Original Article

*Caspian Journal of Internal Medicine 2025 (Spring); 16(2): 305-313*
DOI: 10.22088/cjim.16.2.305

# Astonish yourself while worrying about another: Patients' reactions of HTLV-1-associated myelopathy/tropical spastic paraparesis diagnosis

**Malihe Davoudi (MSc)** [1]
**Reza Boostani (MD)** [2]
**Zahra Sadat Manzari (MSc)** [3*]

1. Nursing and Midwifery Care Research Center, Mashhad University of Medical Sciences, Mashhad, Iran
2. Department of Neurology Department of Neurology, School of Medicine, Ghaem Hospital, Mashhad University of Medical Sciences, Mashhad, Iran
3. Nursing and Midwifery Care Research Center, Mashhad University of Medical Sciences, Mashhad, Iran

*** Correspondence:**
**Zahra Sadat Manzari,** PhD in nursing, Nursing and Midwifery Care Research Center, Mashhad University of Medical Sciences, Mashhad, Iran

**E-mail:** Manzariz@mums.ac.ir
**Tel:** +98 5138598019

**Received:** 18 June 2022
**Revised:** 27 May 2023
**Accepted:** 7 Dec 2024
**Published:** 21 March 2025

## *Abstract*

***Background:*** This study aimed to explore the patients' reactions when HAM/TSP was diagnosed. This qualitative content analysis study was conducted on HAM/TSP patients referred to an HTLV-1 clinic in Mashhad, Iran.

***Methods:*** We selected a purposive sample of 16 HAM/TSP patients meeting the inclusion criteria to participate in semi-structured interviews to explore their reactions and emotions when they first learned about their diagnosis. A qualitative content analysis was utilized with MAXQDA 2020 software.

***Results:*** Four categories and 14 subcategories were extracted, summarized in the main concept "Astonish yourself while worrying about another." The categories included threatened mental health, fear of falling into the path of ambiguity and darkness, fears and conflicts of deciding to expose the disease, and the double stress of threatening the health of others."

***Conclusion:*** HAM/TSP is an incurable and progressive disease with several physical complications. Its first diagnosis can also cause severe psychological damage to patients and profoundly affect the patient's social and family relationships. Therefore, it seems that education and health policies should integrate multidisciplinary teams to minimize the effects of HAM/TSP on the patients' quality of life.

***Keywords:*** Human T-lymph tropic virus 1, HTLV-1-associated myelopathy/tropical spastic paraparesis, HAM/TSP.

***Citation:***
Davoudi M, Boostani R, Sadat Manzari Z. Astonish yourself while worrying about another: Patients' reactions of HTLV-1-Associated myelopathy/tropical spastic paraparesis diagnosis. Caspian J Intern Med 2025; 16(2): 305-313.

Human T-lymphotropic virus type 1 (HTLV-1) is a human retrovirus associated with persistent infection in humans (1). The virus is thought to infect 10 to 20 million people worldwide. Southern Japan, the Caribbean Sea, South America, Central, and West Africa, and some parts of the Middle East, Australia, and Melanesia are endemic areas for HTLV-1 (2). However, its seroprevalence is still unknown for some populations worldwide, even in the areas adjacent to the endemic areas (3). Most people infected with HTLV-1 remain asymptomatic, but some develop diseases, such as adult T-cell leukemia/lymphoma and HTLV-1-associated myelopathy/tropical spastic paraparesis (HAM/TSP). Studies have shown that 3%-5% of people infected with HTLV-1 develop HAM/TSP (4). This disease is the most common condition among the infected people (5). HAM/TSP develops predominantly in adults, with a mean age of 40 to 50 years, with a higher prevalence in women than in men by a ratio of approximately 3:1. This disease usually progresses slowly without recovery. However, the clinical course and rate of progression may vary significantly among patients (6). HAM/TSP is a chronic, inflammatory, and neurological disorder characterized clinically by progressive lower limb weakness, spasticity, and bladder/bowel sphincter dysfunction (7).

