The Barriers of Coping with HTLV-1-Associated Myelopathy/Tropical Spastic Paraparesis: A Content Analysis Study

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Abstract

Background: HTLV-1-associated myelopathy is associated with constant stress, so it is very important to cope with this disease. To improve the coping of patients with this disease, it is necessary to deeply identify its barriers.

Aim: The present study was conducted with aim to explain the barriers to cope with HTLV-1-associated myelopathy/tropical spastic paraparesis.

Method: This qualitative content analysis approach was performed on 17 patients with HTLV-1-associated myelopathy/tropical spastic paraparesis, who referred to Ghaem hospital clinic. Data were collected by conducting semi-structured in-depth interviews in a private room of the clinic. The Graneheim and Lundman's qualitative content analysis method was used for analyzing.

Results: In this study, 5 subcategories and 2 main categories (internal barriers to coping with the disease, challenges with socioeconomic barriers) were developed. The main theme abstracted was also "chains of stagnation and regression of passing the disease".

Implications for Practice: Considering that health care professionals' knowledge about HTLV-1-associated myelopathy/tropical spastic paraparesis and patients' experiences is very little, the results of this study can be a basis to design a suitable and context-based care framework to improve the coping responses of patients.

Keywords: Adaptation, HTLV-I-Associated Myelopathy, Human T-lymphotropic virus 1, Spastic Paraparesis

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Introduction

Human T-lymphotropic virus type 1 (HTLV-1) is the first human retrovirus which was discovered (1) and infected 10-20 million people worldwide (2). While the majority remain asymptomatic, approximately 3–8% develop HTLV-1-associated myelopathy/tropical spastic paraparesis (HAM/TSP) (3). HAM/TSP is a chronic, neurodegenerative disease characterized by progressive lower limb weakness, spasticity, and bladder/bowel sphincter dysfunction (4). These condition can be a stressful situation causing emotional and physical symptoms (5). However, patients try to find ways to cope with these challenges despite constantly facing the consequences of the disease (6). Coping can cause a wide range of behaviors, actions, internal and external reactions in response to a stressor (7).

Seeking the determinants of adaptive and maladaptive coping responses may contribute to a better understanding of how individuals function in a situation of serious threat to health and life (8). Moreover, these results may make it possible to adopt measures to reduce the occurrence of maladaptive coping responses, as well as increase the likelihood of adaptive coping behaviors (9). In this regard, qualitative methods provide an opportunity to gain an in-depth understanding of patients' experiences. These approaches also allow assessors to move beyond the limitations of structured questions. In this way, traditional qualitative methods such as interviews may be a powerful tool to record the patients' experiences (10). Unfortunately, despite the endemicity of HTLV-1 in Iran, there is limited information about the coping experiences of patients. This shows that the disease is invisible among the general public and professionals. On the other hand, previous research on this group of patients is limited to their lived experience, and as a result, our knowledge about coping with the disease and its barriers in this group of patients is very limited. Therefore, the present study was performed with aim to identify the barriers to cope with HTLV-1-associated myelopathy/tropical spastic paraparesis in Iranian patients.

Methods

The present study was performed with the conventional content analysis approachwhich is a suitable choice for examining the daily experiences of human emotions and feelings (11). This study was reported according to the consolidated criteria for reporting qualitative studies (12).

The participants included 17 HAM/TSP patients selected by purposeful sampling. Also, they were over 18 years old and had satisfaction to share their experiences. Maximum variation was used to select the participants (age, gender, place of residence, disease symptoms, education and marital status). Sampling was done among the clients of the HTLV-1 specialized clinic of Ghaem Hospital in Mashhad, Iran. The first author visited an HTLV-1 specialist clinic to collaborate with specialists on the research and care programs; then she volunteered to assist and educate patients before contact, and communicated with potential participants. She was proficient in qualitative research and conducted the interviews between July 2021-January 2022. Initially, she explained the objectives of the study to the participants, and none of the patients refused to participate in the interviews. Then, an informed consent was obtained from all participants for their informed participation and voice recording. Data were collected through face-to-face, in-depth and semi-structured interviews. Each session lasted for about 65-105 minutes. Also, to obtain further information, two participants were invited to the second round of the interviews. The time and place of the interviews were chosen by the participants, usually in one of the rooms in the clinic. Patients were interviewed separately in order to minimize the mutual influence. The first author conducted initial interviews with two patients to develop the topics presented in the interview guide. Finally, these two interviews were analyzed after completion. In the next step, the interviews started with warm-up questions about the demographic characteristics of the participants. Then, the interviews continued with a general question to enter the interview by recalling the initial events such as "How did you first find out about your illness?" and then the discussion gradually entered the stage of "barriers to coping with the illness". At this stage, the interviewer asked, "How did you cope with this disease?" and "What factors prevented you from coping with this disease?" If necessary, more exploratory questions were asked such as "Please elaborate on that", "What preoccupied your mind?". In each session, the interview ended with two questions: "Is there another question to be asked?" Or "Do you have a question from me?" Sampling continued until data saturation was reached (13). As the study progressed, the interviews were conducted based on the developed questions and the researcher directed his questions based on the salient and important classes developed. The first author also took field notes during the interviews.

