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Brief communication

Quality of life and pain multidimensional aspects in individuals with HTLV-1

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ABSTRACT

HTLV-1 creates a chronic health condition that involves moderate to severe pain with a negative impact on quality of life (QoL). There is no consensus on which attitudes to pain are more related to the worsening of QoL in HTLV-1 infected patients. The aim of this study was to investigate the correlation between QoL and multidimensional aspects of pain in patients with HTLV-1. A cross-sectional study was conducted in Salvador, Bahia, Brazil. The study included individuals diagnosed with HTLV-1. The Short Form 36 Questionnaire was used to analyze QoL, and the Brief Pain Inventory was used to assess multidimensional aspects of pain. The mean pain intensity was 4.88 ± 3.06 on the visual pain scale, and the average impact on QoL corresponded to a loss of approximately 40%. Moderate to high correlations between pain intensity and all domains of QoL were observed and compared reaction attitudes for general activity, mood, ability to walk, ability to work, relationships, sleep, and ability to enjoy life ($r > 0.40$; $p < 0.05$). Moderate correlations were found between all domains of QoL, pain intensity, and reactive attitudes to pain. The greatest pain intensity impacts involved difficulty to walk and to work, and interpersonal relationships in the emotional aspect of QoL.

The Human T-cell Lymphotropic Virus Type 1 (HTLV-1) is a retrovirus endemic in several regions of the world.[1–3] In Brazil, its prevalence is higher in Salvador city, corresponding to 1.76% of the population.[4] Only 5% of patients with HTLV-1 develop symptoms associated with such retroviruses. It frequently manifests with spasticity, gait disturbances,

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weakness and stiffness of the lower limbs, impaired dynamic balance, and pain.[5,6]

In Salvador, 84.3% of infected individuals experience pain, which is more than twice the prevalence in the general population (41.4%).[7,8] The pain in these individuals mainly affects the lower back and legs, worsens with long periods in one position and physical effort, and presents daily. The pain, lack of bladder control, and changes in gait patterns lead to limitations that have a high impact on activities of daily living (ADLs), contributing to a reduced quality of life (QoL).[9,10]

Because HTLV-1 is a neglected health condition, aspects such as the impact on the QoL of infected individuals have been poorly explored, especially using specific tools for delineation of multidimensional aspects of pain and assessment of different domains of QoL. Studies on QoL can guide education and health promotion programs focusing on self-care and the functional independence of individuals affected by HTLV-1.[11]

As the impact of different sensory and reactive characteristics of pain on QoL of infected individuals remain unclear, this study aimed to correlate the multidimensional aspects of pain and levels of QoL for individuals with HTLV-1.

A cross-sectional observational study was conducted in the Advanced Physical Therapy Clinic (CAFis) of the Bahia School of Medicine and Public Health (EBMSP) in Salvador, Bahia, Brazil. The study included men and women aged 18 and older who were diagnosed with HTLV-1 according to criteria defined by the World Health Organization, classified as defined and probable for HAM/TSP, and able to remain upright without support. Patients additional disorders such as arthritis, orthopedic impairments, and other neurological disorders, or who had difficulty understanding the questionnaires were excluded. The clinical team responsible for the Integrative Care and Research Center selected the participants.

Given the scarcity of studies in the literature that served as the basis for this study, the sample size was calculated based on a correlation coefficient of 0.5. A sample of 43 subjects was estimated with a power of 80% and an alpha of 0.05. This sample was increased by 20% due to the large biological variability in this condition.

Data were collected in a standardized manner after the participants signed an Informed Consent form. The project was approved by the Ethics Committee in Research of the Bahia School of Medicine and Public Health (registration number CAAE 13568213.8.0000.5544).

Social class was defined according to criteria of the Brazilian Association of Survey Companies (ABEP), which divides the population into six socioeconomic strata namely A, B1 (high), B2, C1 (middle), C2, D, and E (low).

The Brief Pain Inventory (BPI) was used to assess pain intensity and interference.[12] To assess pain intensity we used two of the four sensory questions of this instrument (maximum and average pain intensity in the last 24 h). To assess pain interference we used the seven items of the pain interference section of the BPI (general activity, mood, walking ability, normal work, relations, sleep, and enjoyment of life).

