Original Article

Impact of pandemic social restriction measures of COVID-19 on the social participation of people with HTLV-1: a transversal study

Impacto das medidas de restrição social da pandemia da COVID-19 na participação social de pessoas com HTLV-1: estudo transversal

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ABSTRACT | INTRODUCTION: Human T-cell Lymphotropic Virus type 1 (HTLV-1) is classified as a retrovirus and may be directly associated with neurological diseases. As it is a disease neglected by health and governmental authorities in a world panorama, there is still a lack of scientific evidence that investigates the impact of HTLV-1 in the scope of the social participation of this population. **OBJECTIVE:** To analyze the impact of the COVID-19 pandemic on the social participation of individuals with HTLV-1. **MATERIAL AND METHODS:** This is a transversal observational study carried out with individuals with HTLV-1, linked to the HTLVida Association. The data collection was carried out through interviews in a videoconference. The first interview aimed to explore the clinical and sociodemographic characteristics of the participants. In contrast, the second one investigated the social participation of individuals comparing two periods (before and during the COVID-19 pandemic) through the application of the Community Integration Questionnaire (CIQ). **RESULTS:** Eleven individuals were interviewed, predominantly female (72.7%), with a median age of 57 (52-66). About the results regarding social participation evaluated by the CIQ, was observed maintenance of the score in the domain of Integration in the home environment, a difference of 3.00 points in the domain of Integration in the social environment, a difference of 2.00 points in the domain of Integration in the work and school environment, and a difference of 6.00 points in the total CIQ score. **CONCLUSION:** A decrease in the social participation of individuals with HTLV-1 during the COVID-19 pandemic was compared to the period before the start of the pandemic.

KEYWORDS: COVID-19. Social participation. Human T-lymphotropic virus 1.

RESUMO | INTRODUÇÃO: O vírus linfotrópico de células T humana tipo 1 (HTLV-1) é classificado como retrovírus e pode estar diretamente associado às doenças neurológicas. Por ser uma doença negligenciada pelas autoridades sanitárias e governamentais num panorama mundial, ainda existe uma carência de evidências científicas que investigam o impacto do HTLV-1 no âmbito da participação social dessa população. **OBJETIVO:** Analisar o impacto da pandemia da COVID-19 na participação social de indivíduos com HTLV-1. **MATERIAL E MÉTODOS:** Trata-se de um estudo observacional do tipo transversal realizado com indivíduos com HTLV-1 vinculados à Associação HTLVida. A coleta de dados foi realizada através de entrevistas via videoconferência; a primeira entrevista teve como objetivo explorar as características clínicas e sociodemográficas dos participantes, já a segunda investigou a participação social dos indivíduos comparando dois períodos (antes e durante a pandemia de COVID-19), através da aplicação do Questionário de Integração na Comunidade (QIC). **RESULTADOS:** Foram entrevistados 11 indivíduos, com predominância do sexo feminino (72,7%), com mediana de idade de 57 (52-66) anos. No que tange os resultados referentes à participação social avaliada pelo QIC, observou-se a manutenção do escore do domínio de integração no ambiente doméstico, uma diferença de 3.00 pontos no domínio de integração no ambiente social, uma diferença de 2.00 pontos no domínio de integração no ambiente do trabalho e escola, além de uma diferença de 6.00 pontos no escore total do QIC. **CONCLUSÃO:** Identificou-se uma diminuição da participação social de indivíduos com HTLV-1 durante a pandemia da COVID-19, quando comparado ao período prévio de início da pandemia.

PALAVRAS-CHAVE: COVID-19. Participação social. Vírus T-linfotrópico humano 1.

