

Impact of accessibility on adherence to physiotherapeutic treatment of people living with tropical spastic paraparesis: qualitative study

Impacto da acessibilidade na adesão ao tratamento fisioterapêutico de pessoas convivendo com paraparesia espástica tropical: estudo qualitativo

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ABSTRACT | INTRODUCTION: Tropical Spastic Paraparesis / Myelopathy Associated with HTLV-1 (HAM / TSP) presents chronic degenerative changes that compromise individuals in their daily activities, especially those related to locomotion. Accessibility is an important means of adhering to physical therapy for all these people. **OBJECTIVE:** To investigate the impact of accessibility on adherence to physical therapy treatment in people infected with HTLV-1 with HAM / TSP. **METHOD:** a study with a qualitative approach, with 38 participants, over 18 years old, with a confirmed diagnosis of HAM / TSP. Those with difficulty understanding the questionnaires or communicating were excluded. For the collection of information, 11 focus groups and 12 semi-structured changes were performed. The researcher herself recorded and then transcribed the statements. The analysis of thematic-Categorical content systematized the information. **RESULTS:** After analyzing the focus groups and related, the following categories emerged: access difficulty, external dependence (climatic/accompanying), financial dependence, and dependence on medical appointments. **CONCLUSION:** The precariousness of infrastructure and accessibility in the city of Salvador, in addition to the economic condition, climate change, and difficulties in accessing the Unified Health System, directly impact adherence to physical therapy treatment. Failure to attend physical therapy can affect the evolution of treatment and the health of this population.

KEYWORDS: Accessibility. Treatment adherence. HAM/TSP. Physiotherapy. Qualitative Research.

RESUMO | INTRODUÇÃO: A Paraparesia Espástica Tropical / Mielopatia Associada ao HTLV-1 (HAM/TSP) apresenta alterações crônico-degenerativas que comprometem os indivíduos nas atividades diárias, principalmente aquelas ligadas à locomoção. A acessibilidade é um parâmetro importante para a adesão à fisioterapia nestas pessoas. **OBJETIVO:** investigar o impacto da acessibilidade na adesão ao tratamento fisioterapêutico em pessoas infectadas pelo HTLV-1, com HAM/TSP. **MÉTODO:** estudo com abordagem qualitativa, com 38 participantes, maiores de 18 anos, com diagnóstico confirmado de HAM/TSP. Excluídos aqueles com dificuldade de compreensão dos questionamentos ou de comunicação. Para a coleta das informações, foram realizados 11 grupos focais e 12 entrevistas semiestruturadas. Os depoimentos foram gravados e depois transcritos. As informações foram sistematizadas pela análise do conteúdo temática-Categorial. **RESULTADOS:** Após as análises dos grupos focais e entrevistas, emergiram as seguintes categorias: dificuldade de acesso, dependência externa (climática/de acompanhante), dependência financeira e dependência de consultas médicas. **CONCLUSÃO:** A precariedade da infraestrutura e acessibilidade na cidade de Salvador, além da condição econômica, mudanças climáticas e dificuldades ao acesso do Sistema Único de Saúde, impactam diretamente na adesão ao tratamento fisioterapêutico. O não comparecimento à fisioterapia pode afetar a evolução do tratamento e a saúde dessa população.

PALAVRAS-CHAVE: Acessibilidade. Adesão ao tratamento. HAM/TSP. Fisioterapia. Pesquisa qualitativa.

Introduction

Tropical Spastic Paraparesis / HTLV-1 Associated Myelopathy (HAM/TSP) is 5% of people infected with Human T-Cell Lymphotropic Virus (HTLV-1). The virus is present in several regions of Brazil, and Salvador, Bahia, is the city with the highest prevalence. It is estimated that approximately 2.5 million people have been infected in Brazil. Worldwide, high endemicity was verified, especially in the Caribbean basin, southwestern Japan, and sub-Saharan Africa. The disease is acquired through horizontal transmission, blood transfusion, sexual contact, common use of contaminated syringes, or vertical transmission, mainly through breastfeeding.