After listening, data mining, and reading the data, a general image of the data was obtained and meanings were extracted (14). The Graneheim and Lundman's qualitative content analysis method (15) was used for analyzing data of all participants' handwritten text. All textual data were read several times by the first and third researchers to obtain a complete understanding of the image. At the next step, the text related to the barriers to coping with disease in HAM/TSP patients was extracted and grouped into meaningful units. Each unit was coded and then the codes were compared based on differences and similarities and categorized into sub-categories. The subcategories were then classified into broader categories constituting the manifest content. Finally, the categories were linked by their underlying meaning and grouped into themes, described by Graneheim and Lundman (15) as "an expression of the latent content of the text". During the analysis process, two researchers (first and third) independently performed each step. Discrepancies between the two analyzes were identified and discussed until an agreement was reached. Handwritten notes were taken to facilitate conceptual comparison. The coding team used MAXQDA10 software during the coding process.

Three methods were used to ensure the reliability of data. First, the patients were assured about the confidentiality of reports during the interviews to encourage them to freely express their thoughts, opinions, and impressions. Second, data triangulation between data sources (using 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 by the first author to confirm the consistency of the identified concepts. Third, coding results were provided to 4 participants prior to submission and publication. They confirmed the findings.

Results

A total of 17 patients participated in this study. Demographic characteristics of patients is presented in Table 1.

Table 1: Demographic characteristics of patients participating in the study

No.	Interview time	Gender	Age	Employment status	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	Housewife	Diploma	Married
6	75 min	Female	26	Student	Master's degree	Single
7	90 min	Female	34	Housewife	Secondary school	Single
8	95 min	Male	21	Student	Associate's degree	Single
9	105 min	Female	62	Housewife	Bachelor	Widow
10	85 min	Male	61	Retired	Diploma	Married
11	95 min	Female	39	Housewife	Primary school	Married
12	100 min	Female	61	Housewife	Diploma	Widow
13	85 min	Male	43	Retired	Illiterate	Widow
14	80 min	Female	51	Housewife	Diploma	Divorced
15	65 min	Female	22	Student	Associate's degree	Divorced
16	95 min	Female	50	Housewife	Bachelor	Married
17	80 min	Female	65	Housewife	Diploma	Divorced

Data analysis obtained from the interview led to the emergence of 936 primary codes. After summarizing and removing duplicates, 294 initial codes was obtained. After classifying the codes, 199 initial subcategories were created. After comparing the subclasses with each other and categorizing them, the overall structure of "barriers to coping with HAM/TSP" emerged with the main theme, 2 main categories, and 5 subcategories (Table 2).

Table 2. Subcategories, categories, and final theme extracted from the participants' experiences of barriers to cope with HTLV-1-associated myelopathy/tropical spastic paraparesis

Subcategories	Categories	Main theme
Personality barrier Medical mistrust and unrealistic beliefs about disease	Internal barriers of coping with the disease	Chains of stagnation and regression passing through the disease
Stress caused by limited access to medical services Sadness caused by imposing exorbitant costs on the patient Loneliness and reduced communication	Challenge with socio-economic barriers	

Internal barriers of coping with the disease

- *Personality barrier*

It means the inherent traits and characteristics which prevent a person from coping with his illness and overcoming it. This group of personality traits affects the patient's readiness, ability, thinking, action or feeling in response to the situation. Patients expressed this group of characteristics in the form of the habit of postponing serious life issues, admitting that they do not have the spirit to solve problems, depending on the guidance of others to learn problem solving management methods, personality traits of nervousness, excitability, anxiety, being shy, and desire to be fashionable.