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Introdução

Human T-cell lymphotropic virus type 1 (HTLV-1) is classified as a retrovirus and may be directly associated with neurological diseases such as tropical spastic paraparesis/HTLV-1 associated myelopathy (HAM/TSP), chronic neuroinflammatory disease of the central nervous system, characterized by progressive spinal demyelination.[1,2] It is estimated that there are 15 to 20 million people infected by the virus globally, Brazil being one of the largest endemic areas for HTLV-1, with the city of Salvador having the highest global prevalence rate 1.8%.[2,3]

Most of those infected by HTLV-1 remain asymptomatic throughout their lives; however, approximately 4% develop HAM/TSP, and as a consequence, develop motor, sensory and autonomic disorders.[4] Symptoms are evidenced by changes in gait, balance deficit, loss of strength in the lower limbs, and urinary incontinence.[4,5] In addition, due to the evolution of the disease, these individuals show a progressive decrease in mobility, which can impact the level of social participation.

Social participation refers to the involvement of human beings in real-life situations in society, in an interactive way with other individuals, through situations that go from the home to the community environment.[6,7] In this sense, individuals with reduced mobility, such as the population with symptomatic HTLV-1, may face important challenges to be included in this process. Scientific findings show that 47.6% of symptomatic individuals have restrictions in social participation compared to asymptomatic individuals.[8]

Discussions about social participation have been taking place since the 1960s, from the gradual change in society's paradigm towards people with disabilities, which started to consider disability as a socially created structural problem and not something that belongs to the individual.[8] Currently, the investigation of social participation is essential within the rehabilitation process. However, it can be accomplished by any individual, with or without illnesses, based on aspects related to mobility, personal care, communication, domestic life situations, interpersonal interactions, education, work, and community life.[9,10]

It is known that HTLV-1 is still a neglected disease by health and governmental authorities in a world panorama. Given this, there is a lack of scientific evidence exploring disease consequences within the scope of the social participation of this population. Therefore, the investigation of this marker becomes essential so that the authorities are aware of the reality faced by this population, and based on this, develop public and health policies. Therefore, this study aimed to analyze the impact of the COVID-19 pandemic on the social participation of individuals with HTLV-1.

Methods and materials

This is a cross-sectional observational study conducted with individuals with HTLV-1, linked to the HTLVida Association. The present study is part of a mother project entitled "Effect of teleservice with the Pilates method on the functional performance of people with HTLV-1 in the period of social isolation by the COVID-19 pandemic: Pilot study".

The project mentioned above had a general objective to verify the effect of teleservice with the Pilates method on the functional performance of people with HTLV-1 in the period of social isolation due to the worldwide health emergency COVID-19 pandemic. The specific objective was to investigate the impact of social distancing because of the COVID-19 pandemic on motor aspects of individuals with HTLV-1. The outcome was the social participation of individuals with HTLV-1 as a factor of exposure to the COVID-19 pandemic. Individuals linked to the HTLVida Association, diagnosed through a medical report with HTLV-1, older than 18 years, of both sexes, who participated in the mother project mentioned above were included in the study. Individuals who could not understand the assessment instruments were excluded from the study.

The HTLVida association, in which the study participants are linked, is configured as a non-governmental organization located in Salvador, responsible for providing voluntary assistance to individuals with HTLV, family members, and the community. The association also contributes to health promotion and the establishment of efficient public

health policies and care for HTLV I and II patients in the state of Bahia.

The sample size was determined by convenience, in which all participants of the project "Effect of teleservice with the Pilates method on the functional performance of people with HTLV-1 in the period of social isolation by the pandemic of COVID-19: Pilot Study" were invited to participate via text message, e-mail, and WhatsApp, with acceptance of all individuals.

Due to the social distancing measures, data collection was performed through videoconference interviews through the WhatsApp platform. This process was conducted by two physical therapists at different times, with satisfactory performance of patients in handling the platform due to their previous experiences. The first interview aimed to explore the clinical and sociodemographic characteristics of the participants, to investigate possible potential confounders and effect modifiers, and factors such as age; HTLV-1 diagnosis time; sex; diagnosis associated or not with HAM/TSP; use of auxiliary gait device; occurrence of falls and the location of the fall.