HTLV-1 infection is at risk of generating a motor deficit in this population, causing gradual difficulties in walking and locomotion, thus interfering with accessibility.^{1,2}

Accessibility covers the possibility and condition of reach, perception, and understanding for the safe and autonomous use of buildings, space, furniture, urban equipment, and elements (ABNT 9050 standard).³ Although that should be everyone's right, free access to the physical environment and free movement, although recognized by the Federal Constitution, is very far from the reality experienced by individuals affected by HAM/TSP, especially those who need physical therapy treatment.

Adherence to physical therapy treatment is especially linked to the patient's interaction with the physical therapist, expressed through attention, approach, affection, and receptivity.⁴ A person with HAM/TSP presents muscle weakness, joint restriction of the lower limbs, and pelvic girdle, in addition to compromised dynamic balance and gait disturbance.⁵ There is a limitation in social ambulation and the need for progressive mobility aid: walking sticks, walkers, and the wheelchair represent the final stage of evolution.¹ The rehabilitation process in this population is related to extrinsic aspects that go beyond the motivation or will of the infected individual⁴, as it involves situations of displacement such as irregularities in sidewalks, difficulty in means of transportation, among other difficulties in urban environments.⁶

Accessibility provides equivalent opportunities for accessing activities or services among individuals or social groups, including healthcare.⁷ Access to health services can be understood in three dimensions: 1) geographic - physical barriers, such as the long-distance between home and the place of treatment; 2) organizational - deficit in reception and difficulty in scheduling appointments, in addition to the dimension 3) economic - loss of days at work, sick leave, high cost of therapeutic resources and extra cost of travel due to reduced mobility.^{8,9}

Knowing the subjective aspects concerning accessibility to physical therapy treatment for this population can contribute to the greater participation of these individuals in the rehabilitation process. Therefore, given the above, this qualitative study investigated the impact of accessibility on adherence to physical therapy treatment in people infected by HTLV-1 with HAM/TSP.

Method

This is a secondary descriptive study that used information from qualitative approach research that was part of a larger project, a randomized clinical trial (RCT)⁸ in which an exercise booklet was used for patients with HAM/TSP, to evaluate the effect of the exercise program in these patients in the parameters: pain, posture, gait, and quality of life. Regarding qualitative research, we sought to know the signs, meanings, and practices of this population, based on medical anthropology, through the theory of signs, meanings, and practices⁹ which were evidenced through the narratives that emerged from the semi-structured individual interviews and focused groups (FG), with individuals from the Neuroscience Center of the Bahia School of Medicine and Public Health and the information was collected at the Physiotherapy Clinic of the Bahia School of Medicine and Public Health, located in Salvador, Bahia.

Inclusion criteria were: confirmed diagnosis of HTLV-1 infection by ELISA and Western Blot and clinical tests for HAM/TSP performed by a neurologist, according to the criteria of the World Health Organization (WHO), who participated in the ECR described above,

over 18 years of age, excluding those with difficulty in understanding the questions or in communication. Fifty-six patients participated in the RCT, and all were invited to the qualitative study; however, 18 reported not being able to participate due to financial problems (8), living in another city (3) or living far away (5), working (1) and for not having a companion (1). The qualitative research sample consisted of 38 participants. Eleven FG were carried out, six pre-training (before using the exercise booklet) and five post-training (after using the exercise booklet), and twelve semi-structured face-to-face interviews, in the period from August 2014 to October 2015.

The collection of information was conducted by a properly trained researcher, who was introduced to the participants before the start of data collection for the clinical trial, in a previous meeting when the stages and objectives of the quantitative and qualitative research were presented; physiotherapist, Master in Human Development and Social Responsibility, a teacher for 25 years and with 32 years of clinical practice, accompanied by two undergraduate students in physiotherapy, trained by the researcher to participate in the FG, having one being an observer, responsible for taking notes of observed aspects. The other is a reporter, responsible for the phonographic records. Thus, the participants were invited to participate in the FG, which telephone contact by the researcher confirmed.

