



# Lived Experience of Human T-cell Leukemia Virus type-1 -Associated Myelopathy/Tropical Spastic Paraparesis (HAM/TSP): A Phenomenology Study

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## What's Known

- Human T-cell Leukemia Virus type-1 -associated myelopathy/tropical spastic paraparesis has severe physical consequences for the patient.
- These patients have a communicable virus and a debilitating disease at the same time, so they have a unique experience.

## What's New

- This disease is not only a physical disorder, but it has serious consequences for the dignity of the patients. The psychosocial changes of this disease are deeper and more painful than its physical problems.
- In addition to symptomatic treatment, it is necessary to provide palliative care for this group of patients to live with dignity.

## Abstract

**Background:** Human T-cell Leukemia Virus type-1 (HTLV-1) -associated myelopathy causes sufferers to experience changes in several aspects of their lives. Gaining a deeper understanding of these changes can help healthcare professionals improve care, enhance strategic decision-making, meet expectations, and manage patients effectively. However, there is no information about the experience and problems of patients with HTLV-1-associated myelopathy/tropical spastic paraparesis in Iran. Therefore, this study aimed to explain the lived experience of patients with HTLV-1-associated myelopathy/tropical spastic paraparesis.

**Methods:** This qualitative study used hermeneutic phenomenology in 2022 in Mashhad, Iran. Participants were selected using purposeful sampling. Data were collected through 21 semi-structured in-depth interviews with 20 eligible patients with HTLV-1-associated myelopathy/tropical spastic paraparesis. The data were analyzed in MAXQDA/2020 using the six stages proposed by Van Manen.

**Results:** The main concept of “Reduced self-sufficiency and social dignity” emerged from the narratives of the patients, which included three main categories: “Disruption of desirable personal and social life”, “reduced perception of role competencies”, and “obligatory unpleasant lifestyle changes”.

**Conclusion:** HTLV-1-associated myelopathy/tropical spastic paraparesis slowly makes patients feel insufficient and causes a sense of degradation in dignity. The disease can fundamentally change personal and social life. Thus, due to its incurability and progressiveness, palliative care should be provided to them to live with dignity.

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## Introduction

In 1980, Poiesz and others Discovered the Human T-cell Leukemia Virus type-1 (HTLV-1).<sup>1</sup> The HTLV-1 affects up to 10 million people worldwide.<sup>2</sup> Given that most current studies analyze specific subsets of the population (usually blood donors or pregnant women), the number of HTLV-1-infected individuals is likely much higher

than currently estimated.<sup>3</sup> While most remain asymptomatic, approximately 3–8% develop HTLV-1-associated Myelopathy/Tropical Spastic Paraparesis (HAM/TSP).<sup>4</sup> HAM/TSP is a chronic, neurodegenerative disease characterized by progressive lower limb weakness, spasticity, and bladder/bowel sphincter dysfunction.<sup>5</sup> The same as other chronic diseases, people with this disease “live with the disease until they die.” Therefore, it is necessary to study the impact of the disease on people’s lives.

Researchers need to learn from the experiences of others. In fact, this is a fundamental assumption for research. Research involves the detailed study of a topic to discover information or gain a new understanding. Such careful study often requires understanding the experiences of others to gain new insights into a particular phenomenon. Phenomenology is a qualitative research approach uniquely positioned to support this research.<sup>6</sup> Therefore, conducting a qualitative study in our country’s cultural, social, and health context seems necessary.

Reviewing qualitative studies published on HAM/TSP patients showed that qualitative studies were mostly conducted on patients infected with HTLV-1,<sup>7-12</sup> and a limited number of these studies assessed a few people with HAM/TSP as part of their study samples.<sup>13-15</sup> This means none of the qualitative studies have been conducted exclusively on HAM/TSP. This is while these patients are simultaneously experiencing virus infection and suffering from a progressive and debilitating chronic disease, making the situation more complicated. Moreover, qualitative studies, phenomenological approach, content analysis, and ethnography have investigated part of patients’ lived experiences. For example, Zihlmann and others investigated the meaning of not breastfeeding in mothers infected with HTLV-1.<sup>12</sup> Teixeira and colleagues examined the feelings and experiences of women infected with HIV/HTLV-1 concerning not breastfeeding their babies.<sup>9</sup> Santos and others aimed to understand the experiences of women infected with the virus concerning their disease and imposed limitations on their daily lives.<sup>7</sup> Orge and others aimed to assess how infected patients perceive infection and its consequences.<sup>16</sup> Rivemales examined the concept of sexual behavior in the patients.<sup>17</sup> Paranhos and others investigated the sexual behavior of women infected with the virus and suffering from urinary incontinence.<sup>14</sup>