"…In life, no one taught me that you should go and solve your problem. I didn't even try. No one taught me... I never thought very seriously about solving my problems" (Man, 51 years old, married)

- *Medical mistrust and unrealistic beliefs about illness*

In some patients, medical mistrust and unrealistic beliefs about illness were clearly identified as a disturbing factor to cope with the disease. It means that they believed that health care providers, especially doctors, do not have the possible competence to comment on their illness. The doctor's comments about the lack of treatment and incurability of the disease is the most common factor which increase mistrust. Also, the development of unrealistic beliefs about the disease causes an attitude in patients that affects their treatment decisions and health behaviors. Imaginations based on illusions and far from the true nature of the disease, such as the treatability of the disease, the same as AIDS, or its lack of progress over time, are among the unrealistic beliefs affecting a person's behavior and actions. Incorrect information and knowledge about treatment approaches also affects behavior change and acceptance of the main treatments of the disease. Participants often receive false information from social networks and believe it. The similarity of the HTLV-1 with HIV and the perception of social consequences related to it are also seen in the incorrect beliefs of some patients. Also, when the patient imagines that he cannot control the personal and social consequences of the disease or the use of interventions to manage the disease and has no control over the existing situation, he faces difficulties in overcoming the disease. These patients think that their actions are not significantly effective and inevitably accept the existence of the disease. This acceptance is out of necessity and surrender, because the patient, as an important effective factor in the path of disease management, realizes that he is not able to play a role in facing the disease. Some of these misconceptions are deeply rooted in a person's experiences. For example, some participants admitted that absence of symptoms in the sexual partner during many years of cohabitation means that the virus cannot be transmitted during intercourse, therefore, they expressed negligence and inability to use condoms during intercourse.

"…We don't stress about our sex. Because if it was possible for the virus to be transferred to her, there would have been a problem for my wife in the past few years" (woman, 36 years old, married)

Challenge with socio-economic barriers

- *Stress caused by limited access to medical services*

This category refers to the limitations that patients face due to the structural, political and geographical obstacles of the health system governing the society when receiving services and specialized care. Among the interviewees, some stated that the volatility of the drug market as a result of the sancation, limited access to essential drugs of high quality and affordable prices are among their common constraints that directly affects their ability to cope with the diseaese. Travel to access specialized care can also be costly and burdensome for patients living in remote areas. This issue can be a significant burden in terms of travel time, cost and time away from work and life, and it can be an obstacle to overcome the disease. These patients may substitute local primary care providers for subspecialists or may choose to delay or forgo care. Gender inequalities such as additional childcare responsibilities and children's over-dependence on the mother's presence can also worsen this scenario. The shortage of health care professionals also affects access to safe and satisfactory health care and coping with illness. The frequent change of care team physicianswithout the patients' wishes disrupts access to a regular source of care. According to the patients' statements, the crisis of the Covid-19 epidemic, as a sudden and increasing event, can affect their behaviors and responses to the situation. Due to transportation restrictions and fear of infection, Covid-19 epidemic caused most of the patients' medical appointments to be canceled. Participants stated that Covid-19 caused additional barriers to access health care. In such situations, people do not seek care and delay it.

"…Another problem happened to me... Pegasis ampoules did not enter Iran for a while and I had to inject Iranian interferon instead. When I injected three interferons, I had hair loss. Another problem was added to my problems" (woman, 34 year old, married).

- *Sadness caused by imposing exorbitant costs on the patient*

Another obstacle to overcome the disease in this group of sufferers is financial issues and the cost of medical services. The patients stated that the skyrocketing price of medicine and medical services are not affordable, and health insurances does not have a significant effect on drug costs, especially most patients do not have an acceptable economic-social level and belong to the low-income strata. The simultaneity of several physical or mental medical disorders in these patients also makes the conditions more complicated in terms of financing treatment costs. The expansion of health insurance coverage also affects the behavior of patients. Especially, the lack of social and private insurance in the field of rehabilitation services lead to the late start of care, less use of effective services, or inappropriate adherence to recommended treatments. In particular, the effectiveness of such services requires long-term and continuous use, therefore, these services are less used among different groups of patients.

"…The costs are high, for example, I have a pension of 2-3 million tomans now, but I go to occupational therapy three times a week, and it costs me 100/000 tomans. Since I fell, I also got diabetes and obesity. I have insurance, but it's hard to cover the expenses" (man, 39 years old, divorced)

- *Loneliness and reduced communication*

Loneliness and lack of communication can also be considered as other obstacle which affects dealing with the disease. For some patients, loneliness is caused by being in a context or physical environment without the presence of others. Some of them feel that the quality of their communication with the people around them is not suitable and they are not able to share their concerns and needs. Physical presence was also clearly important to some participants. The size of the network, the frequency of social interactions, and the inappropriate number of friends can be seen in the narratives of some of these patients. Some interviewees also revealed the loneliness and reduced communication with relatives in the form of lack of deep family attachment and lack of sincere and real communication with family members.