Each FG took place in a private and air-conditioned environment at the School of Physiotherapy Clinic of the Escola Bahiana de Medicina. After clarifying the study's objectives, the participants signed the free and informed consent terms (FICT). Participants were offered a snack (juice and cookies). The duration of FG was, on average, 1 hour. The atmosphere of the environment and the dialogues took place in a respectful and friendly way. Everyone answered all the questions. Six FG (pre-training of the booklet) were held with 23 participants and five FG (post-training with the booklet) with 15 people.

This technique makes it possible to exchange ideas, experiences, feelings, beliefs, behaviors, and points of view, promoting reflection.¹⁰ The guiding questions for the pre-FG were: 1) How did you discover the

diagnosis of the disease? 2) What was the feeling when you found out about the diagnosis? 3) What do you expect from participating in this project? 4) What are the reasons that could prevent your participation in this project? And the guiding questions for the post-FG were: 3) How was your participation in this project? Did you manage to comply with the protocol? 4) Can you do the exercises alone, or did you need the help of the physiotherapist? What did you prefer?

The semi-structured interview was also used as a technique for collecting information, consisting of making a script with basic questions or topics of a central problem, complemented by other relevant situations of the participants.¹¹ The semi-structured script consisted of the following questions: 5) How is your daily life in terms of activities? 6) How do you do your exercises in your routine? Twelve interviews, with an average duration of 35 minutes, were carried out by the main researcher at the physiotherapy school clinic of the Bahia School of Medicine and Public Health. The interviews were interrupted when the main researcher and another researcher observed the saturation of information, who also participated in the analyses.

The testimonies were recorded and later transcribed by the main researcher. After transcription, the information was systematized by the Thematic-Categorical Content analysis¹², manually, by two researchers separately, and after consensus, the study categories and subcategories were generated. Finally, meetings and seminars were held with the participants to make corrections, learn about the results and give feedback on the surveys, which were moments of much exchange of ideas, empathy, and affection.

In order to preserve the identity of the participants in the research results, the interviews were represented by codes "E," focus groups by codes "G," and each participant was represented by the letter "P." The project was approved by the Research Ethics Committee of the Bahia School of Medicine and Public Health, under CAAE 13568213.8.0000.5544, following the recommendations of resolutions 466/12 510/16 of the National Health Council (CNS).

Results

The study included 38 individuals whose sociodemographic characteristics were: mean age of 54.2 (± 10.28) years, 57.89% female, 42.10% married, 36.84% with complete primary education level, 57.89% of African descent, and 55.26% socioeconomic class C. Regarding the clinical characteristics of the study participants, the mean duration of illness was 11.45 (± 8.31) years and the mean BMI was 24.67 (± 3.21) Kg/m². Furthermore, according to the total sample, 20 (52.64%) do not undergo physical therapy regularly, and 16 (42.10%) use a crutch to aid walking.

The categories below identify the main limitations imposed on the accessibility of individuals with HAM/TSP. From the analysis of the focus groups and interviews, the following categories and sub-categories emerged: A) Difficulty of access: (1) Transport, (2) Driver behavior, (3) Architectural barriers: (Step height and sidewalk maintenance); B) External Dependence (Weather and/or companion): (1) Weather, (2) Companion, (3) Fear of falling; C) Financial dependence (1) Financial difficulty; and D) Dependence on medical appointments: (1) appointments scheduled at the same time as physical therapy – Table 1.

Table 1. Categories and subcategories of the narratives of people with HAM/TSP, from the Neuroscience Center of the Bahiana School of Medicine and Public Health, information collected at the Physical Therapy Clinic of Bahiana, located at Bahiana Health in Salvador, Bahia. 2014/2015 (to be continued)