Despite the same study question, these studies have reached different results and concepts, which can be expected considering the differences in socio-political structures, cultural backgrounds, and health policies

of societies. For example, in the study of Rivemales, whose aim was to investigate the sexual experience of people infected with HTLV-1, the following concepts were extracted from the interviews: “The experience of a positive serology test, the discovery of HTLV-1, the experience of its consequences, the experience of sexual intercourse with HTLV-1.”<sup>17</sup> In contrast, the sexual experiences of women with urinary incontinence caused by HTLV-1 in the study of Paranhos and others, showed four categories: “perception of sexual desires”, “experience of incompatibility and violence”, “experience of sex without pleasure”, and “experience of urination during sex.”<sup>14</sup>

Even though, after Japan, Iran is the second Asian country where this virus is endemic,<sup>18</sup> so far, no study has been done on this group of patients in Iran, and there is no information about the effects of this disease on their lives. Therefore, this study was conducted to identify the lived experiences of patients with HAM/TSP.

## Methods

### *Design*

This qualitative study was based on hermeneutic phenomenology utilizing the Standards for Reporting Qualitative Research (SRQR).<sup>19</sup> Ethical approval was obtained from the Ethics Committee of Mashhad University of Medical Sciences (IR.MUMS.REC.1399.391). Participants signed consent forms after being informed about the research objectives. In addition, they gave their verbal consent before audiotaping. They were also assured that their statements would remain confidential.

### *Recruitment and Participants*

Through purposive sampling, participants were recruited from the HTLV-1 specialized clinic in Mashhad, Iran. The inclusion criteria were age over 18 years, no cognitive disorders, no psychiatric problems (physician’s confirmation), having the approval of a neurologist, and consent to participate. Sampling continued until data saturation. Saturation is usually described by the term “when no new categories or related themes emerge”.<sup>20</sup> At the beginning of the interviews, general explanations about the study objectives and the need for confidentiality of information were given verbally. Written informed consent was obtained from all the interviewees, and they were ensured that they could withdraw from the study at any time if they were not satisfied.

### *Data Collection*

Face-to-face semi-structured interviews took

place in a private room in the clinic (from July 2021 to January 2022), and each session lasted 65-105 minutes. The first author explained the study's objectives to the participants, and none of the patients refused to participate in the interviews. Before each interview session, coordination was done with the participants. The first author conducted the interviews. She volunteered to assist, educate, and communicate with potential participants for competency reasons. She was also educated in qualitative research methodology and interviewing.

The interview guide was developed after conducting and analyzing the first interview. 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 discover the disease?" Then, the interview gradually evolved with questions, "Please tell me how living with HAM/TSP influences your everyday life?" The subsequent questions were to deepen the interview, such as "Please explain more. What does this mean?" Interviews continued until no new idea emerged,<sup>21</sup> which was reached after 20 interviews. Maximum variation was ensured in selecting the participants. One participant was invited to the second interview round to obtain further information. An audio recorder was used during the interviews after obtaining the consent of the participants.

#### *Data Analysis*

In this study, six steps of van Manen's approach were followed. MAXQDA/2020 software (VERBI, Germany) was used to facilitate data management. Van Manen presented three methods for extracting thematic elements: holistic, selective, and partial. In the holistic approach, the researcher considers the text as a whole and tries to understand the full meaning of the text. The researcher asks himself, "What is the keyword that expresses the main meaning of the text?" This approach is called "judgment call for a text".<sup>22</sup> In the present study, each interview text was read many times. After forming a general understanding, the researchers interpreted the interviewees' answers and texts as descriptive using the research question guide. This stage made the researchers more involved in the studied phenomenon. Finally, the researchers expressed general impressions of the texts in one or more sentences. Under the selective approach, the researchers created phrases or sentences to help clarify the target phenomenon and then extracted topic sentences or paragraphs. Following the detailed approach, the researchers read the text of each text line by line and extracted

keywords or phrases that were somehow related to the phenomenon of contracting HAM/TSP. After extracting thematic expressions (descriptive codes), by comparing the main content of each interview with previous interviews, similarities and relationships between them were identified. Then, based on the relationships identified, they were classified into primary codes. By comparing and identifying relationships between primary codes, subclasses emerged based on their relationships and similarities. Finally, the main classes were created. The main research question was addressed during this process. The researchers went back and forth from the entire text of the interviews to the extracted themes or components in all stages of the study.