The second interview was directed to investigate the level of social participation of individuals, comparing two periods (before and during the COVID-19 pandemic) through the application of the Community Integration Questionnaire (CIQ). The researcher started the interview by applying the questionnaire based on the experiences before the pandemic. Soon after, an interval of one minute occurred. Then the CIQ was applied again, this time asking the participant to respond to the items taking into account their experiences at the time of the interview.

The CIQ is an adapted cross-cultural instrument for Brazil, intending to evaluate the integration of the individual into the community, considering the following domains: home environment, social integration, and productive activity in individuals who have suffered a traumatic brain injury (TBI).[11] However, it is also used in studies that investigate the social participation of other specific populations.[12-14]

The instrument consists of 15 questions, and its total score ranges from 0 to 29, being a higher score synonymous with greater integration/social participation.[11]

The study was approved by the research ethics committee, according to Resolution 510/16 of the National Health Council (NHC). All study participants signed the free and informed consent form, and the confidentiality of the data was maintained, which were stored and will be stored in the study database under the responsibility of the researchers, for five years and after this period will be all documents excluded (CAAE: 32489520.6.0000.5028).

The data were analyzed using SPSS version 21.0 for Windows. Data presentation occurred in the form of absolute frequency and/or relative frequency for categorical variables (gender, presence of HAM/TSP, use of auxiliary gait device, occurrence of falls and place of falls), and measures of central tendency and dispersion for continuous variables (age and time of diagnosis). Initially, the data were tested for normal distribution using the Shapiro-Wilk test, where they did not present normal distribution. Then, in the statistical inference, the Wilcoxon test was used to compare the paired variables. The statistical significance adopted was $p<0.05$.

Results

Initially, 11 participants were recruited, and after applying the inclusion criteria, the 11 participants were analyzed. Of the subjects investigated, 8 (72.7%) were female, 10 (90.5%) had PET/MAH, 7 (63.6%) used a walking device, and 7 (63.6%) reported no occurrence of falls (Table 1).

Table 1. Demographic data of participants with HTLV-1, assisted at the HTLVida Association, November 2020

Variables	n (%)	Median
Age in years (median and quartiles)		57 (52-66)
Time of diagnosis in years (median and quartiles)		11 (9-19)
Sex		
Female n (%)	8 (72,7)	
Presence of PET/MAH	10 (90,5)	
Use of a reversing device	7 (63,6)	
Occurrence of falls		
No	7 (63,6)	
One	4 (27,3)	
Two or more	0 (0,00)	
Local of remains		
House	3 (27,3)	
Street	1 (9,1)	

PET/MAH: Tropical spastic paraparesis/ HTLV-1-associated myelopathy

Regarding the result related to the social participation of these individuals, investigated from the CIQ, it was possible to notice a decrease in the scores in the following domains: integration in the social environment 5.00 (4.00 - 6.00), in the integration into the work and school environment were 0.00 (0.00 - 2.00), in addition to the total score of the CIC, when we compared the period before and during the pandemic, as shown in Table 2.

Table 2. Values referring to the Community Integration Questionnaire (QIC) scores, applied to patients with HTLV-1, in November 2020

Items	*PrePandemic Score*	*Pandemic Score*	*p-value*
Integration into the home environment			
Q50	1.00 (1.00 – 1.00)	0.00 (0.00 – 1.00)	0.020
Q51	1.00 (0.00 – 2.00)	1.00 (0.00 – 2.00)	0.317
Q52	1.00 (0.00 – 2.00)	1.00 (0.00 – 2.00)	0.655
Q53	0.00 (0.00 – 0.00)	1.00 (1.00 – 1.00)	0.157
Q54	1.00 (1.00 – 1.00)	1.00 (0.00 – 1.00)	0.739
Subtotal domain Integration in the home environment	4.00 (3.00 – 5.00)	4.00 (1.00 – 5.00)	0.102
Integration into the social environment			
Q55	1.00 (0.00 – 2.00)	1.00 (1.00 – 2.00)	1.000
Q56	1.00 (1.00 – 1.00)	0.00 (0.00 – 1.00)	**0.008**
Q57	1.00 (1.00 – 2.00)	0.00 (0.00 – 0.00)	**0.004**
Q58	1.00 (1.00 – 2.00)	0.00 (0.00 – 1.00)	**0.007**
Q59	1.00 (1.00 – 2.00)	1.00 (0.00 – 1.00)	**0.034**
Q60	2.00 (2.00 – 2.00)	2.00 (2.00 – 2.00)	1.000
Subtotal domain Integration in the social environment	8.00 (7.00 – 9.00)	5.00 (4.00 – 6.00)	**0.003**
Integration into the work and school environment			
Q61-Q63	2.00 (1.00 – 2.00)	0.00 (0.00 – 2.00)	**0,024**
TOTAL:	14.00(12.00-15.00)	8.00 (7.00 – 12.00)	**0.003**