**Publisher: Babol University of Medical Sciences**

It is not clear how HTLV-1 causes neuronal injury. However, spontaneous T cell proliferation and proinflammatory responses are characterized by increased production of interferon (IFN)-γ and tumor necrosis factor (TNF)-α by peripheral blood mononuclear cells, which are related to HAM/TSP (8). In addition, HAM/TSP patients show increased proviral loads associated with rapid disease progression (3). HAM/TSP diagnosis, according to Osama criteria (1990), is based on clinical findings, including anti-HTLV-I antibodies in serum and cerebrospinal fluid (8). Currently, no treatment significantly alters the long-term disability associated with HAM/TSP. The clinical management of HAM/TSP is based on treating symptoms such as back pain and muscle spasm, which align with the underlying pathological process and counseling patients and families (3). About 50% of HAM/TSP patients become wheelchair-dependent within 20 years of the first symptoms due to the disease's chronic progressive deterioration. Rates of progression vary widely, with a subset remaining stable over many years while a small minority become rapidly bedbound (9). In addition, the diagnosis of HTLV-1 as the causative agent of the disease adds to its difficulty and complexity for the patient (10). Also, a general lack of understanding about HTLV-1 and HAM/TSP, even among health workers, is particularly stressful for communities where HTLV-1 is endemic. Therefore, primary care's role is to work with specialized services to care for people affected by HTLV-1.

Nevertheless, a prerequisite for successful planning and intervention is approaching the patients and conducting in-depth interviews to discover their true feelings and experiences. Measuring patient experience is essential because it allows healthcare organizations to improve care, enhance strategic decision-making, meet patient expectations, effectively manage and monitor healthcare performance, and document benchmarks (11). Qualitative methods provide an opportunity to gain a deeper understanding of the patient's experiences. These approaches also allow assessors to move beyond structured questions (in quantitative surveys) through open-ended questions in which patients are encouraged to describe their experiences and perceptions in their own words. Thus, traditional qualitative methods such as interviewing may be a powerful tool in recording the patient's experience (12).

Even though Iran is endemic to this disease, so far, no study has been conducted on Iranian patients with unique cultural, social, religious, and health contexts, which differ in many features from other endemic countries. Additionally, as HTLV-1 is similar to another family member, Human Immune Deficiency Virus (HIV), in transmission route, possibly with similar socio-psychological consequences, such studies can help understand the patients and improve the quality of care services. Therefore, the current qualitative study explored the reactions of HAM/TSP patients when they first learned about their diagnosis.

## Methods

**Design:** Qualitative content analysis extracts the main themes and discovers data patterns (13). In this study, the conventional content analysis approach was used. This approach is mainly used in an inductive way and in the design of qualitative studies, the purpose of which is to describe a phenomenon in depth. This qualitative approach is suitable for examining the daily experiences of human emotions and feelings (14). Our study was reported according to the consolidated criteria for reporting qualitative studies (15).

**Participants:** The study population included HAM/TSP patients referring to the HTLV-1 specialized clinic of Ghaem Hospital in Mashhad, Iran. The inclusion criteria have included a recent diagnosis of HAM/TSP (no later than three months; for better memory recall), age of over 18 years, and consent to participate in the study. The first author (MD, a Ph.D. candidate in Community Health Nursing) conducted the interviews. For competency reasons, she visited the HTLV-1 clinic to collaborate with specialists on research and care programs before the interviews. She also volunteered to assist, educate, and communicate with potential participants. She was also educated in qualitative research methodology and interviewing.

The interviews were held between July 2021 and January 2022. Initially, the first author explained the study's objectives to the participants, and none of the patients refused to participate in the interviews. Data were collected through face-to-face, in-depth and semi-structured interviews, and each interview session lasted for 65-105 minutes. Also, two participants were invited to the second round of interviews to obtain further information. The participants appointed the time and place of the interviews, usually a private room in the clinic. Patients were interviewed separately to minimize the mutual influence. An audio recorder recorded the interviews after obtaining the consent of the participants.