#### *Trustworthiness*

Four criteria developed by Guba and Lincoln were considered to increase accuracy: credibility, confirmability, transferability, and dependability.<sup>23</sup> Long-term participation and continuous observations increased the credibility. As a result, the researchers were fully involved in the study, established sufficient communication with the participants, and accepted the general concepts emerging during the study. To increase the confirmability of the findings, the coded data were presented to the participants to confirm their accuracy. The transferability of the findings was also improved by explaining the conditions of the knowledgeable participants in the research and the interview method in a comprehensible manner. Attempts were made to select the sample in line with the research objectives and without bias. The data were analyzed in parallel with their collection so that the researchers were familiar with the principles of theoretical research. The coding process of concepts, themes, audio, and text information was employed to increase the dependability of the study findings. To ensure this, the two researchers analyzed the content separately and discussed the themes to reach an agreement.

## **Results**

20 HAM/TSP patients with a mean age of 45.55±14.73 years were interviewed (table 1).

Table 2 confirms the coherence of the emerging data. According to Van Manen's phenomenological analysis method, the content analysis discovered 1,091 codes, which were reduced to 411 primary codes after removing duplicates. The primary codes were classified into 13 subcategories, three categories, and one main concept to describe the lifestyle change experience in patients with HAM/TSP (table 3).

**Table 1:** Characteristics of patients with HTLV-1-associated myelopathy/tropical spastic paraparesis participating in the study

No.	Sex	Age (years)	Duration of HAM/TSP (years)	Being employed	Education	Marital status
1	Female	34	10	Yes	Master's degree	Married
2	Female	58	3	No	Diploma	Widow
3	Male	62	15	No	Associate degree	Married
4	Male	52	15	Yes	Master's degree	Married
5	Female	26	4	No	Master's degree	Single
6	Female	31	3	No	Middle school	Single
7	Male	42	20	Yes	Elementary school	Married
8	Male	21	7	No	Diploma	Single
9	Male	38	3	Yes	Elementary school	Married
10	Female	70	9	No	Associate degree	Married
11	Female	61	18	No	Bachelor	Widow
12	Female	39	1	No	Elementary school	Married
13	Female	36	16	No	Diploma	Married
14	Female	65	14	No	Elementary school	Divorced
15	Female	53	3	No	Illiterate	Widow
16	Female	26	8	No	Bachelor	Divorced
17	Male	39	2	No	Bachelor	Divorced
18	Female	44	12	No	Diploma	Married
19	Male	66	23	No	Middle school	Married
20	Male	48	9	Yes	Elementary school	Married

**Table 2:** An example of semantic units, codes, subcategories, and category

Meaningful unit	Codes	Subcategory	Category
I used to work but couldn't sleep due to fatigue and leg pain. I left the store to my sons two years ago.	Leaving work due to pain and fatigue caused by illness	Impaired job performance	Reduced perception of role competencies
I used to farm and raise livestock in the village, but I could no longer continue my work due to pain and spasms in my legs.	Leaving work due to leg pain and spasms		
This disease has made me unable to communicate well with my students because I am unhealthy.	Impairment in effective communication with students		
Sometimes, I think this physical weakness makes me unable to control the class.	The feeling of lack of control over work situations		

**Table 3:** The main construct of lifestyle experience associated with HAM/TSP in patients

Concept	Category	Subcategory
Reduced self-sufficiency and social dignity	Disruption of desirable personal and social life	<ul style="list-style-type: none"> <li>● Illness as a barrier to life preferences, fear of permanent celibacy, perception of marital threats</li> <li>● Dissolved marriage, understanding the risk of degradation of social dignity</li> </ul>
	Reduced perception of role competencies	<ul style="list-style-type: none"> <li>● Schema of inadequacy in the spousal role</li> <li>● Unsuccessful parenting</li> <li>● Impairment of job performance</li> <li>● The sadness of giving up the interest of having children</li> </ul>
	Obligatory unpleasant lifestyle changes	<ul style="list-style-type: none"> <li>● Experiencing a situation reminiscent of disability</li> <li>● Broken social relationships</li> <li>● Restrictions in routine life</li> <li>● Irregularity in the sleep-wake pattern</li> </ul>

**Disruption of Desirable Personal and Social Life**

This category refers to the gap between reality and patients' perceptions of life. On one side is the reality that is the truth of their life, and on the other side is the reality that they desire. After a cognitive evaluation of the situation, they conclude that their living arrangement is messed up, and they cannot follow the normal course of life. Some patients said they canceled their career and marriage plans.