*(n- absolute frequency) and (%) relative frequency. The significance level for this study is p<0.05 - 5% - Wilcoxon test. Q50- Who usually buys food and other basic necessities in your home?; Q51-Who usually prepares (kitchen) or heats or serves food in your home?; Q52 Who usually does daily housework in your home?; Q53-Who is generally responsible for (taking care) of children in your home?; Q54-Who usually has initiative or organizes social activities such as meetings with family and friends?; Q55-Who usually takes care of money issues like bank accounts or payment of bills?; Q56-Approximately, how many times a month do you leave home to shop?; Q57-Approximately, how many times a month do you participate in activities to have fun outside the home?; Q58-Approximately, how many times a month do you visit your friends or relatives?; Q59-When you participate in activities for fun you usually do it alone or with other people?; Q60-Do you have a great friend you can trust?; Q61-How often do you travel?; Q62-Please choose the best answer that matches your current work situation?; Q63-In the last month, how often have you participated in voluntary activities?

According to the CIQ, the domestic environment showed no difference before and during the pandemic. Most patients performed cooking, cleaning, and caring for children with or without the help of partners/family members compared to social/external activities. Concerning the social environment, there was a more significant impact during the pandemic on shopping activities, markets, leisure activities, and family/friends' meetings outside the home when compared before the pandemic. It is noteworthy that basic, domestic or social life activities become difficult at the evolution of PET/MAH, that is, at the level of functionality.

Discussion

The present study aimed to analyze the impact of the COVID-19 pandemic on the social participation of a group of 11 individuals, aged over 50 years and a diagnosis time of HTLV-1 greater than 10 years, being mostly females diagnosed with PET/MAH associated with HTLV-1, in addition, most participants used auxiliary gait device and did not report episodes of falls in the last 3 months.

It was observed the maintenance of the score referring to the integration into the domestic environment before and during the COVID-19 pandemic. In this sense, since the activities investigated were performed by individuals with HTLV-1 in partnership with someone else living together, social isolation measures allowed a longer stay of most people at home, not changing the dynamics of tasks in the homes of people with HTLV-1.

The individuals in the study showed a decrease in the integration into the social environment assessed by the CIQ and a significant decrease in the social participation of the general population due to severe measures of social isolation, with this phenomenon directly related to low levels of satisfaction with life.[15] Considering that some individuals with HTLV-1 had a history of depression and low quality of life before the pandemic, the impact of this period and its repercussions may be greater and more severe for this population.[16]

There is a gap in the literature regarding the social participation of people with HTLV-1 in the scope of work and study. However, it is known that people with multiple sclerosis (MS), a chronic degenerative neurological disease that resembles symptomatic cases of HTLV-1, face great challenges to be inserted in the labor market.[17] The presence of pain, depression, difficulty walking, and reduced mobility are directly associated with unemployment in patients with MS. That way, people with HTLV-1, also affected by these symptoms, may face similar difficulties, especially during the pandemic, where there was a reduction in social participation in the scope of work and study in the population interviewed in this study.[17-20]

Since in patients with HTLV, in the perspective of accessibility, structural changes in society can help in the comfort of patients by clinical and functional condition, besides impacting self-image, psychological and everyday life.[21] I emphasize that physical limitations intervene in freedom, privacy, and leisure. Moreover, there is injury and additional cost, so that the carriers become dependent on third parties to carry out their activities before society.