The interviewer also took notes during the interviews, which were analyzed later. The interview guide was developed after conducting and analyzing the first two interviews. The interviews started with warm-up questions about the demographic characteristics of the participants. Recall early events were asked to enter the interview, such as "how did you learn you have the disease?" Then, the interview gradually evolved with questions "what was your feeling when you first learned you have the disease?" "What was your reaction?" and "What did you do thereafter?" The subsequent questions were to deepen the interview, such as "Please explain more... what does this mean?" Interviews continued until no new idea emerged (16), which reached after 16 interviews. Maximum variation was ensured to select the participants.

**Data analysis:** The recorded interviews were transcribed verbatim. After data mining, the first and third researchers obtained a general data image. Then, a qualitative content analysis (17) was conducted on all transcripts to extract meaningful units using MAXQDA 2020 software. Each unit was coded and compared based on differences and similarities to generate subcategories and categories. Finally, the categories were linked by their underlying meaning and grouped into the main concept. All data analyses were performed by two researchers independently, and discrepancies were resolved by consensus. Handwritten notes were used to facilitate conceptual comparisons.

Four methods were used to ensure trustworthiness. First, the confidentiality of information was emphasized to encourage patients to express their thoughts, opinions, and impressions freely. Second, data triangulation between data sources (interviews and observations) was done during data analysis. For example, after coding the text of each interview session, the corresponding set of documents was reviewed to confirm the consistency of the identified concepts. Third, the coding results were confirmed after being checked with four participants.

**Ethical considerations:** Ethical approval was obtained from the Ethics Committee of Mashhad University of Medical Sciences (IR.MUMS.REC.1399.391). Participants signed consent forms after informing of the research objectives. In addition, they gave their verbal consent before audiotaping. They were also assured that their statements would remain confidential.

## Results

We interviewed 16 HAM/TSP with a mean age of 43.75±12.43 and female predominance (n=10). The demographics of participants are shown in table 1. The content analysis discovered 1,003 codes, reduced to 371 primary codes after removing duplicates. The primary codes were classified into 14 subcategories, four categories, and one main concept to describe the reaction of patients to HAM/TSP diagnosis. Table 2 confirms the coherence of the emerging data.

**A. Threatened mental health:** This category consists of the subcategories "Anxiety and mental confusion arising from being informed of infection, suffering from lack of health, Low self-esteem and humiliation, and abnormal sensitivity to the quality of health and illness." This implies that negative emotions surround the person because these patients receive a diagnosis of progressive neurological disease, and at the same time, they become aware that their disease results from a preventable and transmissible virus.

**Anxiety and mental confusion Informed of infection:** Patients experience high anxiety, stress, shock, suffering, sorrow, and grief. Some patients became involved in why and how they became infected, the nature of the disease and the virus, the role of others in contracting the virus, and mental arguing with God. The notion that a virus is similar to HIV can also cause negative feelings. *"My doctor said people call it AIDS. I was distraught, firstly because of the word AIDS and secondly because there is no cure." (Man, 21 years* old)

**Suffering from lack of health:** This subcategory refers to the feelings of suffering that patients experience following the experience of illness-induced gaps in life. Restrictions on performing roles against their desires can also cause suffering; *"I hugged my baby. He touched my breast. I cried so much. My breasts are full of milk, but I cannot give a drop to my baby" (Woman, 38 years old)*

**Low self-esteem and humiliation:** This feeling arises from the feeling of being inferior to others and the authentic self that the patient always experiences this feeling or only in situations reminiscent of disability. *"I always think that if I go out with my siblings, their reputation will be damaged. I have not insisted on going out at all. "(Woman, 34 years old)*

**Abnormal sensitivity to the quality of health and illness:** The possibility of disease progression and more symptoms causes the person to be extremely sensitive to any symptoms and changes in their health that are unreal in some cases. *"I told myself that everything that happens in my body is related to this disease" (Woman, 22 –years old)*

**B. Fear of falling into the path of ambiguity and darkness:** This category consists of subcategories "Sadness and stress arising from an incurable and progressive disease, fear of contracting/experiencing unavoidable complications of the disease, and drowning in the dark and unknown future of illness." It shows that HAM/TSP, with its unique nature, determines the future in medical, personal, and social aspects of patient life and causes the patient to have many negative thoughts about the future.