Categories and subcategories of / number of participants	Participant speech
Category: Access Difficulty	
1) Transport (8)	"The difficulty of buses is terrible, they don't respect, the passengers themselves don't respect their seat." (G1P2) "Those buses are all high, just yesterday when I went to the station I had to ask the guy to suspend my leg to get hold of the railings on the door to go up". (G7P5)
2) Conductor behavior (2)	"Drivers don't have the patience for us to close our umbrellas, to hold a cane and everything". (G1P5)
3) Architectural Barriers (6) 3.1) Step Height (4) 3.2) Sidewalk Maintenance (2)	"Height of the step, then I'm afraid of falling". (G4P19); "Where I live it's horrible, to go to the bus stop, walk and go down and there's a huge staircase, go down this whole staircase and still walk, it's horrible where I live". (GP1) "Because the sidewalks are all broken, we can slip." (G1P5); "Then I fell in my sandals. The second time I walked there was a gap and I didn't see it, then I fell. I have difficulty, I prefer to walk on the asphalt than on the sidewalk". (EP28) "For me to go down and go to the street and to come back I have to go up and down stairs". (EP6)
Category: External Dependence (Climate and companion)	
1) Weather (5)	"Let's put it this way, if it's raining today and I can't come to Bahiana". (G2P10) "The weather, if it's uneasy, I have to cross by ferry or speedboat, I'll have to call to let you know that I can't come." (G5P24)
2) Companion (5)	"If I was going to come alone, I wouldn't come, it's really discouraging, just because of the distance we walk". (G1P1) "I also have car problems, because I depend on whoever comes to bring me." (G4P21)
3) Fear of falling (6)	"I don't walk on the street because I'm also afraid of falling". (EP37). "I had to leave work because I couldn't take it anymore because of the falls, I took a lot of falls" (G1P3).
Category: Financial Dependence (3)	
1) Financial difficulty (3)	"I've improved a lot, because there are also financial conditions that get in the way." (G3P12) "I also paid 120 reais for the car, for me it's complicated". (G4P14)

Table 1. Categories and subcategories of the narratives of people with HAM/TSP, from the Neuroscience Center of the Bahiana School of Medicine and Public Health, information collected at the Physical Therapy Clinic of Bahiana, located at Bahiana Health in Salvador, Bahia. 2014/2015 (conclusion)

Category: Dependence on Medical Appointments	
1) Appointments scheduled at the same time as physical therapy (5)	"No, it prevents, only if you have a doctor's appointment". (G5P23) "In my case also, because I have a lot of appointments, only if one day coincides with an appointment on the same day as the physiotherapy". (G5P24)

Source: Doctorate Databases Genildes Santana. Dec /2020.⁸

Discussion

This qualitative research on the impact of accessibility on adherence to physical therapy treatment in HAM/TSP people demonstrated the main limitations imposed on this population, according to the categories and subcategories that emerged from the participants' statements: access difficulty and external dependencies (climate and / accompanying person), financial and medical appointments. Therefore, knowing the users' perception regarding accessibility and adherence to physical therapy treatment is essential for better monitoring these patients' kinetic-functional function and pain.

In the context of accessibility, the following stood out as "access difficulties": transport, driver behavior, and architectural barriers. It was found that the participants in this research, given their physical mobility conditions, might have an exclusive life from society due to urban barriers. In contrast, the NBR9050 standard of the Brazilian Association of Technical Standards (ABNT) advocates that every individual can move in an environment with safety and independence.³

Among the situations of low adherence to physical therapy, the relevance of accessibility was evidenced in the participants' speeches, as it has an essential role in the effectiveness of the treatment and possible delay in the progression of the disease or better adaptation. Therefore, one study cites users' preference for health units close to their residence¹³, facilitating movement and reducing the risk of falls and the prospect of recovering work and social life in people with HAM/TSP. However, it is noteworthy that few physical therapy centers treat these patients in the City of Salvador.

In 2011, a study found that 26.4% of individuals with HAM/TSP could not remain standing on the bus, and 48% had difficulties. The bus is the most common means of public transportation for accessing healthcare. This inability is explained both by the limitations of movement caused by the disease, as well as by the barriers to accessing residential areas and the means of transportation (buses)^{14,15}, which can certainly be an obstacle in traveling to health centers, corroborating with what was reported by the participants of this research.

A qualitative study, carried out in 2010 with interviews, identified attitudinal issues generated by the lack of understanding, prejudice, unpreparedness, and disrespect of bus drivers to users with physical disabilities.¹⁶ Corroborating the data obtained in the present study, which showed inadequate behavior of public transport drivers, this being the most cited means of transportation, considering the financial issue of the participants, thus hindering accessibility. It is suggested that training be carried out in bus companies, for drivers and collectors, to develop empathy and be better prepared to deal with more inclusion and respect, with this population and other physically challenged people.