"…I'm alone now, it's very hard, the hardest thing is loneliness, there's no one to talk to" (woman, 65 years old, divorced)

Chains of stagnation and regression passing through the disease
Patients suffering from HAM/TSP face obstacles arising from their internal and external environment on the way to overcome their disease. The sequence of negative and undesirable personality traits, the development of negative ideas and perceptions of the disease, the stress of limited access to medical services, and the grief caused by the exorbitant costs imposed on the patient act as "chains of stagnation and regression of the disease" that is the most important factor. It r the patient's speed on the path of passing through the disease. These synergistic circles affect the way a person evaluates the situation and the stressful factor and coping strategies, causing adverse changes in the patient's emotions and feelings, and inducing additional stress to him or minimizing the motivation to adopt useful strategies to overcome the disease. Therefore, it seems that the main theme "chains of stagnation and regression in passing the disease" can explain the nature of the obstacles experienced by the patients while coping with their disease.

Discussion
The main theme "chain of stagnation and regression during the course of illness" which explain the barriers experienced by the patients in coping with HAM/TSP was extracted from the data. This concept represents internal and external obstacles affecting the patient through passing the disease. One of the basic assumptions of psychological stress theories is that the course of a stressful event is modulated by a range of external and internal factors described as resources (16). Resources mean "characteristics of individuals, groups, environment or culture that may facilitate the avoidance of stressful factors and/or increase the ability to cope with demands by preventing the transformation of stress" (16). Accordingly, the internal barriers in the present study included personality traits, medical mistrust and unrealistic perceptions of the disease. Personality affects compatibility in several ways; they may directly, by limiting or facilitating the use of certain strategies, or indirectly, by influencing the nature and intensity of experienced stressors or the effectiveness of strategies, affect the choice of coping strategy. Besides, some characteristics occur before coping and can affect the frequency of exposure to stressful factors, the type of stress experienced and evaluations (17). Additionally, the lack of a relationship based on trust and perception between patient and physician that is based on illusions of the disease can slow down the patient's movement on the path of passing through the disease. According to the literature, doctors always influence the process of patients' coping with their disease (18). A relationship based on trust between patient and physician can strengthen the patient's ability to cope with illness. While weak communication may lead to low quality of health care, patient anxiety, difficulty in coping, poor coping, and frequent search to find physicians (19). In addition, certain beliefs can undermine or inhibit coping efforts. For example, belief in fate can lead to helplessness, which in turn discourage problem-focused coping. Similarly, a negative belief about one's capacity to control a situation, or about the effectiveness of a particular strategy to which one is committed, can inhibit problem-focused coping efforts. Beliefs also determine how a person evaluates what is happening or about to happen (20).
The present study also found that the barriers in the person's external world can significantly impact on how the patient overcomes the health-threatening problem. The environment, both psychosocial and physical, has important consequences on behavior and emotion. The nature of the environment in which a particularly stressful episode occurs can be considered a potential resource which may influence the types of coping used (18). Also, environmental events or their interpretations which lead to the perception of threat or danger can trigger a stress response (21). For example, limited care policies, frequent switching of care providers, inability to get timely refills of medications, lack of access to specialists, and unclear insurance plans will cause many problems (22). Environments may differ in terms of the nature and frequency of threats to the individual and the range of options available to address threatening situations. Also, the environment may respond to individuals' adaptive coping efforts in such a way to neutralize their strategies (23). In addition, research shows that social networks can also act as a barrier to coping efforts. They may affect coping methods in different ways. One of these ways is the use of social referral (24). It means thar people look at others to find out what is appropriate for a particular situation. Social relationships also affect coping efforts through the direct provision of information about the possible effects of specific coping strategies (25). Also, when patients feel supported, they use a greater variety of coping strategies because supporters encourage patients' adaptation efforts, which may serve both to increase satisfaction with

support and to increase adaptation efforts (26). In line with the results of the present study, numerous studies on HAM/TSP patients in other native countries also show that this disease, in addition to physical suffering, causes many mental injuries to patients, which increases the stress caused by the disease and affects their coping responses (27-30). Also, some other studies also provide evidence of the influence of geographical, cultural and social context on the coping process of patients (31-33). Although the present study was conducted in a different social context than other indigenous countries, these similarities in the obtained results confirm that coping responses are influenced by the social, cultural, cognitive, and physical environment (34).

Implications for practice
The results of this study help to better understand the obstacles of coping with HAM/TSP. In Iran, various social, political and economic factors are effective to create a variety of coping styles and how people deal with a progressive and incurable disease caused by a sexually transmitted virus. The narrative of the patients in the present study seems to support the hypothesis that coping with the disease depends on resources (personal characteristics, social situation and interactions) and their availability. The results obtained in the current research are especially important for nursing, which historically is a holistic and humanitarian profession which is very involved in caring for human life. Therefore, nurses can design individualized care plans for patients with HTLV-1-associated myelopathy/tropical spastic paraparesis. These cae plans increase the quality of life of these patients and their family members. Coping with a disease and its subsequent consequences as one of the basic concepts and important factors, play a significant role in disease management.

Conflicts of interest
The authors declared no conflict of interest.

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