**Sadness and stress Incurable and progressive disease:** The lack of knowledge about the nature of the virus, disease, and effective treatments can cause constant worry and sad thoughts for the patient. *"When I was told there was no place in the world for this disease, I was heartbroken"(Man, 70 years old)*

**Fear of contracting/experiencing unavoidable complications of the disease:** Secondary consequences of disease and treatment are essential sources of anxiety and worry. These sources cause fear of the future, some panic, and a sense of persistent danger in the patient. *"When I read the side effects in the drug brochure, I said to myself, no, I'm satisfied with this situation. But I do not like to experience the side effects of drugs, so I did not use drugs." (Man, 43 years old)*

**Drowning in the dark and unknown future of illness:** This subcategory refers to the ambiguity about the consequences of the incurable and progressive nature of the disease. The patient often thinks about what effects they will have on his or her lifestyle. A young pregnant woman described her immersion in the unknown future when she was diagnosed with the disease. *"I was terrified that I would be paralyzed in the future. When I discovered my child is a girl, I told myself it was a gift from God because if I became disabled in the future, this girl would help me." (Woman, 34 years old)*

**C. Fears and conflicts decided to disclose:** This category includes three subcategories: "Fear of stigma, Conflict and mental stress of deciding to disclose, Decision to disclose." On the one hand, the patients need support, and on the other hand, they are hesitant to disclose the infection due to the fear of individual and family stigma.

**Fear of stigma:** Having the same virus as HIV is a disgrace to infected people. Fear of involuntary exposure to infection and the possibility of negative feedback from others cause great suffering to the patient. Part of the fear of stigma relates to the family. *"I was afraid of disclosing to my family because I did not know what would happen next… There is no reason to tell him. Because I don't have sex with my husband" (Woman, 71 years old).*

**Conflict and mental stress of deciding to disclose:** The patient's intellectual conflict with him/herself concerning the disclosure issue is also seen in the structure of the patient's experience. A young man who worked as a nurse in a hospital and was worried about being exposed to job tests says: *"I'm confused, and I do not know if I should tell them or not?" (Man, 33 years old)*

**The decision to disclose:** This subcategory indicates that part of the structure of patients' experience is their decision to disclose the disease. The addressees of this revelation are his/her close relatives and friends. In some patients, however, the diagnosis is made exclusively for the homosexual family member. *"Only my daughter knows. She understands what this is. But my sons do not understand me." (Woman, 62 years old)*

**D. Double stress of threatening the health of others:** This category also includes the subcategories of "Stress and worry about the possibility of transmitting the disease to the family, a sense of social responsibility in protecting others, suffering from a change in the lifestyle of family members, and double fear and sadness caused by the infection of another." Part of the patient's emotional stress is due to the danger to other family members and the community, and this is because the patient considers him/herself a threat to others. The simultaneous presence of a person infected with the virus in the family can also be double stress for the person, whether the patient is involved in the infection or not.

**Stress and worry about the possibility of transmitting the disease to the family:** When the patient realizes that the virus is always inside his body, it is incurable and can be transmitted, another source of stress and anxiety is created for him/her. Fear of transmitting the disease to others is reflected in patients' behaviors. *"Wherever my blood drops in the house, I quickly engage in disinfection. I am careful to put disinfectants where it is infected" (Woman, 71 years old)*

**A sense of social responsibility in protecting others:** After being informed of the infection, the patient feels responsible for breaking the chain of infection with the virus and the appearance of symptoms in the community. In this regard, one reviews his/her social and individual health behaviors. *"When I want to go for a blood test, I'm embarrassed to tell them about my illness, but I tell them to put on gloves." (Man, 51 years old)*

**Suffering from a change in the way of life of family members:** In a situation where the patient imposes material and spiritual costs on his family members, he/she suffers too much. Transmission of the virus to family members is also painful for the patient. *"I do not have income myself. Unfortunately, my father provides these tests and medicines." (Woman, 26 years old)*