The Short Form 36 (SF-36) Questionnaire was used to assess quality of life according to the following domains: functional capacity, physical aspect, pain, emotional aspect, general health, social aspect, mental health, and vitality.[13]

After assuring data had normal distribution, the Spearman test was used to assess the correlation of each of the two sensory items of the BPI with the seven interference aspects of the BPI and to each domain of the SF-36. Numerical variables were expressed as mean and standard deviation. All analyses were performed using the Statistical Package for Social Sciences (SPSS) version 14.0 for Windows (Chicago, USA).

Of the 56 participants, 66.1% were female. The mean age was 52 ± 11.1 years old, and the body mass index (BMI) was $24.5 \pm 4.5\,kg/m^2$. There was a higher proportion of non-white individuals (92.9%) and individuals belonging to class C (51.8%). Of these, 42.9% used a device such as a cane or crutch for walking, and 26.8% made systematic use of muscle relaxants for pain relief. The mean disease duration was 10.7 ± 7.9 years. The mean most pronounced pain in the last 24 h was reported to be 4.88 ± 3.06 in intensity, while the mean pain score was reported to be 4.66 ± 3.75. The sites most affected by pain were the lumbar region, reported by 37 participants (66.1%); the knee, reported by 33 (58.9%); the leg, reported by 18 (32.1%); and the feet, reported by 26 (48.4%).

Table 1 shows how sensory aspects of pain impacted interference aspects. Moderate to high correlations were observed between the level of pain intensity in the last 24 h and the average pain in the last 24 h with all areas of pain interference. A correlation analysis between the most pronounced level of pain and average pain in the last 24 h with the domains of the SF-36 showed that a higher intensity of pain corresponded to worse scores in different domains of the QoL (Table 2). Table 2 shows correlations between the SF-36 domains and the BPI interference of pain items. All but the social aspects of the SF-36 domains were negatively correlated with pain interference.

This study confirmed the hypothesis that pain appears to be moderate in this population; with increased pain intensity,

Table 1 – Correlation between reaction and sensory aspects of pain, according to the Brief Pain Inventory.

Interference pain	Worst level of pain (last 24 h)	*p*	Average pain (last 24 h)	*p*
General activity	0.625	**<0.001**	0.584	**<0.001**
Humor	0.590	**<0.001**	0.527	**<0.001**
Ability to walk	0.422	**0.001**	0.548	**<0.001**
Capacity to work	0.561	**<0.001**	0.620	**<0.001**
Interpersonal relationships	0.589	**<0.001**	0.507	**<0.001**
Sleep	0.413	**0.002**	0.569	**<0.001**
Ability to appreciate life	0.478	**<0.001**	0.479	**<0.001**

Spearman correlation test, alpha 5%.

Table 2 – Correlation between domains of quality of life (SF-36) with the intensity of pain and reaction to pain attitudes front (IBD).

	Worst level of pain	*p*-Value	Average pain	*p*-Value	General activities	*p*-Value	Humor	*p*-Value	Ability to walk	*p*-Value	Work	*p*-Value	Relationship	*p*-Value	Sleep	*p*-Value	Appreciate life	*p*-Value
Functional capacity	−0.24	0.070	−0.18	0.160	−0.41	0.002	−0.37	0.004	−0.40	0.002	−0.42	0.001	−0.35	0.008	−0.54	0.083	−0.17	0.180
Physical appearance	−0.43	≤0.001	−0.57	≤0.001	−0.47	≤0.001	−0.44	0.001	−0.44	0.001	−0.46	≤0.001	−0.53	≤0.001	−0.43	0.001	−0.34	0.010
Pain	−0.59	≤0.001	−0.54	≤0.001	−0.57	≤0.001	−0.57	≤0.001	−0.67	≤0.001	−0.46	≤0.001	−0.39	0.003	−0.47	≤0.001	−0.54	≤0.001
General state	−0.37	0.004	−0.47	≤0.001	−0.46	≤0.001	−0.54	≤0.001	−0.35	0.007	−0.37	0.005	−0.46	≤0.001	−0.37	0.005	−0.38	0.004
Vitality	−0.52	≤0.001	−0.47	≤0.001	−0.52	≤0.001	−0.49	≤0.001	−0.41	0.001	−0.47	≤0.001	−0.50	≤0.001	−0.35	0.007	−0.51	≤0.001
Social aspect	−0.29	0.029	−0.23	0.080	−0.42	0.001	−0.37	0.005	−0.23	0.077	−0.39	0.003	−0.48	≤0.001	−0.37	0.004	−0.50	≤0.001
Emotional aspect	−0.42	0.001	−0.48	≤0.001	−0.51	≤0.001	−0.56	≤0.001	−0.35	0.007	−0.41	0.002	−0.64	≤0.001	−0.56	≤0.001	−0.46	≤0.001
Mental health	−0.41	0.001	−0.38	0.004	−0.52	≤0.001	−0.55	≤0.001	−0.32	0.015	−0.40	0.002	−0.52	≤0.001	−0.29	0.028	−0.49	≤0.001