The present study observed a decrease in the social participation of individuals with HTLV-1 during the COVID-19 pandemic. However, it is known that before this period, individuals with HTLV-1 already had restrictions on social participation, mainly when HTLV-1 was associated with PET/HAM, as is the case of 90.5% of the interviewees in this study. Therefore, there is a possibility that this specific population has been more impacted by social isolation measures than the healthy population, thus requiring special attention from health and government authorities.

This study provides important information related to the social participation of individuals with HTLV-1, a theme still little explored in the scientific literature, enabling a greater understanding of health professionals and managers about the barriers faced by this population and thus making more assertive the development of public health actions and policies, capable of fostering and increasing the social participation of these individuals.

It is worth mentioning the presence of a memory bias in this study, characterizing a limitation, taking into account that the participants, when answering the CIQ, based on their previous experiences of the pandemic, reported at the time of the interview information experienced in the past, so although the questionnaire response alternatives are direct and cohesive, there is the possibility that this information is not precisely reliable at that time.

Conclusion

This study demonstrated a decrease in the social participation of individuals with HTLV-1 during the COVID-19 pandemic compared to the previous period of onset of the pandemic.

Authors' contributions

Nascimento HS participated in the conception and design of the study, interpretation of the results, and writing of the scientific article. Nélo VJS participated in the conception and design of the study, data collection, and writing of the scientific article. Fonseca EP participated in the conception and design of the study, guidance, and critical review of the manuscript. Finally, Matos IG participated in the conception and design of the study, data collection, guidance, and critical review of the manuscript.

Competing interests

No financial, legal, or political conflict involving third parties (government, companies and private foundations, etc.) has been declared for any aspect of the work submitted (including, but not limited to grants and financing, participation in the advisory board, study design, manuscript preparation, statistical analysis, etc.).

References

1. Ribas JGR, Melo GCN. Human T-cell lymphotropic virus type 1 (HTLV-1) -associated myelopathy. Rev Soc Bras Med Trop. 2002;35(4):377-84. https://doi.org/10.1590/S0037-86822002000400015

2. Araujo AQ, Silva MT. The HTLV-1 neurological complex. Lancet Neurol. 2006;5(12):1068–76. https://doi.org/10.1016/s1474-4422(06)70628-7

3. Dourado I, Alcantara LCJ, Barreto ML, Teixeira MG, Galvão-Castro B. HTLV- I in the General Population of Salvador, Brazil. J. Acquir Immune Defic Syndr [Internet]. 2003;34(5):527-31. Disponível em: https://www.arca.fiocruz.br/handle/icict/8136

4. Franzoi AC, Araújo AQC. Disability and determinants of gait performance in tropical spastic paraparesis/HTLV-I associated myelopathy (HAM/TSP). Spinal Cord. 2007;45(1):64-8. https://doi.org/10.1038/sj.sc.3101919

5. Franzoi A, Araújo A. Disability profile of patients with HTLV-I associated myelopathy/tropical spastic paraparesis using the Funcional Independence Measure (FIM). Spinal Cord. 2005;43(4):236-40. https://doi.org/10.1038/sj.sc.3101677

6. Farias N, Buchalla CM. The International Classification of Functioning, Disability and Health: Concepts, Uses and Perspectives. Rev Bras Epidemiol. 2005;8(2):187-93. https://doi.org/10.1590/S1415-790X2005000200011

7. Hammel J, Magasi S, Heinemann A, Whiteneck G, Bogner J, Rodriguez E. What does participation mean? Na insider perspective from people with disabilities. Disabil Rehabil. 2008;30(19):1445-60. https://doi.org/10.1080/09638280701625534

8. Aben-Athar CYUP, Pinto DS, Lima SS, Vallinoto IMVC, Ishak R, Vallinoto ACR. Limitations in daily activities, risk awareness, social participation, and pain in patients with HTLV-1 using the SALSA and participation scales. Braz J Infect Dis. 2020; 24(6):497-504. https://doi.org/10.1016/j.bjid.2020.08.009

9. Fougeyrollas P. Social participation: contextualizing - From institutional exclusion to social participation. International Encyclopedia of Rehabilitation. Buffalo, NY: Center for International Rehabilitation Research Information and Exchange (CIRRIE); 2010.