**Double fear and sadness caused by the infection of another:** Patients experience fear and grief for another family member infected with the virus. A young woman whose father was infected with the virus at the same time and showed mild signs of illness says: *"I grieve every day. I pray every night that my father will not be as disabled as I am." (Woman, 35 years old)*

**Astonish yourself while worrying about another as the main concept:** After the patient is diagnosed with a progressive, debilitating, and incurable neurological disease caused by a little-known virus, this awareness confuses one's health and future. At the same time, another part of his/her attention is focused on his/her family members because he realizes that this disease can be communicated. Also, screening tests on other family members are often advisable after the diagnosis. Knowing another person is carrier or symptomatic in the family will cause additional suffering. In the meantime, imposing material and immaterial costs on the family due to the functional disabilities of the sick person also makes him/her more confused. Therefore, it seems that the concept of "Astonish yourself while worrying about another" can well explain the reaction of these patients to HAM/TSP diagnosis.

**Table 1. Demographic information of the participants**

| No | Interview time | Gender | Age | Job | Educational level | Marital Status |
|---|---|---|---|---|---|---|
| 1 | 70 min | Male | 52 | teacher | Master’s degree | Married |
| 2 | 75 min | Male | 33 | nurse | Bachelor | Married |
| 3 | 70 min | Male | 38 | farmer | Primary school | Married |
| 4 | 65 min | Male | 42 | shopkeeper | Primary school | Married |
| 5 | 80 min | Female | 35 | house maker | Diploma | Married |
| 6 | 75 min | Female | 26 | student | Master’s degree | Single |
| 7 | 90 min | Female | 34 | house maker | Secondary school | Single |
| 8 | 95 min | Male | 21 | student | Associate’s degree | Single |
| 9 | 105 min | Female | 62 | house maker | Bachelor | Widow |
| 10 | 85 min | Male | 61 | retired | Diploma | Married |
| 11 | 95 min | Female | 39 | house maker | Primary school | Married |
| 12 | 100 min | Female | 61 | house maker | Diploma | Widow |
| 13 | 85 min | Male | 43 | retired | Illiterate | Widow |
| 14 | 80 min | Female | 51 | house maker | Diploma | Divorce |
| 15 | 65 min | Female | 22 | student | Associate’s degree | Divorce |
| 16 | 95 min | Female | 50 | house maker | Bachelor | Married |

**Table 2. An example of the formation of semantic units, codes, subcategories, and category**

| Meaningful unit | Codes | Subcategory extracted after collecting other data | Category extracted from subcategories |
|---|---|---|---|
| Maybe if I tell others about our illness, they might think bad things about me, and they may not think very well of me. | Fear of changing the behavior and attitude of others | Fear of stigma | Fears and conflicts decided to disclose |
| I did not tell my relatives about this disease so as not to create unpleasant thoughts about me. | Fear of being labeled | | |
| My children want to get married and I'm afraid there will be a problem with their marriage. So I did not talk to anyone about this problem | | | |

| | |
|---|---|
| I was afraid it would spread throughout the hospital that I had this disease. I thought to myself that I might lose my reputation and no one would communicate with me anymore.<br>I think if I tell my sons about this disease, they think that because their father is dead, I may have done something wrong. | Fear of the negative impact on the marriage of children<br>Fear of disclosure in the workplace due to damage to reputation<br>Fear of rejection by colleagues after disclosure<br>Fear of being accused by family after exposure |

**Table 3. The main structure of patients' experience in facing the diagnosis of the HAM/TSP (concept, category, and subcategory)**

| Concept | Category | Subcategory |
|---|---|---|
| Astonish Yourself While Worrying About Another | threatened Mental health | • Anxiety and mental confusion Informed of infection<br>• Suffering from lack of health<br>• Low self-esteem and humiliation<br>• Abnormal sensitivity to the quality of health and illness |
| | Fear of falling down the path of ambiguity and darkness | • Sadness and stress Incurable and progressive disease<br>• Fear of contracting/experiencing unavoidable complications of the disease<br>• Drowning in the dark and unknown future of illness |
| | Fears and conflicts decided to disclose | • Fear of stigma<br>• Conflict and mental stress of deciding to disclose<br>• The decision to disclose |
| | Double stress of threatening the health of others | • Stress and worry about the possibility of transmitting the disease to the family<br>• A sense of social responsibility in protecting others<br>• Suffering from a change in the way of life of family members<br>• Double fear and sadness caused accompanying the experience of being infected by another |

