leads to a higher probability of the individual developing work activities that require greater physical wear and using the body as the main work tool, with lower financial compensation. When hit by a chronic illness that prevents the individual from using the full

potential of the body, feelings of frustration, limitation, low self-esteem and dependency appear. The unfavorable perception of the physical domain and social and financial factors such as unemployment, retirement, and work absenteeism results in a poor perception of their quality of life and mood. On the asymptomatic HTLV-1 patients there were a negative perception about the quality of life and a fear of becoming carriers of HAM/TSP symptoms and being unable to exercise their profession, which explains the correlation between educational level and high level of depression and physical domain.

Another variable of great relevance in the management of patients with HAM/TSP is the family/social support regarding physical and emotional dependence that these patients lay in the disease process and for maintaining life, being a determinant factor for stroke disease and the perception of quality of life. The results indicated that the control group showed a significant correlation with the physical domain, social relationships and environment, and the latter two areas also with the group of HAM/TSP. There is a concern among asymptomatic patients whether the support of their physical domain is jeopardized by the outcome of the infection.

In this study we observed that coinfection presented itself as a significant variable within the control group when related to the degree of depression, anxiety, satisfaction with health, physical dominance and social relations. Infection with HIV or HCV make the subject vulnerable and calls into question the fantasy of being less immune to the effects of time and death; therefore, possibly suffering from diseases caused by these viruses. The illusion of self-sufficiency and immortality is intermittently confronted by a real threat (much more real than the less than 5% possibility of having HAM/TSP). This threat is inner the subject, having nowhere to escape from it and may lead to suffering from social discrimination, multiple loss (healthy body, relationship, occupation, leisure, etc.) and often the need to live a double life not be discriminated.

## CONCLUSION

Based on the results presented on this study we conclude that patients with HAM/TSP have higher levels of depression and anxiety, as well as greater impairment in quality of life than patients in the control group (asymptomatic), particularly in following areas: dissatisfaction with health, physical, environment.

The highest levels of depression and anxiety as well as the worst scores of quality of life and knowledge about the virus correlated with poor education, low family income and social class. The impact is determined by perception of the restriction and inability to perform activities that are essential for humans, as in the case of subjects of this

research with fewer financial, professional and intellectual resources, and not due to the physical disability arising from changes in HAM/TSP.

One of the ways suggested in order to reducing health inequities and quality of life is the adoption of public policies aimed at patients with HTLV that should consist of three parts: physical and mental health, socio-economic and educational care.

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