10. Piškur B, Daniëls R, Jongmans MJ, Ketelaar M, Smeets RJ, Norton M, et al. Participation and social participation: are they distinct concepts? Clin Rehabil. 2013;28(3):211–20. https://doi.org/10.1177/0269215513499029

11. Fraga-Maia HMS, Werneck G, Dourado I, Fernandes RCP, Brito LL. Translation, adaptation and validation of "Community Integration Questionnaire". Ciênc. saúde coletiva. 2015;20(5):1341-52. https://doi.org/10.1590/1413-81232015205.08312014

12. Negahban H, Fattahizadeh P, Ghasemzadeh R, Salehi R, Majdinasab N, Mazaheri M. The Persian version of Community Integration Questionnaire in persons with multiple sclerosis: translation, reliability, validity, and fator analysis. Disabil Rehabil. 2013;35(17):1453-9. https://doi.org/10.3109/09638288.2012.741653

13. Hirsh AT, Braden AL, Craggs JG, Jensen MP. Psychometric properties of the community integration questionnaire in a heterogeneous sample of adults with physical disability. Arch Phys Med Rehabil. 2011;92(10):1602-10. https://doi.org/10.1016/j.apmr.2011.05.004

14. Gerrard P, Kazis LE, Ryan CM, Shie VL, Holavanahalli R, Lee A, et al. Validation of the Community Integration Questionnaire in the adult burn injury population. Qual Life Res. 2015;24(11):2651-5. https://doi.org/10.1007/s11136-015-0997-4

15. Ammar A, Chtourou H, Boukhris O, Trabelsi K, Masmoudi L, Brach M, et al. COVID-19 home confinement negatively impacts social participation and life satisfaction: A worldwide multicenter study. Int J Environ Res Public Health. 2020;17(17):6237. https://doi.org/10.3390/ijerph17176237

16. Castro AVG, Boa-Sorte N, Kruschewsky RA, Grassi MFR, Galvão-Castro B. Impact of depression on quality of life in people living with human T cell lymphotropic virus type 1 (HTLV-1) in Salvador, Brazil. Qual Life Res [Internet]. 2011;21(9):1545-50. Disponível em: https://www.arca.fiocruz.br/handle/icict/8084

17. Raggi A, Covelli V, Schiavolin S, Scaratti C, Leonardi M, Willems M. Work-related problems in multiple sclerosis: a literature review on its associates and determinants. Disabil Rehabil. 2015;38(10):936-44. https://doi.org/10.3109/09638288.2015.1070295

18. Messmer Uccelli M, Specchia C, Battaglia MA, Miller DM. Factors that influence the employment status of people with multiple sclerosis: a multi-national study. J Neurol. 2009;256(12):1989-96. https://doi.org/10.1007/s00415-009-5225-0

19. Honan CA, Brown RF, Hine DW, Vowels L, Wollin JA, Simmons RD, et al. The multiple sclerosis work difficulties questionnaire. Mult Scler. 2012;18(6):871–80. https://doi.org/10.1177/1352458511431724

20. Patten SB, Williams JV, Lavorato DH, Metz LM. Depression as a predictor of occupational transition in a multiple sclerosis cohort. Funct Neurol. 2013;28(4):275–80. Cited: PMID: 24598395

21. Santos ACC, Soares DJ, Rivemales MCC. (Un)Familiarity, illness and limitations imposed by HTLV: experiences of HIV positive women. Cad. Saúde Colet. 2017;25(1):45-50. https://doi.org/10.1590/1414-462X201700010186