"I decided to become a soccer player. But now, because of walking and running problems, it won't happen." (Participant No. 8, male, 21 years old, single)

Anxiety and apprehension caused by the feeling of threat from the continuation of marital life and the fear of jeopardizing the common life were also seen in the narratives of some patients. Besides, most female patients experienced limitations and lack of success in playing the role



of mother, which casts a shadow on the stability of their married life and emotional relationships with their spouses. Others narrated failure in marital life. After the infection is revealed to the spouse, the fear of contracting a sexually transmitted virus disrupts the continuation of marital life, and a fatal blow is inflicted on the body of their marital life. Divorce may even occur. This condition often occurs when the spouse is free of the virus. Additionally, suffering from HAM/TSP, which leads the patient from independence to dependence, is associated with a reduced perception of social status and dignity. In addition, the loss of some capabilities and physical changes challenge patients' self-image and make them concerned about the image others have of them.

"No man was willing to marry and have sex with me. I couldn't get married." (Participant No. 14, female, 65 years old, divorced)

#### *Reduced Perception of Role Competencies*

This category refers to the fact that suffering from HAM/TSP causes a person to face serious problems in performing assigned tasks in the family and society. In this disease, affected people are disturbed in the spouse, parent, and employee roles. They realize that due to the disease, they lack the necessary competence and ability to play family and social roles. In this regard, a disorder in playing the role of spouse (sexual and emotional role in marital relations) is one of the common experiences of patients. The disease causes patients to see themselves as unworthy spouses who cannot meet their partners' natural needs. Moreover, contracting this disease scares them from having children, because they think that in such a situation, the fetus may be born with this virus or suffer from abnormalities due to it. They also feel they are inadequate parents because they cannot care for their children due to physical, emotional, and mental disabilities. On the other hand, working patients understand that having an illness is synonymous with failure to perform job duties and reducing their work speed and quality because they are physically and mentally limited.

"This physical weakness makes me unable to control the class. It is not a good feeling." (Participant No. 4, male, 51 years old, married)

#### *Obligatory Unpleasant Lifestyle Changes*

This category means unwanted changes that patients experience in their daily personal and social lives. These changes, although often minor and minimal, are irreversible and undesirable. When the patient is in a situation that reminds them of disabilities and negative

characteristics, for example, when they need to walk for a long time or run, they realize that it cannot be done easily. Some patients also show obvious disturbance in their usual life. For example, they had difficulty traveling, dressing, standing, or caring for themselves. Besides, the inability to walk or obvious deformity in the lower limbs reduces social presence, leading to physical isolation and restrictions in commuting and benefiting from social services. Experiencing sleep and wakefulness disorders due to urinary problems such as incomplete emptying of the bladder, urinary incontinence, the feeling of urgency in defecation, and physical discomfort in the leg and back areas causes discomfort. Additionally, thinking and mental conflicts due to the disease can change the patient's sleep pattern.

"I can't wear jeans because it accentuates the unpleasant changes in the shape of my legs." (Participant No. 8, male, 21 years old, single)

#### *Reduced Self-sufficiency and Social Dignity as the Main Concept*

Based on an in-depth interview with the participants, the main structure of the lived experience of these patients was revealed as the main concept entitled "Reduced self-sufficiency and social dignity." This concept means that, unlike other healthy people, patients understand that they cannot fulfill their roles. They find that their work abilities, daily life, independent living, and society are impaired, so they feel that they lack personal, family, and social dignity. Moreover, they understand that the disease has changed their appearance. When they compare their self-image to culturally defined standards of beauty and health, they feel inadequate and degraded.

## Discussion

The main concept of "Reduced self-sufficiency and social dignity" emerged from the patients' narratives. It included three main categories: "disruption of desirable personal and social life", "reduced perception of role competencies", and "obligatory unpleasant lifestyle changes". According to patients' narratives, HAM/TSP disturbs the sufferers' lives, isolates the individual from family and society, brings a sense of loss of sufficiency, and disrupts personal and social arrangements.

The category "disruption of desirable personal and social life" includes marital changes to marriage, marital life, and the person's societal position, mostly seen in single women. This is while the sexual transmission of HTLV-1

commonly occurs from men to women. This problem could be due to the lack of information about the risk of infection transmission during sexual intercourse. Additionally, stereotypical ideas about gender roles that often equate being a woman with being a caregiver seem to be a barrier to building an intimate and lasting relationship because disability can be associated with the need for care and conflicts with the mentioned gender stereotype. Thus, these women lack the self-confidence to engage in an emotional relationship. Besides, the presence of more men with disabilities in society has made men's disabilities more accepted. Therefore, it is more likely for disabled men to get married. The threat to social dignity is also because patients are worried about being accused of deviant behavior by society. Moreover, due to physical defects, obvious disfigurement, and dependence on others, they observe, evaluate, and judge their health status and fear being marginalized by society or humiliated.