## Discussion

The study revealed the main concept for patients' experience of being diagnosed with HAM/TSP. The concept "Astonish yourself while worrying about another" shows the nature of patients' experiences in the face of diagnosis. This concept reflects the individual response to the awareness of HAM/TSP and the social and familial consequences. Patients' narratives show the influence of mental health threats in their experiences. This experience is not far from the mind because after receiving the diagnosis, they often compare it with HIV/AIDS, which creates a horrible image of the disease for them. Diagnosing a chronic illness such as disability or loss of function of an organ or part of an organ can be bad news. A painful, lengthy, and costly treatment plan can also negatively impact. Also, this disease causes suffering experience because of both the possibility and the reality of losing motor capacity, restricting the patient's lifestyle, desires, and occupation. Fear of falling into the path of ambiguity and darkness of the disease is also part of the structure of patients' experience. In this study, patients narrated this with sadness and stress about the incurable and progressive disease, fear of contracting/experiencing unavoidable complications of the disease and drowning in the dark and unknown future of illness. It was observed from these reports that HAM/TSP is felt as a rebellious disease and creates a shock in the person's current situation, explaining these fluctuations of views about the future. In fact, patients experience great uncertainty about the nature of the disease and its future. This is an uncertainty in the medical, personal and social spheres. Another part of the structure of these patients' experiences is their internal fears and conflicts about the subject of the revelation. The source of these emotions is the semantic similarity of HTLV-1 with HIV/AIDS, which is associated with ethical behaviors. On the one hand, the feeling of inability to deal with the disease and the need for emotional, psychological, and informational support leads patients to disclose the diagnosis, and on the other hand, the possibility of receiving negative and unpleasant reactions from others puts them in two paths of doubt. Therefore, the participants invoked "justifications" to hide their illness, arguing that "I don't have sex with my partner". The double stress of threatening the health of others is also part of the meaning of the experience of these patients. The notion that a person as a carrier may infect others adds to his/her emotional distress. According to patients, this feeling can play a dual role in people's mental and behavioral health. On the one hand, it is considered a destructive emotion, and on the other, it is considered a constructive and effective emotion. Because patients usually experience the destructive effects of these emotions, they are motivated to pay more attention to behaviors such as feeling responsible for maintaining the health of others. Another part of annoying thoughts is that patients feel that they put a lot of effort and burden on the family and take the time of those around them, and their medical expenses put pressure on the family and disrupt the dynamism of the family.

In many studies, similar narratives can be seen. Another study found that women with the disease were afraid of being abandoned by society and feared the stigma, low self-esteem, worthlessness, and being forced to entrust childcare responsibilities to others (18). Santos et al. (2017) also showed a lack of awareness about this disease. Also, in line with the present study, the suffering of living in a happy and joyful past was observed in the participants (19). In another study in 2021, patients' stories showed that HTLV-1 manifestations cause functional impairment (20). Zihlmann's (2013) study suggests that trying not to breastfeed increases anxiety in these women due to the idealization of breastfeeding as a symbol of the basic concept of femininity and motherhood (21).