Among the symptoms of HAM/TSP, the following stand out: muscle weakness in the lower limbs, spasticity, and balance deficit, all associated with gait disturbances.^{7,17} This population is characterized by having reduced mobility and environmental factors contributing to the occurrence of falls, taking into account the evolution of the pathology. With this, similar findings in the research can be noted.¹⁷⁻²⁰ Outpatient physical therapy care, through functional kinesiological diagnosis, as early as possible, and treatment in an immediate, continuous and resolute manner will have an impact on damage limitation, rehabilitation, and, consequently, on the health of vulnerable individuals and/or with some degree of functional disability.¹⁵

Regarding the climate, especially on rainy days, the accessibility of these individuals is compromised because of the precarious infrastructure of Brazilian cities that do not have support for heavy rain events. The most vulnerable individuals are the physically disabled, especially people with HAM/TSP, because they have this limitation of the lower limbs. A recent study related the environmental conditions of housing and the physically disabled, who live in urban outskirts, where flooding, landslides, unpaved streets without any structure for locomotion usually occur, compromising their routines, such as the absence of physical therapy care.²¹

Adherence to physical therapy treatment in this sample is directly linked to the scarcity of financial resources and lower level of education, related to previous studies, with worse living conditions, which hinder access to information and knowledge about the prevention of pathologies.^{15,22} Individuals with low socioeconomic conditions usually interrupt physical therapy because it requires an adjustment in the family organization to adjust the financial costs of these individuals. Thus, the need for caregivers is highlighted, generating an increase in family costs.^{4,23,24}

Regarding the organizational dimension of accessibility, in user embracement, the following situations may occur difficulty in scheduling medical appointments, incompatibility with the schedule of physical therapy appointments, and difficult access to the Unified Health System, with long waiting lines.¹⁵ The bureaucracy for scheduling and availability of vacancies interferes with the continuity of treatment and, consequently, its resoluteness. Difficulties in using physiotherapy services are related to the distance between users' homes and clinics and the bureaucracy involved in making appointments. Distance limits physical and financial access, and bureaucracy interferes with the continuity and, consequently, with the resoluteness of the treatment. Due to the serious clinical condition that these participants have, effective attendance at medical appointments is necessary to identify the changes that occur in the clinical picture of HAM/TSP.^{15,18,22,25}

According to the analysis of the information in this study, the lack of accessibility significantly impacts the adherence to physical therapy treatment of people living with HAM/TSP. However, other conditions such as the low socioeconomic level of respondents, climatic factors, lack of public policies and infrastructure contribute to the worsening of the kinetic-functional condition of people with HAM/TSP, compromising the health of this population.

Study limitation

The reduced number of participants in the FG (after using an exercise booklet) is a limitation of the study, as it was impossible to know most participants' perceptions. As in all qualitative research, the risk of bias can happen due to the interpretation of information by the researcher.

We envision future perspectives, studies that focus on qualitative aspects that encompass the users' understanding of the health services that are available to them, strengthening the improvement of public policies aimed at urban issues for people with little mobility, like those with HAM/TSP.

Conclusion

The precariousness of the infrastructure and accessibility in the city of Salvador, low economic conditions, climate change, and difficulties in joining and/or remaining in the Unified Health System directly impact adherence to physical therapy treatment. Failure to attend physical therapy can affect the evolution of treatment in this population. The subjective look of physical therapists and their understanding of people's daily lives with Tropical Spastic Paraparesis are important for the effectiveness of health treatment.

Other studies should be carried out to deepen this theme in this population.

Authors' contributions

Reis AS participated in the project development, data analysis, and construction of the final text. Santana GO and Dubois-Mendes SM guided the work, supported the study planning, guided the collection and interpretation of data, and the writing and final review of the article. Sá KN participated in the writing and review of the scientific article.

Conflicts of interest

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

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