Concerning reduced perception of role competencies, changes in the role of the spouse, feelings of inadequacy as parents, loss of interest in having children, and disruption in professional roles were seen in patients' narratives. HAM/TSP and co-infection with a contagious virus can affect patients' ability to perform family and social roles according to their expectations and be an obstacle to successfully performing a role because being healthy is necessary for playing social roles. People can be fully active when they feel healthy, and society considers them healthy. Movement disability, sensory and nervous disorders, urinary and sexual disorders, severe muscle weakness, and fatigue are among the symptoms of this disease, all of which reduce patients' mental and physical ability to play family and social roles.

The category "obligatory unpleasant lifestyle changes" can be explained by the sensory and motor limitations caused by the disease, which limit them in their normal life routine. HAM/TSP is a progressive and chronic disease. The main symptoms of this disease are spastic paraparesis or paraplegia and autonomic changes of sphincters, along with urinary retention and incontinence or constipation. Impotence and loss of libido are also often observed. Profound sensory changes such as paresthesia, dysesthesia of the limbs, cramping, and pain in the lower back and lower limbs have also been described. Patients often experience movement problems, loss of balance, and muscle fatigue. These symptoms can interfere with activities of daily living.

The findings of the present study are

consistent with other studies on these patients. As an example, in some studies, some participants showed narratives that are in line with the category of "disruption of desirable personal and social life" and its subcategories. In the study of Orge and others, patients revealed the dissolution of their previous life plans.<sup>16</sup> In the study of Paranhos and others, patients stated that the disease caused them to be unable to find a life partner.<sup>14</sup> Gascón and others' study also revealed that this disease endangers the sense of dignity by making the person dependent on others and mobility aids.<sup>24</sup> Some studies also showed similar results with the category of "reduced perception of role competencies disruption" and its subcategories. As an example, the study of Paranhos and others revealed the disruption in the role due to the disruption in sexual function and emotional relationships.<sup>14</sup> In another study, women with HTLV-1 showed a feeling of inadequacy in the role of parents in the form of suffering due to the inability to breastfeed the baby.<sup>12</sup> Teixeira and others also showed that HAM/TSP has the power to disrupt job performance and cause patients to face problems in choosing a job and performing job duties.<sup>25</sup> In line with the category of "obligatory unpleasant lifestyle changes" and its subcategories, the study of Gascón and others showed that the disease limits patients' work and leisure activities. Orge and others also realized from the narratives of the patients that urinary problems caused by the disease make disturbances in the sleep pattern.<sup>16</sup> Rivemales also found that HAM/TSP can disrupt and limit patients' social relationships.<sup>17</sup>

In our study, one of the patients' reports was the experience of failure or feeling threatened in their married life. This finding was not identified in other similar studies on HAM/TSP patients. This could be due to the difference in the study context. Because factors such as cultural and social norms and the individual value system of patients can create differences in the meaning of experience and perception. On the other hand, the different participants in our study, the severity and type of symptoms, and different goals and research questions can also justify this difference. This finding emphasizes that in the process of caring for Iranian patients with HAM/TSP, it is necessary to consider family counseling sessions and interventions to make the experience of the disease less painful.

The most important limitation of this study was that the participants were limited to one province, so the cultural, ethnic, and social diversity in sampling was limited. However, as this study is the first qualitative study on Iranian

HAM/TSP patients conducted to explain their lived experience, a picture was obtained of the meaning of having this disease. This is because the studies that have been done so far have dealt with limited aspects of the lives of these patients, causing an incomplete understanding and image of the meaning of life HAM/TSP. This complete picture can help to plan and implement personalized and holistic health care for these patients.

### Conclusion

Considering the extensive changes in the lifestyle of people with HAM/TSP, focusing only on symptom management and medical care seems insufficient. These patients need palliative care to live with dignity during the long course of the disease, which should be started as soon as possible. Early attention to their concerns may reduce the patient's worry and grief about their sense of dignity. In this context, the role of nursing is important, because nursing is a historical and cultural profession that brings professionals closer to care and has a holistic view.

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### Authors' Contribution

M.D: Study design, data gathering, data analysis, and drafting; R.B: Study design, drafting, and critical reviewing of the manuscript; ZS.M: Study design, data gathering, data analysis, drafting, and critical reviewing of the manuscript; All authors have read and approved the final manuscript and agreed to be accountable for all aspects of the work, ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

**Conflict of Interest:** None declared.

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