In a study, many participants thought their disease was HIV/AIDS and reported the concealment of the diagnosis. More complex problems were seen in symptomatic patients because patients experience changes in daily activities and limitations of movement. The study showed that subjects' experiences changed when their family members were symptomatic (22). Although these studies have been conducted in a different context from Iran's, some of their findings are consistent with Iranian studies. In general, this shows that the most critical factor influencing the meaning of patients' experiences is the issue of illness and the unique nature of the disease. Also, these patients experience adverse consequences such as disability, dependence, and social limitations much in the same way, regardless of the context, because values such as health, beauty, and independence are universally accepted. On the other hand, some similar contextual factors that exist in the health structure of Iran and Brazil regarding policies related to this disease can lead to similar experiences in patients. In both Brazil and Iran, HTLV infection can be considered a public health problem that has not been adequately addressed and therefore remains "unattended." For example, mandatory serological screening is performed only for blood donors in Brazil (23) and endemic areas in Iran. Similar to Brazil (21), in Iran, after diagnosis, individuals face limited access to services and medical care due to geographically (physical barriers such as long distances between a person's place of residence and treatment setting), organizationally (lack of patient observation by some healthcare centers, health professional specialists and managers) or economically (losses due to lost working days, high costs of treatment and transportation). Hence, despite some differences, there are similarities in both contexts that can lead to similarities in experiences. However, some studies differ in part from the present study.

In the Dos Santos et al. (2022) study, patients were hopefully looking for ways to delay or minimize disability (22). There are also narrations of hope and happiness in some research (21-23). How the infection is reported, the quantity and quality of the information provided to the patient, and the medical support perceived by patients may play an essential role in creating hope in them. Unlike Brazil, where in some endemic areas, there is an integrated protocol for patient care, in Iran, despite the identification of the virus in 1986, no coherent action has been taken so far for medical management and support of these patients. In other words, in addition to the general ignorance of Iranian society, health professionals also have very little information about this disease. In this regard, a study confirms that the level of knowledge of medical students about HTLV-1 infection is not good (24). This leads to very little medical support for patients, so there is no hope for the future and finding treatment for patients. Also, one of these differences could be that we examined patients who had been diagnosed for up to three months, which may affect the results. Some results are unique to this study, such as the subcategory "A sense of social responsibility in protecting others." In other studies, patients' sense of responsibility was limited to transmitting the virus to the family. Nevertheless, our study also includes protecting others in the community. This difference may be due to the information provided to patients when the diagnosis is made. This information emphasizes transmission prevention and almost no other disease-related issues. On the other hand, patients try to prevent the disease by informing about it due to exposure to the suffering and experiencing the limitations caused by the disease, called "guilt and conscience."

Also, with the experience of regret due to not being diagnosed with the virus early and before the onset of symptoms, the patient tries to prevent the painful experience for another by informing the public. HAM/TSP is an incurable and progressive disease. In addition to physical complications, many factors contribute to the psychological damage of people suffering from this disease. They have a sexually transmitted infection that affects their social and family relationships. In addition, HTLV-1 infection is a neglected disease, and the general Iranian society does not have enough knowledge and attitude to recognize this disease, increasing the stigma among patients. On the other hand, HAM/TSP, as a debilitating disease, may also affect the patient's independence and workability and disturb their financial situation. Therefore, it seems that education and health policies should integrate multidisciplinary teams to minimize the effects of this infection on the quality of life of HAM/TSP patients.

## Acknowledgments

The authors of this article thank the Vice Chancellor for Research of Mashhad University of Medical Sciences for the financial support of the director of the hospital and specialized clinic, as well as all patients and their families.

**Funding:** The project is funded by Mashhad University of Medical Sciences.

**Ethics approval:** Ethical approval was obtained from the Ethics Committee of Mashhad University of Medical Sciences (IR.MUMS.REC.1399.391).

**Conflict of interests:** There is no conflict of interest.

**Authors' contribution:** All of the authors contributed to the concept and purpose of the study. MD, RB performed sampling. MD were performed the first draft of the manuscript. MD, ZSM involved analysis and interpretation of data. ZSM revised the manuscript. All authors read and approved the final manuscript.