Spearman correlation test, alpha 5%.

the greater the impact on quality of life the more intense are reactive attitudes toward pain.

Santos et al.[14] investigated the pain profile in 191 subjects of low socioeconomic status in the same city, using the BPI. They found that pain was of moderate intensity in 46.8%, most often in the knees (46.1%) and the lumbar spine (42.4%). These findings correspond to results of the present study. It is possible that low socioeconomic status increases the frequency of pain in the lower back and knees because of environmental conditions, labor, and transportation, regardless of the health conditions generated by HTLV-1.[4,7]

The moderate inverse correlation between mean pain intensity and the ability to work can be explained by the low socioeconomic status of our sample. This socioeconomic condition is associated with physically demanding jobs and menial work, which generally is limited by physical dysfunction associated with high intensity pain.[15] Ratifying this negative influence of pain on the performance of menial labor activities, Herrero et al.[16] demonstrated improved productivity of workers in manual labor after drug therapy for pain relief.

The impact of pain in the functional capacity of the SF-36 and the correlation between the most pronounced pain level and general activity of the BPI were moderate. Perhaps these findings are justified by characteristics of the sample, which largely consisted of people who were not wheelchair-bound or used assistive devices, and of people who needed only one crutch. In addition, we included only patients who had been diagnosed with or were probable of HAM/TSP and who were likely able to stand by themselves.

Martins et al.[10] found a high impact of the disease in functional capacity and observed lower scores in wheelchair-bound patients compared to the subgroup of those who still could walk. It is possible that those patients who are not wheelchair-bound feel able to implement most daily activities, even with compensation of movement. Furthermore, myelopathy does not affect function of the upper limbs, which enables patients to participate in many tasks. Reinforcing the idea that locomotion itself is not the main factor interfering with functional capacity in HTLV-1, Franzoi et al.[9] showed that the loss of bladder control is worse than loss of locomotion.

The physical aspect domain showed a moderately negative impact from pain. This domain assesses how daily activities and work are affected in relation to the intensity of the activity, the number of tasks, and the level of effort. This population presents reduced muscle and cardiorespiratory endurance, and thus susceptible to an increased sedentary lifestyle. The degree of fatigue increases in individuals who remain in a bent posture, such as people with HAM/TSP, and those with spinal cord injury because of muscle weakness.[17–19] Severe fatigue associated with spinal cord injury can have negative implications in QoL and activities of daily living.[9,19]

We observed a weak correlation between the level of pain and the social aspect domain. Although the assessment tools used to measure the social aspect domain have certain weaknesses, this result might be related to a sample consisting of lower social class of individuals who often have higher levels of resilience.[20]

In this study we did not assess the subgroups of patients with neuropathic pain, nociceptive pain, and both types of pain separately. As neuropathic pain is often associated with more severe impact in QoL, it is possible that our results cannot be extended to all patients with HTLV-1. We also did not identify patients with urinary and sexual dysfunction, which are also leading causes of decreased QoL in this population. Future studies should address these points in longitudinal studies to collect more consistent data about the impact of those aspects in the QoL of people infected by HTLV-1.

The SF-36 and BPI, although generic assessment tools, were shown to be adequate in evaluating the issues faced by patients with HTLV-1. The quality of life and reactive attitudes to pain were inversely correlated. The greatest impacts of pain intensity involved difficulties with walking and working. In addition, difficulties in interpersonal relationships undermined the emotional aspect of quality of life.

Conflicts of interest

The authors declare no conflicts of interest.

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