## References

1. Poiesz BJ, Ruscetti FW, Gazdar AF, et al. Detection and isolation of type C retrovirus particles from fresh and cultured lymphocytes of a patient with cutaneous T-cell lymphoma. Proc Natl Acad Sci U S A 1980; 77: 7415-9.
2. Gessain A, Cassar O. Epidemiological aspects and world distribution of HTLV-1 infection. Front Microbiol 2012; 3: 388.
3. Enose-Akahata Y, Jacobson S. Immunovirological markers in HTLV-1-associated myelopathy/tropical spastic paraparesis (HAM/TSP). Retrovirology 2019; 16: 35.
4. Teixeira MA. Soropositividade de mulheres para os vírus HIV e HTLV: significados do contágio do leite materno. PhD thesis (Doutorado em Enfermagem). Escola de Enfermagem da Universidade; Escola de Enfermagem, Federal da Bahia – Salvador 2009. [in Portuguese]
5. Romanelli LC, Caramelli P, Proietti AB. Human T-cell lymphotropic virus type 1 (HTLV-1): When you suspect the infection? Rev Assoc Med Bras (1992) 2010; 56: 340-7. [in English, Portuguese]
6. Yamano Y, Sato T. Clinical pathophysiology of human T-lymphotropic virus-type 1-associated myelopathy/tropical spastic paraparesis. Front Microbiol 2012; 3: 389.
7. Olindo S, Lézin A, Cabre P, et al. HTLV-1 proviral load in peripheral blood mononuclear cells quantified in 100 HAM/TSP patients: a marker of disease progression. J Neurol Sci 2005; 237: 53-9.
8. Osame M. Review of WHO Kagoshima Meeting and diagnostic guidelines from HAM/TSP In: Blattner WA. Human retrovirology: HTLV 1990: 191-7.
9. Sato T, Yagishita N, Tamaki K, et al. Proposal of classification criteria for HTLV-1-associated myelopathy/tropical spastic paraparesis disease activity. Front Microbiol 2018; 9: 1651.
10. Carneiro-Proietti AB, Catalan-Soares BC, Castro-Costa CM, et al. HTLV in the Americas: challenges and perspectives. Rev Panam Salud Publica 2006; 19: 44-53.

11. Bjertnaes OA, Sjetne IS, Iversen HH. Overall patient satisfaction with hospitals: effects of patient-reported experiences and fulfilment of expectations. BMJ Qual Saf 2012; 21: 39-46.
12. Morse JM, Field PA. Qualitative research methods for health professionals. 2nd ed. SAGE Publications 1995; pp: 249-52.
13. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. Nurse Educ Today 2004; 24: 105-12.
14. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. Qual Health Res 2005; 15: 1277-88.
15. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care 2007; 19: 349-57.
16. Armat MR, Assarroudi A, Rad M, Sharifi H, Heydari A. Inductive and deductive: Ambiguous labels in qualitative content analysis. Qual Rep 2018; 23: 219-21.
17. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. Nurse Educ Today 2004; 24: 105-12.
18. Orge G, Travassos MJ, Bonfim T. Convivendo com o HTLV-I. Gazeta Médica da Bahia 2010; 79: 68-72. [in Portuguese]
19. Santos AC, Soares DD, Rivemales MD. (Un) Familiarity, illness and limitations imposed by HTLV: experiences of HIV positive women. Cadernos Saúde Coletiva 2017; 25: 45-50. [in Portuguese]
20. Teixeira MC, Hennington ÉA. Pessoas vivendo com HTLV: sentidos da enfermidade, experiência do adoecimento e suas relações com o trabalho. Ciência & Saúde Coletiva 2021; 26: 6049-57. [in Portuguese]
21. Zihlmann K. Reproductive decisions among people living with human T-cell lymphotropic virus type 1 (HTLV-1). J Infect Dis Ther 2013; 1; 1-5.
22. dos Santos AC, Sampaio DC, Oliveira LL, et al. Impacto do adoecimento crônico em mulheres com Vírus Linfotrópico T Humano (HTLV). Revista Enfermagem Contemporânea 2021; 10: 197-204. [in Portuguese]
23. Zihlmann KF, de Alvarenga AT, Casseb J. Living invisible: HTLV-1-infected persons and the lack of care in public health. PLoS Negl Trop Dis 2012; 6: e1705.
24. Rafat Panah Bayegi H, Kimiafar K, Ahmadian B, et al. Awareness of laboratory students of Mashhad University of Medical Sciences about human T-cell lymphotropic virus type 1 (HTLV-1). Paramed Sci Military Health 2022; 17: 40-50. [in Persian]